

**Rights to Accommodation in Healthcare:
Self-Advocacy Experiences of People with Disabilities**

BY

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DISSERTATION

Submitted as partial fulfillment of the requirements
for the degree of Doctor of Philosophy in Disability Studies
in the Graduate College of the
University of Illinois at Chicago, 2018

Chicago, Illinois

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ACKNOWLEDGEMENTS

The process of this work has drawn upon experiences and knowledge from all parts of my life. This dissertation is dedicated to my mother, Anita, who taught me how to explore and my father, Gary to wonder. Without those foundational elements, I likely would never have begun this adventure. I must acknowledge the love, support, and tolerance of my family, Darren, Rachel, Marc, and Evan and friends. Your daily encouragement saw me through to the end. My PhD cohort – thank you. I could not have done this without this amazing support system and hope we spend years together exploring the rabbit hole.

My world view has been enriched by “exploring others’ world view” (Gill, 1994, p. 45). I gratefully and respectfully acknowledge the contributions of the participants of this study. I am forever indebted to these six amazing self-advocates who participated in this journey of discovery with me. Each of you shared your sense making of this world we live in and I am thankful for your wisdom. I also must thank members of my dissertation committee. Dr. Sarah Parker Harris, Dr. Carol Gill, Robin Jones, and Dr. Anders Kottorp, your knowledge and guidance helped me to understand what I was looking for and recognize things I may never have seen. Thank you, thank you!

Finally, I will be forever, deeply grateful for and indebted to my dissertation advisor, Dr. Susan Magasi. You complete my hermeneutic circle of understanding and knowledge by guiding me to the essence of the meanings and aiding me to ways of elucidating the lived experience. You are an exceptional qualitative researcher and mentor - I am so fortunate to have the opportunity to learn from you.

LHV

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LIST OF ABBREVIATIONS

ACA	Affordable Care Act
ADA	Americans with Disabilities Act
ADAAA	Americans with Disabilities Act Amendment Act
ADAAG	Americans with Disabilities Act Accessibility Guidelines
CIL	Center for Independent Living
CLT	Critical Legal Theory
CRT	Critical Race Theory
IPA	Interpretative Phenomenological Analysis
NODD	Normalization of Disability Discrimination
PA	Personal Assistant
PPACA	Patient Protection and Affordable Care Act
PWD	People with Disabilities

SUMMARY

Despite laws to prevent exclusion, people with disabilities (PWD) experience socially constructed barriers to accessing basic health services and as a result must self-advocate for accommodations. In order to examine how contextual and personal factors inform decisions to self-advocacy and the perceived impact of these experiences, this dissertation explores the meanings that people with physical disabilities give to their healthcare and self-advocacy experiences. Critical disability theories and the social model of disability were used to highlight the essence of participants' experiences in decisions to request healthcare accommodation.

This study was designed and implemented using an Interpretative Phenomenological Analysis (IPA) approach to explore the complicated phenomenon of healthcare access for PWD. IPA acknowledges that merely describing people with disabilities' experiences in healthcare is not enough to fully understand how these experiences shape future decisions about how and when to self-advocate. Using this phenomenological lens provided for an inter-actionist perspective of how the social construction of disability and encounters of barriers to healthcare are more than failed accommodations but may be a phenomenon of significant meaning for PWD.

The meanings of participant experiences emerged to identify unknown or little appreciated factors that influence decisions to self-advocate in healthcare encounters as well as impact the person's disability identity. Findings show that while individual approaches to self-advocacy varied, participants all made sense of experiences in barriers to care as a process of 'recognizing normalization of disability discrimination and disability stigma' that influences 'provider understanding of disability' necessitating the development of agency in self-advocacy with varying factors influencing 'decisions to self-advocate'. This process has a 'lasting impact'

on people that includes a shared ‘embodied experience of disability and health’ as well as a ‘sense of empowerment’ based on their collective and individual identities as disabled people.

I. INTRODUCTION TO THE STUDY

People with disabilities (PWD) experience well-documented socially constructed barriers to healthcare access and must make decisions to self-advocate for accommodation. This dissertation explores the meanings that people with disabilities give to their healthcare and self-advocacy experiences. The social model of disability was used to understand and analyze the social construction of these barriers and critical disability and critical legal theories were used as a conceptual framework to interpret the findings. This dissertation explores individual and shared meanings of people with disabilities' experiences of self-advocacy for healthcare accommodations by addressing three questions:

- How do people with a physical disability make sense and give meaning to experiences of barriers to healthcare?
- What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?
- Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?

Interpretative Phenomenological Analysis (IPA) was used to explore the meanings that people with mobility disabilities ascribe to times when they confronted barriers to receiving appropriate healthcare and recognized the need to self-advocate.

In order to frame the background and significance of this study, I review the relevant literature in Chapter II focusing on rights to accommodation for people with disabilities, barriers to healthcare for the disability community and extant literature on experiences of self-advocacy and accommodation requests from other occupational areas of daily life such as employment, education and tourism. In Chapter III, I provide an examination of the overarching theoretical

framework supporting the methodological approach used for data collection and analysis. In Chapter IV, I detail the methodology, study design and specific methods for all aspects of data collection including development of the research question, use of IPA, participant purposive recruitment, and the two-phase approach to interviewing. In this chapter, I also offer a detailed description of the techniques used for establishing trustworthiness.

Chapters V and VI provide the findings. Chapter V includes individual case studies and ideographic analysis of each participant to illustrate how their individual experiences inform the findings. I then provide an analysis across the individual cases in Chapter VI, using four broad contextualizing categories to organize and describe those themes that emerged as superordinate themes from the shared experiences. Chapter VII provides an in-depth discussion of the findings from this across case examination with implications and suggestions for future research.

II. PEOPLE WITH DISABILITIES AND ACCESS TO HEALTHCARE

A. Introduction

Over 56 million people with disabilities (PWD) live in the United States (Brault, 2012). Even with the existence of civil rights legislation, this large minority group continues to experience socially constructed barriers to participating in every aspect of life - including accessing basic health services. Full participate in the activity of accessing healthcare often requires that a PWD¹ self-advocate for accommodations in order to receive services that are part of the routines of everyday health (Hammel et al., 2008). Despite a growing body of literature on identifying and describing the existence of barriers to care, continued lack of accommodations, and research linking barriers to health disparities for people with disabilities; there is limited knowledge of how people make sense of these experiences and in turn use them to inform their decisions of when and how to self-advocate for accommodations with the healthcare system. Understanding the individual's sense-making² of these barriers and resulting need for self-advocacy to access healthcare might increase recognition of the broader impacts that failed implementation and enforcement of Americans with Disabilities Act (ADA) accommodations in

¹ Within Disability Studies individuals with differently functioning bodies (physical, mental, cognitive, sensory) are viewed as *disabled* by society versus locating the disability within the person. *People with disabilities* and *disabled people* are both used to describe a social/political category of people with a variety of conditions and common social and political experiences (Linton, 1998, p. 11). However, Linton critiques medicalization of the term *disabilities* or use as a characteristic of a person and suggests *disabled* better defines membership within the larger minority group. Within this dissertation I use both terms but specify *disabled* as aligning with identity within this larger group.

² Sense-making is defined by Jon Kolko in *Sensemaking and Framing: A Theoretical Reflection on Perspective in Design Synthesis* (Kolko, 2010) as a “constant cyclical process of acquisition, reflection, and action that people continually and fairly automatically go through in order to integrate experiences into their understanding of the world around them in order to make decisions and act effectively” (p. 1).

healthcare settings have on the health of people with disabilities. This research study sought to understand the impact of these barriers – specifically, the experiences of the demands of self-advocacy and accommodation request - for people with disabilities. In this chapter, I provide background on the ADA's role on rights to healthcare accommodations, literature describing continued barriers to healthcare and their impact, and the need for PWD to self-advocate for accommodation due to failures of ADA enforcement mechanisms.

1. **The ADA and accommodations in healthcare for people with disabilities**

President George H.W. Bush signed the Americans with Disabilities Act of 1990 (Pub. Law No. 101-336) more than 25 years ago, and compared its passage to the tearing down of the Berlin Wall. The simplicity of that liberating visual – that removing a physical barrier might beget inclusion, acceptance and participation in society – makes for a good sound bite, but it fails to acknowledge the challenges of implementing and enforcing the accommodations promised by the ADA. The analogy implies that one act is enough to lead to the large-scale system and policies changes needed for reformation of social attitudes³. The originators of the ADA recognized this first civil rights act dedicated to PWD would face legislative and judicial challenges before providing the promises of inclusion and participation (Switzer & Vaughn, 2003). In fact, the Americans with Disabilities Amendments Act (ADAAA, 2008) was passed as a result of the many legal battles that emerged from the ADA too narrowly interpreting definitions of disability.

³ Balazs, Bozoki, Catrina, et al., (2014) provide a thorough analysis of the persistence of “intolerance, populism, corruption and the regular political eruptions that continue to play a role in oppression and marginalization of minorities” (p. 10) throughout the new Member EU States in the report *25 years after the fall of the Iron Curtain: The state of integration of East and West in the European Union*. Retrieved from https://ec.europa.eu/research/social-sciences/pdf/policy_reviews/east-west_integration.pdf

Extending the definition of disability and applying and implementing the law has created opportunity to access many built environments although implementation in healthcare has been exceedingly poor (Kailes, 2007). In the context of healthcare access ADA compliance would include attending to physical access into a facility as well as communication, programs and services, and medical equipment access and use (Winters et al., 2007). However, lack of accessible and easily used healthcare accommodations persist throughout the United States and are frequently described by people with disabilities as a leading cause for limited use of healthcare (Reichard, Nary, & Simpson, 2014; Reichard, Stoltze, & Fox, 2011). Unlike other civil rights laws for racial and gender equality that demand affirmative action, the ADA challenges society to re-conceptualize the causes of and constructs of disability itself as well as health with disability (Heyer, 2007; Travis, 2008). The “intent of the ADA is that PWD would receive equally effective healthcare” (Kailes, 2007, p. 6) as those without disability, but this is far from the reality.

Historically, disability has been equated with infirmity, illness, and biological insufficiency. As a result, social and political agendas have invested in medicalization and institutionalization rather than ensuring participation in routine and expected health practices of the ‘healthy population’ (Drum, Krahn, Peterson, Horner-Johnson, & Newton, 2009). The ADA asks providers to make ideological shifts in their approach to working with individuals with disabilities from focusing on ‘fixing’ or ‘curing’ the disability to provision of basic primary and preventive healthcare service – requiring accommodation for equal access.

Since its passage, the ADA has had impact on improving helped improve access and participation for PWD in the areas of education and employment but relatively unchanged disparity levels in access to healthcare (Taylor, Krane, & Orkis, 2010). Disability and health law

scholar Mary Crossley (2000) illustrates that there may be times when the need for PWD to access preventive and primary care services are of more critical importance to “enable individuals to maintain the health and functioning that allow them full participation in society” (p. 2) or avoid onset of preventable illness or chronic disease. In a scoping review of the use of clinical preventive services by PWD, researchers report access disparities across different service types but “more significant access disparities for individuals with increased disability severity” (Peterson-Besse, Walsh, Horner-Johnson, Goode, & Wheeler, 2014, p. 391) those who arguably require it the most.

The Patient Protection and Affordable Care Act (2010) amended Section 510 of the Rehabilitation Act of 1973 (Public Law 93-112, 504 Stat. L. 394) and directs the United States Access Board to develop and issue regulatory standards for medical diagnostic equipment for accessible entry, use of, and exit for PWD (Pharr, 2013). Language within the Affordable Care Act (ACA) also provides for increased enforcement capability of accepted standards. In January of 2017 the Access Board issued final accessibility standards and guidelines for medical diagnostic equipment (82 Federal Register 5, January 9, 2017, available at: <https://www.access-board.gov/news/access-currents-march-april-2017>) including but not limited to, exam tables and chairs, scales, mammography equipment, and other screening equipment for diagnostic purposes.

The U.S. Veterans Health Administration system has announced plans to implement and enforce these standards among its 152 medical centers and 800 community-based outpatient clinics (Singer, Dickman, & Rosenfeld, 2017). As a direct result of the ACA’s accessibility mandate, the Centers for Medicaid and Medicare Services recently incorporated directives for improving accessibility to provider’s offices and equipment (CMS, Office of Minority Health, 2015). However, at this time, it is uncertain if the Department of Justice will make final

recommendations for mandatory and enforceable standards for the general United States population. The laws are there, the equipment is available (Switzer & Vaughn, 2003) but the current system, structure and attitudes of providers fail to acknowledge that accommodating the health needs of PWD is both important and urgent (Pendo, 2015). As the disability community waits for changes to occur, people with disabilities continue to experience barriers to care which contribute to health disparities.

2. **Barriers to healthcare for PWD**

Despite the American with Disabilities Act, Affordable Care Act and the Access Board's new medical equipment standards and guidelines that come with the ACA, this study explored how healthcare practices, policies, and provider attitudes that stem from normative approaches to preventive healthcare contribute to disparities in health outcomes of PWD. Research in access and the access barriers to healthcare for PWD describes the influences of the physical as well as attitudinal environment on reducing decisions to utilize primary and preventive care services (Dillaway & Lysack, 2014; Kailes, 2007).

It is well documented that individuals with disabilities experience major *health* disparities compared with their non-disabled peers and causal factors include disparities in healthcare access and quality of care (Kroll, Jones, Kehn, & Neri, 2006). *Access* disparities are defined as “a mismatch between need and care associated with membership in one socially identifiable and disadvantaged group compared with the non-disadvantaged counter-part” (Franks, 2008, p. 672). For people with disabilities multiple barriers have been reported preventing access to primary, secondary, and preventive healthcare (Kroll et al., 2006). *Healthcare* disparities are “differences in the quality and outcomes of health services that are not due to access related factors or clinical needs, preferences, and appropriateness of interventions” (Nelson, 2002, p. 666). For people with

disabilities reports of higher unmet needs and use of fewer preventive and health maintenance services may be attributable to healthcare access as well as healthcare quality. Each of these might contribute to the fact that people with disabilities experience higher rates of early death and preventable chronic disease (Meade, Mahmoudi, & Lee, 2014).

Experiences of PWD in barriers to accessing primary, preventive healthcare and health promotion have been reported in research literature from public health (Krahn, Walker, & Correa-De-Araujo, 2015; Pharr & Chino, 2013), medicine (Iezzoni, McCarthy, Davis, & Siebens, 2000; Mahmoudi & Meade, 2015), and disability advocates (Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009; Panko-Reis, Breslin, Iezzoni, & Kirschner, 2004). Many of the barriers to healthcare continue to exist despite existence of easily implemented alternatives (Winters & Story, 2006). PWD report receiving fewer referrals to preventive healthcare services (Chevarley, Thierry, Gill, Ryerson, & Nosek, 2006; Diab & Johnston, 2004), and a lack of referral and access to health promotion programs (Downs, Wile, Krahn, & Turner, 2004).

Although physical entry barriers do exist (Iezzoni, Davis, Soukup, & O'Day, 2002), the most difficult barriers to overcome are not caused by lack of access into health provider's offices. The ADA has made entry into buildings and offices less of a challenge (Lagu, Iezzoni, & Lindenauer, 2014). The most significant barriers preventing access to care include: accessing medical diagnostic equipment (Drainoni et al., 2006; Winters & Story, 2006) access to exam tables, rooms, and weight scales (Yamaki, Lamp, & Cox, 2015); access barriers due to provider attitude (Dillaway & Lysack, 2015; McDoom, Koppelman, & Drainoni, 2014) and access barriers from economic and systemic mechanisms (Crossley, 2000; Kroll et al., 2006; Scheer, Kroll, Neri, & Beatty, 2003).

Attitudinal barriers that PWD may not be in need of preventive and health promotion referral (Peterson, Hammond, & Culley, 2009) may be redolent from a history of abuse, neglect, denial of services, and euthanasia (Adams, 2007; Braddock & Parish, 2001; Carlson, Smith, & Wilker, 2012; Ouellette, 2011). This legacy of discrimination may partially explain attitudes that prohibit incorporating disability accommodations into medical equipment design and service provision (Seelman, 2007). In fact, in describing reasons why PWD receive substandard care and limited referral to necessary healthcare services, the U.S. Access Board states as a cause “clinician’s failures to understand the values, preferences, needs, and expectations of persons with disabilities for their health care” (Access Board available at: <https://www.access-board.gov/guidelines-and-standards/buildings-and-sites/about-the-ada-standards>) as a primary factor. These “common misperceptions” combine with inaccurate perceptions by providers of appropriate or accurate inclusion of provision of accessible care (Sanchez et al., 2000).

In addition to documented barriers to healthcare access, there is a growing body of research documenting the health disparities of people with disabilities in chronic illness and levels of mortality rates (WHO, 2011). While people with disabilities are at greater risk for some illnesses and chronic conditions due to their impairments (Rimmer, Chen, & Hsieh, 2011) this fails to fully explain inequities in chronic disease and mortality rates of people with disabilities compared to their non-disabled peers (Drum, 2014; Reichard et al., 2011; Reichard et al., 2014). For example, McCarthy et al. (2006) found that people with disabilities had reduced rates of referrals to recommended standards of treatment following cancer diagnosis. PWD also report higher levels of behavioral risk factors such as smoking and obesity (Brucker & Houtenville, 2015; Stoddard, 2014) and equally disparate referrals to preventive programs (Beatty et al., 2003) contribute to an understanding of the causes of these disparities. Disparities in healthcare

receipt and health outcomes for PWD likely result from inequitable practices and programmatic policies that neglect if not ignore the need to implement and enforce the rights to healthcare access guaranteed by the ADA. This places the onus on the person to advocate for access to the basic healthcare services those without disability readily receive.

The literature is dense with reports of access and quality barriers to healthcare for people with disabilities. There exists substantial evidence that barriers to access and quality healthcare is not because of factors that impact physical access but rather because of factors associated with the design of healthcare systems and health policies as well as negative attitudes and discrimination that occurs at the level of the provider (Peterson-Besse, O'Brien, et al., 2014). These policies and discrimination have been linked to strongly embedded ideologies that disability is not equated to health (Drum, 2014). Negative provider beliefs and behaviors may be further exacerbated by structural level barriers created when practice administrators hold these same ideologies (Pharr, 2014).

How experiences of discrimination within a healthcare environment impact the decision-making process to advocate – or not -- for accommodations for care is not known. Descriptions exist from consumers of the frustrations and fear of providers withholding or refusing treatment if a request is made (Kailes, 2007). There is also evidence that consumers elect not to pursue preventive care due to past negative experiences (Dillaway & Lysack, 2014). Dillaway and Lysack (2014) found that “considerable agency in overcoming barriers” (p. 257) was a common character trait of participants that were routinely successful in ultimately accessing care. This form of self-accommodation is found in literature exploring how the ADA influences requests for accommodations outside of the healthcare context (Baldrige & Veiga, 2006; De Vries McClintock et al., 2016; Engel & Munger, 2003). In these studies, negative interactions or

discriminatory climates influence study participants' decisions not to activate⁴ knowledge of ADA rights to accommodation. In a review of the ADA literature and its impact on PWD, Gould et al. (2015) find instances of self-advocacy especially beneficial in settings where employer knowledge on accommodations and the ADA were deficient. However, self-advocacy in a healthcare setting - as a disabled person attempting to receive primary and preventive care health services - requires confronting long standing dogmas dealing with health and disability and health with disability (Raveslout et al., 2007; Shakespeare & Kleine, 2013; Smeltzer, 2007).

These reports describe the many access barriers people with disabilities continue to experience when attempting to manage their health, critical to their ability to participate in all other contexts of society (Pharr, 2013; Pharr & Chino, 2013; Shakespeare, 2012). Despite rights to access, the continued presence of well documented barriers create recurrent demands on PWD to self-advocate for an accommodation when managing their own health needs. This requires PWD have knowledge of the existence of the many environmental barriers, legal rights to accommodations to overcome the barriers, and the efficacy to self-advocate - all within a context with a history of discrimination and oppression – in order to receive basic healthcare services. How often do these negative experiences shut down a request for accommodation? Currently there is little appreciation for the factors that PWD take into consideration when choosing to self-advocate within a healthcare context. Therefore, it is critical to understand the meaning of these experiences and how they impact decisions to self-advocate for accommodations and potentially contribute to health disparities in PWD.

⁴ Engel and Munger (2003) describe interviewee's awareness of rights and readiness and willingness to invoke them in requests to accommodations in the workplace as 'activating' their knowledge of the civil rights in *Rights to Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*.

3. **The role of self-advocacy**

Self-advocacy is a “tool that allows people to speak up about how they interpret and understand their lives in order to seek changes, including shifts of power” (Aspis, 2002, p. 30). Within the disability community skills in self-advocacy are linked to concepts of self-determination and challenging society’s negative perceptions of disability (Test, Fowler, Wood, Brewer, & Eddy, 2005). Being a successful self-advocate is linked to greater success in continued receipt of accommodations for students with learning disabilities transitioning from high school to college (Rosetti & Henderson, 2013) and employment success (Wehmeyer & Schwartz, 1997). In a study exploring PWDs experiences with barriers in healthcare, focus group participants described the necessity of having “extensive self-advocacy skills” in order to access health care (Drainoni et al., 2006, p. 112). In their book *Exploring Disability Identify and Disability Rights Through Narratives: Finding a Voice of Their Own*, Malhotra and Rowe (2014) explored the experiences of PWD in advocating for their rights to education, employment, and transportation. What they found in the narratives of their participants was that decisions to advocate, even when the individual understands their need and right to request one, was complicated by the many different contextual aspects of the situation.

The healthcare setting is one area of daily life where PWD must have self-advocacy skills. Yet unlike preparatory programs for youth in transition from high school to secondary education focusing on developing self-advocacy skills, few programs⁵ exist as yet to prepare and

⁵ Educational Webinars have been developed by disability activist Andres Gallegos focusing on strategy development in healthcare self-advocacy for the disability community, recently made available on the Statewide Independent Living Council of Illinois’ website: <https://silcofillinois.org/silc-news>. Other healthcare self-advocacy training programs exist through organizations such as the ARC (<http://www.takingchargeofmyhealth.org/teens-and-young-adults/>), however, these primarily support strategy development for individuals with Intellectual and Developmental Disabilities.

educate PWD in self-advocacy in healthcare settings. There may be no other context where disabled people have a greater need to advocate due to a lack of knowledge of providers on disability and continued reports of inequitable provision of health services (Panko-Reis et al., 2004). However, with a long history of mistreatment of PWD by the medical community that include institutionalization, sterilization, and euthanasia (Carlson et al., 2012) concerns of vulnerability and personal safety when in medical settings (Gill, 2006) may often justifiably seem of greater importance than requesting accommodations. How might these concerns prohibit or influence an accommodation request?

PWD are described as living with a poorer health status and a thinner margin of health (Beatty et al., 2003) making the need for full access to healthcare services - including preventive care and health promotion - vital. Yet, PWD have been a history of being excluded from standardized treatment approaches used in preventive care or treatment of chronic conditions typically provided to their non-disabled peers (Drum, 2014). In a study of health professionals' attitudes toward PWD and knowledge on primary care for PWD participants, including health professionals across many disciplines, all report inadequate education about disabilities and needs for accommodations in healthcare settings (Morrison, George, & Mosqueda, 2008). In exploring why medical practices lack accessible equipment researchers found less than half of the practice administrators even knew that accessible equipment existed (Pharr & Chino, 2013).

What these studies fail to describe is the impact of the need to continually request accommodations on the life and health of PWD. Despite the ADA and recommendations for greater enforcement of accommodations in healthcare settings (Panko-Reis et al., 2004), healthcare continues to be difficult to access and navigate for a group of society most in need of quality care. The problem is significant because it represents more than a lack of implementation

and enforcement of civil rights legislation. It represents a failed commitment to social justice and social equity of a society to its citizens.

There is a dearth of literature exploring the experiences of PWD's requests for accommodations and the majority that does exist, focuses on accommodation requests within the workplace setting. Baldrige and Veiga (2001) explored the contextual elements that influence PWD's willingness to request accommodations. They found that "situational characteristics" influenced people's sense of deservedness and ultimate decision to make an accommodation request to an employer. Specific "situational characteristics" include perceived monetary costs and beliefs that requests would be an imposition on others negatively influenced the likelihood of requesting accommodations. These perceptions also negatively influenced the requester's assessment of the social consequences of making such requests, reducing their likelihood of requesting future disability accommodations. This study concluded that 'under-accommodation' by employers and placing the onus onto the PWD negatively influenced decisions to advocate and importantly suggested might also have significant psychosocial impacts. The authors suggest organizations must embrace the spirit as well as the letter of the ADA by providing equal opportunity for PWD versus acting to simply avoid penalty.

Baldrige and Veiga (2006) also explored the experiences of hearing impaired employees and their recurring requests for accommodations in the workplace. They looked specifically at the requester's perceptions of the monetary costs and social consequences of making recurrent requests and how this may influence the likelihood of future requests. The study findings identify that perceived social consequences or belief that a request is an imposition to an employer play a larger role than concerns for the monetary costs in a person's decision to make a request (Baldrige & Veiga, 2006, p. 175).

Gold, Oire, Fabian and Wewiorski (2012) examined the employee and employer accommodation negotiation processes and found both stakeholder groups had inaccurate understandings of what the ADA promises and the responsibility each had to the other in order to adhere to ADA rules and regulations (Gold et al., 2012). One primary conclusion for these researchers was that each stakeholder group involved in negotiating accommodation requests in the employment setting should become more knowledgeable of the others' perspective as well as the ADA.

Finally, a study exploring the responses to acts of able-ism of advocates and lawyers with disabilities provides insight into discrimination's influence on decisions to self-advocate (Harpur, 2014). Despite these empowered advocates' capacity for self-advocacy, decisions not to request accommodation were based on fears of retaliation or limited resources (Harpur, 2014, p. 1245). This study concludes by pondering challenges of the average citizen given experiences of those who seemingly would be the most well equipped to utilize disability laws to gain access provided by the laws.

B. **Statement of the Problem**

Requesting accommodations based on civil rights guaranteed by the ADA requires knowledge, self-efficacy, and a preparedness that accommodations might simply not exist at a provider's office. The knowledge of rights to access includes an "awareness that exclusion has occurred" and is described by Malhotra and Rowe (2014, p. 52) in their book *Exploring Disability Identity and Disability Rights through Narratives: Finding a Voice of their own*. These authors and others report how repeated experiences of exclusion from all facets of society – including healthcare - might conceivably overwhelm advocacy efforts. Requesting accommodations also requires what Ruth O'Brien (2004, p. 231) described in *Voices from the*

Edge as the “strength and stamina” to fight battles over control of a provider’s practice and policies.

1. **Attitudes of providers**

In studies asking PWD on the impact of the ADA on their lives, findings depend heavily on each individual’s own personal experience and knowledge of the law (Engel & Munger, 2003; Malhotra & Rowe, 2014). In healthcare access and quality of care, PWD report the ADA has made little to no change in their ability to access and receive necessary care (Frieden, 2015; Lagu et al., 2014; McClain, Medrano, Marcum, & Schukar, 2000). Reasons given often point to an entrenched medical model ideology that people with disabilities and health, are not combatable (Bickenbach, 2013; Bricher, 2000; Yee & Breslin, 2010). In studies of allied health and medical students’ attitudes toward PWD, students tend to see PWD as disadvantaged and dependent and having an overall less positive outlook for health (Tervo, Azuma, Palmer, & Redinius, 2002; Tervo & Palmer, 2004).

Definitions of health often use disability to describe what it is not (WHO, 2011) and the presence of impairment is used to define disability (WHO, 2001). The disability community argues for a more fluid explanation of health (Hughes & Paterson, 1997; Shakespeare, 2012; Tighe, 2001) and identifies disability as a social construction (Oliver, 1996b) yet grapples with the role of impairment within this social construal (Bickenbach, 2013; Crow, 1992; Swain & French, 2000). How health is experienced within disability and within impairment has a rich dialogue in the disability community (Loja, Costa, Hughes, & Menezes, 2013; Oliver, 1996a; Shakespeare, 2012), however, the right to equitable healthcare and barrier free access to services is a cornerstone of disability advocacy, and social justice for disable people (Braveman et al., 2011; Powers & Faden, 2006).

PWD have historically only commanded re-active, rehabilitative, or palliative approaches to care by healthcare providers (Drum, 2014; Reichard & Turnbull, 2004) potentially reinforcing implicit biases toward disabled persons (Larson, 2008) that result in “unequal referral to screenings, health advice and pro-active health treatments” (Gostin, 2015, p. 2234). The inequities experienced in accessing services regularly recommended and easily accessed by those without disabilities begin to expose the pervasive prejudices found within our healthcare system against PWD. This might explain to some extent why healthcare facilities, diagnostic equipment and practices were designed and developed without attending to the needs of PWD. These forms of discriminatory ableism⁶ (Campbell, 2001, 2009) could reveal that these ‘healthcare’ experiences and their meanings directly negatively influence and impact the health of a PWD in ways rarely considered.

Ethnic and minority groups that experience discrimination by healthcare providers have documented the negative impact of these type of experiences on their health and influences on long-term chronic conditions. Research has documented that experiences with discrimination have a direct contribution to negative health outcomes (Dressler, Oths, & Gravlee, 2005; Harrell, Hall, & Taliaferro, 2003; Lewis, Cogburn, & Williams, 2015; Williams & Jackson, 2005) and African American men and women who perceive to have experienced higher levels of discrimination have worse mental and physical health status (Borrell, Kiefe, Williams, Diez-Roux, & Gordon-Larsen, 2006). For PWD the experiences of discrimination in healthcare come from sources and individuals in positions of power to influence the level or quality of care

⁶ Ableism is defined in many ways however for this study I elect to use Fiona Campbell’s (2001) description and definition which is: “ableism is a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then is cast as a diminished state of being human” (p. 44).

receipt. Discrimination as defined by the ADA itself means “not making reasonable accommodations to the known physical limitations” (www.ada.gov). Choices to speak out against this discrimination ask a PWD to risk negative backlash from self-appointed authorities over what care is deserved or potentially risk removal of services. The civil rights provided in the ADA repeatedly require individual efforts to enforce, and as described by Kailes (2007) result in reports from PWD that seeking care becomes too “exhausting or degrading leading to postponing or avoiding care” (p. 5).

2. **Enforcement and implementation of the Americans with Disabilities Act in healthcare**

Provisions targeting access barriers were included in the Affordable Care Act (Peacock, Iezzoni, & Harkin, 2015) and Section 4203 of this act charges the United States Access Board to establish and implement equipment standards for all healthcare facilities (Pharr, 2013). The absence of accommodations to access healthcare may have a much broader impact than on an individual’s immediate healthcare needs. If this omission is interpreted as an intentional lack of concern for clients with disabilities - stemming from provider prejudice against PWD - the long-term consequences of the experience of this form of discrimination might be one of the most significant contributors to the health disparities of disabled people. Findings from research on racial/ethnic bias and discrimination in patient-provider interactions suggest these negative encounters have a direct contribution to health disparities for racial and ethnic communities (Balsa & McGuire, 2003; Dovidio et al., 2008). The attitudinal barriers described by PWD are often similar reports of negative patient-provider interactions.

Research and literature exploring the healthcare disparities of people with disabilities focus on disparities in access (Drainoni et al., 2006; Iezzoni et al., 2000), disparate health

outcomes (Reichard et al., 2011), experiences with barriers and discrimination in healthcare settings (Gill, 2006; Pharr, 2014; Veltman, Steward, Tardif, & Branigan, 2001), and reported consequences of these barriers (Dillaway & Lysack, 2014; Neri & Kroll, 2003). However, among the studies that identify the different barriers and describe the experiences of PWD as they encounter these barriers, no study asks PWD how these encounters influence thoughts, beliefs and behaviors regarding their choices to self-advocate for accommodations to access services. Further, no study has explored the ascribed meanings PWD give to the demands for repeated accommodation requests - often ignored - simply to access healthcare services readily available to the non-disabled population.

Other studies have explored the experiences of self-advocacy for rights to access in contexts such as education (Griffin-Basas, 2015; Malhotra & Rowe, 2014; Paetzold et al., 2008) and employment and work-related accessibility issues (Baldrige & Veiga, 2001, 2006; Engel & Munger, 2003; Gordon, Feldman, Shipley, & Weiss, 1997; Hazer & Bedell, 2000; Malhotra & Rowe, 2014). These studies describe how an individual's past experience, perceptions of fairness, administrative or workplace cultural attitudes, and systems level factors influence a person's decisions to advocate for accommodations more significantly than does knowledge on rights to accommodations. Research on the impact of past experiences in access barriers suggests negative experiences make choices to self-advocate less likely (Kailes, 2007). Dixon-Woods et al. (2006) review of the literature on healthcare access defines the concept of healthcare 'candidacy' that evolves from processes of exchange between individuals and providers when seeking out medical attention. The authors of this systematic review identify this process as critical to choices an individual makes in seeking out future healthcare service. Dixon-Woods et al. (2006) suggest that individual assessment of their own candidacy is a process that contributes

to increasing vulnerabilities in health services utilization, such as use of preventive care versus emergency room care. Perceived ‘candidacy’ for access is “subject to constant negotiation” (Dixon-Woods et al., 2006, p. 10) due to individual, contextual and macro-level phenomenon and these authors encourage further research to understand its role in barriers experienced by PWD.

C. **Purpose of the Study**

While the evidence suggests that past negative experiences directly impact use of services, there is limited exploration of why, when and how people with disabilities choose to advocate for their rights to care. Kailes et al. (2007) suggests that self-advocacy efforts are negatively impacted by the “four F” experiences – frustration, fatigue, fear and failure (p. 5) that develop as the result of repeated discrimination, micro-stressors (Lewis et al., 2015) and micro-aggressions (Sue, 2010). These factors have been documented to contribute to poor health outcomes in other minority communities (Paradies, 2006; Rowe, 1990; Williams, Yu, Jackson, & Anderson, 1997). Griffin-Basas (2015) calls the need to continually request accommodations *advocacy fatigue* and suggests this state “diminishes emotional and physical health” due to “ongoing exposure to stress and discrimination” (p. 1). Understanding the interpretations and meanings of the experiences of PWD as they confront barriers and the need to repeatedly request accommodations may expose how these experiences impact not only immediate care needs but contribute directly or indirectly to secondary or chronic conditions as perceived by the person.

This study seeks to understand the meanings PWD give to their experiences of barriers that necessitate self-advocacy for accommodation to access healthcare facilities or services. Better understanding of PWD’s advocacy experiences can help inform and support advocacy efforts in accessing care and offer greater insight to needed changes within healthcare systems to

make it more inclusive of PWD. It can also provide further evidence of the need for stronger enforcement of the ADA across all of healthcare. Moreover, understanding healthcare access barriers from the perspectives of those that experience and make sense of them is a necessary first step to understanding how lack of accommodations might penetrate and influence the health outcomes beyond lack of receipt of care to include long term and chronic responses.

1. **Research questions**

The overarching aim of this study is to *explore the meaning that barriers to healthcare have for people with mobility impairments as well as the personal and contextual factors that influence decisions to self-advocate for accommodation*. This broad query has two distinct conceptual elements requiring more pointed research questions:

- How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?
- What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?
- Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?

Exploring participant meanings of experiences when barriers exist requiring self-advocacy to receive basic and necessary healthcare can illuminate the factors that influence the choices people with disability make in activating their rights' based requests for accommodations. In the next section of this dissertation I review the existing literature that provides a contextual framework for the study.

III. CONCEPTUAL UNDERPINNINGS

A. Introduction and Theoretical Frameworks

The primary tenet of this study is a disability studies perspective on access to healthcare, using theoretical frameworks from: the social model of disability and critical theories of disability studies and critical legal theories, bridged with hermeneutic phenomenology to explore the lived meaning these experiences might have for PWD in recurring encounters with barriers to healthcare and experiences of self-advocacy. The purpose and goal of the knowledge gained from this exploratory study is to provide a broader understanding of the impact of failures to attend to the health needs of the disability community, and how this represents a continued legacy of discrimination in policy and practice by the U.S. healthcare system against disabled people. It might also demonstrate how the continued presence of barriers to health - despite laws that require their removal – is another example of how “institutions causally interact with impairment in oppressive ways” (Abrams, 2014, p. 3) due to ideologies of disability within healthcare dogmas. I will describe the theoretical understandings that separate the social and medical model perspectives of disability and health and apply a critical perspective from disability and legal frameworks for analyzing the meanings participants give to their experiences.

1. Medicalization and social model analysis of barriers to healthcare

Understanding *why* barriers preventing PWD from accessing healthcare services exist is as important as identifying and understanding *what* barriers exist to comprehensively target barrier elimination and inequitable provision of services. Throughout disability studies literature, descriptions can be found identifying the differences between the medical model and social model of disability. These two models have different views of the causes and remedies of disability and exploring each model provides an appreciation for *why* barriers exist for PWD in

access to healthcare services as well as identifying *what* barriers exist. Exploring the historically dominant medical model offers insight into the ideologies that constrain people with disabilities in access and use of primary and preventative healthcare. The social model provides an understanding of the contextual inequalities of the environment that produce barriers to healthcare for PWD.

B. **The medical model and the process of medicalization**

The medical model locates disability within the individual - as “a tragedy logically separate from and inferior to ‘normalcy’ – instead, in need of cure and treatment” (Corker & Shakespeare, 2002, p. 2). The disabled body is socially categorized with disease and illness, presumably incapable and excluded from participation in activities of health and wellness (Albrecht & Devlieger, 1999). The medical model locates disability within the person and the primary aim of healthcare is to reduce or eliminate disability – optimizing the person’s capacity for normalcy. Rather than seeing an impairment as a natural part of human experience the medical model makes it a pathology (Oliver, 1996a) and if not removed, a mark of inferiority.

A deeper appreciation of the influence of the medical model on the barriers in accessing healthcare services can be gained by analyzing the “medicalization” of the experience of disability (Longmore, 1995; Oliver, 1996b). Medicalization is the process of taking what might be considered a normal life event and turning it “into a medical problem that requires intervention and regulation” (Nettleton, 2013, p. 5). The process of medicalization shifts the production of knowledge from the person to the provider, but also gradually positions the medical community as the social authority over defining and treating disability. Oliver (1996b) offers that “medicalization” occurs because providers “treat disability as an illness rather than as a long-term social state” (p. 36). Medicalization also shifts control to the medical experts (Zola,

1972). In fact, healthcare has been critiqued as a means of maintaining provider social-political control over PWD (Krogh & Johnson, 2006). Jewson (1976) describes the cycle created when providers follow a medical model ideology concerning disability that reinforces a system where all knowledge aligns with disability necessitating medical intervention.

Recent research suggests that many medical experts hold explicit and implicit biases that exclude PWD from receipt of traditional preventive and health promotion referral (Jaffe & Jimenez, 2015) due to pervasive and historical belief that disability and health are incompatible (Drum, 2014; Drum, Peterson, et al., 2009). When providers focus on disability versus health, the medical model oppresses people with disabilities. This begins to expose the complex role that a medical model perspective of disability has on *why* barriers to healthcare services exist for PWD, as *healthcare*, illness prevention or health promotion was never considered to have a place within disability.

C. **The Social Model**

The social model describes disability as “imposed on top of impairment unnecessarily isolating and excluding the individual from full participation in society” (UPIAS, 1975, p. 5). In direct contrast to the medical model, the social model provides a framework for understanding the socially constructed causes of disablement, turning analysis toward the environment versus individual impairment. Disability scholar Oliver’s (1996a) synopsis of the social model is it “insists that disablement has nothing to do with the body...it is a consequence of social oppression” (p. 35). This oppression is in part due to the socially constructed barriers that exclude PWD from achieving full capacity for participation in all life activities. Participation in life activities is described as a “right that is predicated upon access, opportunity, respect and inclusion” (Hammel et al., 2008, p. 1459). Using a social model lens to describe and define

disability exposes multiple barriers to participating in society that grow out of a lack of access, opportunity, respect and inclusion. The barriers stem from “characteristics of the environment that have a discriminatory effect on PWD” (Hahn, 1988, p. 40) furthering the disablement of the person. These characteristics are structural, political, attitudinal, informational and financial and play a major role in limiting participation – disabling – the person in all aspects of social life (Magasi et al., 2015; Panko-Reis et al., 2015).

In accessing healthcare, research describes socially constructed barriers from each of these environmental domains (Iezzoni & Long-Bellil, 2012; Panko-Reis et al., 2004; Panko-Reis et al., 2015). These barriers are social constructions within the environment that fail to consider, include, and incorporate the needs of differently functioning bodies in concerns of maintaining health. Using a more direct social model analysis, the construction of these barriers stem from the medical model ideology of normalcy that prohibits differently function bodies access to healthcare.

The literature on the physical barriers to access and the medical diagnostic equipment clearly identifies that PWD are not considered during design, construction, and implementation (Winters & Story, 2006). Other, less apparent but still palpable barriers, such as a lack of provider knowledge on disability as viewed from the social model might be modifiable if medical curriculums incorporated education on the needs of PWD (Kirschner & Curry, 2009; Shakespeare, Iezzoni, & Groce, 2009). Moreover, disability stigmas are socially constructed attitudinal barriers experienced by disabled people when providers fail to understand a non-medicalized lived experience of disability (Gill, Mukherjee, Garland-Thomson, & Mukherjee, 2016). These are some of the perceived causes to healthcare access barriers and health disparities for PWD when a social model framework is used in analysis. These constructions are also the

primary cause of disablement when exploring the lived world of people with disability through a social model lens.

Using a social model perspective to understand, identify, and target disabling barriers in access to healthcare, health facilities, diagnostic equipment and services provides an appreciation of the different needs of disabled people in order to optimize capacity for health. To attend to the health of all bodies, systems of social organization and environmental structures (Shakespeare, 2006) that disable and prevent participation in healthcare access and health services demands full examination. The historic exclusion of the needs of disabled people in consideration of medical equipment design and use in health services is a direct result of society's exclusion of PWD from full and equal access to participation in activities that promote and enable optimal health. These socially constructed barriers place the onus on the PWD to recognize the disparate treatment and have strategies and skills to overcome them, including the demand for recurring accommodation requests in order to meet basic health needs. If these multiple demands are beyond individual capacity, access may be denied, reducing efficacy for attempts in the future (Panko-Reis et al., 2015). The social model provides a critical evaluative mechanism for analyzing the mismatches between personal capacity and environmental inaccessibility that produce disablement and prevent participation.

The social model has been critiqued for attending solely to the social construction and production of disability. Researchers have argued for attending more specifically to the intersection between individual capabilities and the environment (Drum et al., 2009; Magasi et al., 2015; Shakespeare, 2012). Hughes and Paterson (1997) argue that while the social model's "separation of impairment and disabilities has been of great value in establishing a radical politics of disability" this falls short in attending to the "mutually incorporated experiences of

impairment and disability” (p. 598). Nowhere else might these mutually incorporated experiences occur than in contexts of seeking, interacting and responding to healthcare services and with healthcare providers. In fact, Oliver (1996b) argues that the medical model has a valuable role for working with PWD to care for their impairment condition, treat illness and maintain health but he cautions provider claims of authority in attempts to treat disability (p. 36).

Failure to implement and enforce accommodations to meet the healthcare, health promotion and illness prevention needs of PWD is tantamount to continuing the oppression and discriminatory practices of medicalization. Civil and human rights laws such as the Americans with Disabilities Act (ADA, 1990) and the Rehabilitation Act of 1973 recognize the need to provide accommodations to hurdle socially constructed barriers to optimize access for participation in healthcare (Shakespeare, 2012). However, limited enforcement of these laws places the demand to ask on the person. The ADA as a law rings hollow because of the lack of enforcement coupled with deeply rooted socially constructed prejudices of disability within the context of healthcare.

Understanding the medical model’s influence and use of a social model lens helps comprehend how both providers and people with disability might perceive barriers that prevent access to care. If a person’s view is framed from a medical model perspective the architectural and physical barriers might not be recognized as acts of exclusion and those barriers stemming from the social ideologies that health and disability are mutually exclusive may be hard to recognize for what they are. This posits how being exposed to differing frames of reference might change or influence perceptions. Using the social model as a framework in analysis will assist in identifying and interpreting experiences of PWD as they describe recognizing the need

for an accommodation, and provide for a deeper appreciation of the differing factors that influence decisions to self-advocate.

D. **Critical Theories: Critical Disability Theory – Critical Legal Theory**

Critical race theory (CRT) and critical legal theory (CLT) explore the logic and structure of rights based laws and the relationship these laws have in reducing or supporting the injustices of society (Delgado & Stefancic, 2013). Using a CLT might further an understanding for *why* there continue to be powers that oppress, socially constructed yet modifiable barriers, and lack of accessibility experienced by PWD and increase knowledge and mastery on understanding and targeting *what* barriers we know to exist as informed by the social model of disability.

According to Rioux and Valentine (2006) “theory matters, to unravel the complexities associated with the intersection, meaning, and development of policies, laws and practices of disability” and equality efforts in healthcare access (p. 47). Application of a critical theories perspective in this proposal provides a framework for understanding the civil rights to accommodations in healthcare as they collide with provider assumptions and interactions that produce differential and unequal access. Critical legal theory emerged from critical legal studies to analyze the intersection of laws as created, interpreted, informed and applied by the social organizations they exist within and how these laws often support the status quo for those in positions of power (Unger, 1983). Critical legal theory analysis is appropriate for this research proposal as it challenges the effectiveness of legal discourse and legislation that exists without parallel efforts to implement social change (Asch, 2001). Moreover, critical theories used in research examine the lived experiences of those that are most impacted by the social structures that “maintain a status quo of power despite an existence of legalities” (Scotland, 2012, p. 13).

In healthcare access, despite anti-discrimination language from the ADA that state healthcare facilities and procedures should be fully and equally accessible and healthcare be of equal quality, many systematic and programmatic barriers create patterns that disadvantage PWD (Yee & Breslin, 2010). Critical analysis offers a chance to more deeply explore these patterns as they exist in creating healthcare access barriers as well as how they are maintained. This level of analysis is called for as “patterns of systematic disadvantage linked to group membership are among the most invidious, thorough going, and difficult to escape” (Powers & Faden, 2006, p. 88). Using critical inquiry as a means of interpreting the interpretations of lived experiences of barriers might offer an opportunity to reveal *what* patterns and practices in healthcare exist, to discern better if they are in fact patterns of discrimination against PWD.

1. **Critical theory and civil rights laws**

With the passing of the ADA the United States recognized “people who are disabled share the disenfranchisement and disadvantages which establish a group claim to minority status and that this ‘new’ minority group should have civil rights protections” (Schriner, Rumrill, & Parlin, 1995, p. 487). Schriner et al. (1995) describes this new ideology regarding disability represented a “metamorphosis” in cultural and political thinking about disability (p. 487). Just how organizations recognize how PWD are disenfranchised and systematically discriminated against is complicated by how embedded the old ideologies of disability are within society. Within healthcare, the medical model continues to prevail – the social model is almost an unknown – in how disability is approached, offering a critical understanding for why the legal mandates of the ADA has had minimal influence on healthcare accessibility.

The combined impact of Section 504 of the Rehab Act, Title II and Title III of the ADA and the ADAAA (2008) should have had sufficient enforceability that no clinic or hospital and

its services be inaccessible to any person on the basis of any form of disability. However, lack of accessible accommodations exist throughout the United States healthcare system, and are frequently described by people with disabilities as a leading cause for limited use of healthcare (Reichard et al., 2014). Supreme Court decisions have often been the process for real enforcement of the ADA, such as the 1999 *Olmstead* case that found states have an affirmative obligation to provide services to persons with disabilities who receive Medicaid in the least restrictive environment possible (*Olmstead v. L.C.*, 527 U.S. 581, 1999). The ADA Accessibility Guidelines for Buildings and Facilities (ADAAG)⁷ require architectural features of a building be accessible to PWD but does not include standards for medical equipment (Pendo, 2010).

Concepts of equal and meaningful access⁸ “requires access that enabled recipients of services to benefit from them in a reasonable way comparable to how others have use of them” (Francis & Silvers, 2008, p. 453) do exist. This complex and ambiguous concept has been used in legal claims, such as *Metzler v. Kaiser* that disparate care occurs with failure to provide accommodating equipment (*Metzler v. Kaiser Foundation Health Plan*, 2001). With the addition of the U.S. Access Board’s recommendations, ambiguity of equal and meaningful access is significantly reduced although, without enforceability requires healthcare institutions commit to that metamorphosis in ideologies as well as practice approaches.

⁷ U.S. Architectural & Transportation Barriers Compliance Board, Americans with Disabilities Act (ADA), Accessibility Guidelines for Buildings and Facilities, available at <http://www.access-board.gov/adaag/ADAAG.pdf>.

⁸ The meaningful and equal access debate is frequently used in understanding access to health insurance and is historically significant in the case of *Alexander v. Choate*, 469 U.S. 287 (1985), however, is appropriate when considering equal and meaningful access to medical equipment and healthcare services to those provided to people without disability.

Even with a shift in perspective - that PWD may require accommodations to access care - the persistence of medical model ideologies of disability will cause healthcare systems to respond on a case by case, individual need to accommodate. This approach fails to respond to the intent of the laws that view the disability community as a marginalized minority group demanding sweeping changes at the systems level. This critical application of understanding the law's application within healthcare offers an understanding on *why* barriers continue to exist. Using this framework to understand the persistent and pervasiveness of a lack of accommodation provides a foundation for exploring the lived experiences of accessing necessary healthcare as a PWD.

2. **Critical disability theory**

Critical disability theory delves into “issues of power” focusing a “sharp awareness toward the contexts of inequality based on disability” (Pothier & Devlin, 2006, p. 9). When healthcare providers fail to incorporate accommodations for PWD to access the care those without disability receive with ease, these are issues of power that perpetuate inequalities. The medical model isolates causes of health disparities firmly within the individual with disability (Carlson et al., 2012) and call for remedies through medical intervention. This view systematically segregates the disability community from more than full participation in society, it segregates persons with disabilities conceptually from the capacity of fully participating in *health*. Braveman et al. (2011) describes the need for nondiscrimination and equality in health without distinction based on physical, mental, or emotional disability or illness, that targets intentional but also unintentional treatments embedded in structures and institutions regardless of whether there is conscious intent to discriminate (p. S150). For persons with disabilities,

experiences of discrimination especially in the realm of healthcare are linked to the structures and power created by policies and practices that control much of their access to care.

Critical theories such as critical disability theory reflect on the laws that exist such as the ADA, Rehabilitation Act (1973) and Affordable Care Act (PPACA, 2010, Pub. Law 111-148) and how they might be better used - not just to litigate injustices on an individual basis - but also challenge the social status quo. These civil rights laws⁹ are designed primarily to “promote equality, access, and integration” (Roberts, 2012, p. 1964) for PWD into all of society including healthcare utilization, to citizens of the United States. However equal treatment, access and integration requires fundamental changes in provider’s knowledge and assumptions toward PWD. While these laws prohibit discrimination, the influence of the legislation on reducing access barriers has been questioned (Pendo, 2010; Roberts, 2012).

Where legislation provides the grounds for legal action, often the motivating force for implementing accommodations or changing practices and policies is public pressure (Harpur, 2014). However, how these laws are either upheld or violated in routine healthcare practices and on individual levels rarely become public. Using a critical disability perspective to explore these experiences can expose the layers of oppression that may be acting to dim perceptions that barriers or discriminatory acts have in fact occurred. Oliver (1996b) provides a social analysis that “discrimination exists because of institutionalized practices of society” (p. 76). How embedded these practices are requires a critical disability analysis of the roles of disability and impairment as they intersect with the built and social contexts of healthcare. Critical disability theorists that explore concepts and discourse on impairment and disability (Corker &

⁹ The Affordable Care Act is technically a ‘health law’ that regulates healthcare access and promotes public health and welfare but has been argued to be “one of the most significant civil rights laws for the disability community in recent history” (Roberts, 2012, p. 1964).

Shakespeare, 2002; Shakespeare, 1996, 2012), understandings of disability from a social relational perspective (Thomas, 2004a, 2004b), and how embodied intersections of identities blend with disability and impairment to impact and inform the lived experience (Siebers, 2007, 2017) of healthcare access will be used to inform the analysis of participant experiences.

3. **Critical theory analysis of barriers to healthcare**

Using critical legal and critical disability approaches in analysis of the impact or influence of civil rights legislation in healthcare provides a framework for understanding the complexities involved in forms of discrimination. This form of discrimination can be exposed and analyzed as “claims of discrimination in the forms of differential treatment” people with disability encounter (Crossley, 2000, p. 63) to increase knowledge and mastery on targeting *what* barriers we know to exist. More than removal of physical barriers to get into healthcare facilities – which research shows has been generally successful (Yee & Breslin, 2010) – it is the attitudinal barriers that influence decisions providers make when interacting with PWD that often prove to be most challenging. The choices providers make to avoid treating PWD (Akhavan & Tillgren, 2015), lack of provider knowledge on living with disability (Iezzoni & Long-Bellil, 2012), and administrative level decisions to exclude equipment and practices that accommodate PWD (Pharr, 2013) are the more subversive forms of discrimination that might be critiqued using a critical theory lens. This lens can also explore how individual and collective disability advocates successfully use the laws to gain access.

Critical disability theory serves to analyze the ADA and civil rights legislative impact on how interpretations of meaningful access to accommodations might be influenced by healthcare systems’ biases of disability. What meaning do laws have in the healthcare context for reducing issues of power and inequality for the individual person? Using critical theory can explain how

continued patterns of differential treatment and substandard medical care from providers are acts of discrimination and violations of civil rights but not always perceived as such.

Philosophical underpinnings of critical theories analyze the language contained in laws and how they are interpreted (Creswell, 2013). This highlights why critical theory is an important tool in analysis of the ADA, as how it is interpreted by a single person can represent how it is interpreted by larger society. If the interpretation allows for the continued practice that maintains the status quo to reject requests of accommodations and produce disparate outcomes in health then the ADA, and other law, is of little support to PWD in this context. However, if the ACA and Access Board enforce requirements of all healthcare practices, and medical equipment design, the ADA in conjunction with the ACA may tremendously change the status quo, reducing the power of the provider to control access for PWD in healthcare. I believe choosing critical theory as a conceptual framework to guide this study's analysis offers an opportunity to understand the current hegemony and injustices that exist within the healthcare system as experienced by PWD to identify and understand patterns that limit access and contribute to healthcare disparities of PWD.

IV. METHODOLOGY, STUDY DESIGN, AND METHODS

A. Introduction

Asch (2001) eloquently argues for a better understanding and recognition of how the daily insults and “denied opportunities to participate in routine social roles” are justifiably interpreted by PWD as discrimination (p. 2). Despite literature describing barriers to healthcare and the role of failed accommodations to healthcare receipt, there is little to no research exploring how PWD interpret these experiences and their influences and impact. This research study explores these experiences to fill this gap through the use of Interpretative Phenomenological Analysis. To better understand the human lived experience, IPA demands a researcher examine the meaning and interpretations people give to the experience (Smith, Flowers, & Larkin, 2009). This qualitative approach also recognizes the important role of the researcher to the process of interpretation I recognized as critical to answering the research questions. IPA acknowledges the researcher role (Biggerstaff & Thompson, 2008) and necessitates exploring researcher’s thoughts and inquiries into understanding participants’ experiences as a legitimate component to understanding the answers that emerge to the research questions.

This chapter describes the methods used throughout this research study to explore how PWD make sense of their experiences in healthcare settings when accommodations are needed but absent. This introduction begins (1) with a restatement of the research questions, followed with the (2) rationale provided for a qualitative methodological approach to answer the questions and (3) why the qualitative method of IPA was selected for exploring and analyzing the participants’ experiences in healthcare. Section 4 describes my understanding of how my position as a researcher influences the overall process and findings of the study, detailing my

approach to bracketing, and an analysis of how my role as a researcher informs this study. The following sections will then describe in detail the study design and methods for data collection and data analysis.

1. **Research questions**

This study seeks to *explore the meaning that barriers to healthcare have for people with mobility impairments as well as the personal and contextual factors that influence decisions to self-advocate for accommodation*. Specifically, I sought to address the following research questions for this investigation:

- How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?
- What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?
- Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?

The focus of this research study evolved through work as a research assistant on a variety of funded grants aimed at understanding and addressing barriers and supports to healthcare access, quality and outcomes for PWD. Participants in these studies described a broad range of physical, informational and attitudinal barriers with the healthcare system that limited their access to care and made it necessary for them to self-advocate for accommodations. While not the explicit focus of these studies, I identified that people with disabilities had to make decisions in the moment about when and how to self-advocate. There is a paucity of research that describes the processes and contextual factors that influence people with disabilities' decisions to self-advocate within the healthcare system. These research questions hope to provide a better

understanding of those unknown contextual factors that impact self-advocacy in healthcare for PWD.

a. **Methodological approach**

In their book *Disability and Qualitative Inquiry: Methods for Rethinking an Ableist World*, Berger and Lorenz (2016) argue that use of qualitative approaches in disability studies and of the disability community should “aim to ‘give voice’ to those who have been marginalized by society, making their experiences more visible and accessible to mainstream” (2016, p. 6). Disability scholars recommend using qualitative research approaches to help “develop richer understanding” of a person’s experiences with barriers in healthcare (Shakespeare & Officer, 2014, p. 1487) and “more thoroughly explore complicated phenomenon” concerning the impact of the ADA on the lives of PWD (Harris et al., 2014, n.p.). These arguments make this an ideal approach to understand how the meaning of past experiences informs decisions to self-advocate for accommodations.

The canon of qualitative research is rich and diverse therefore, the qualitative researcher must make decisions about the appropriate methodological framework to address the concepts of interest (Creswell, 2013). Methodological choices in turn guide the tools and techniques used for the rigorous conduct of the qualitative study from design through dissemination. Carter and Little (2007) call for the recognition of the relationship between epistemology, methodology and method and assert that it is the researchers’ careful consideration about their fundamental beliefs about how knowledge is created that drives methodological choices. My theoretical stance is grounded and balanced by two frameworks for knowledge creation. First, the social model of disability as it exposes negative experiences of disability occur when differently functioning bodies and minds encounter barriers in the built and social environment. Second, critical

theories' have the power to explore the rightful interpretations of these experiences as discrimination and oppression. These two epistemological convictions led me to select phenomenology as the appropriate methodological framework for this study.

Phenomenology provides an opportunity to explore the meanings that people construct about their lived experiences and was selected as the most appropriate methodology for addressing my research questions. Phenomenology provides an opportunity to explore the meaning of experiences with barriers in healthcare for PWD and how they make sense of the need to advocate for rights to care within a context with a “historical legacy of discrimination” (Longmore, 1995, p. 83). IPA allows examining the lived experience in detail to understand how participants make sense of these experiences (Smith, 2011).

b. **Qualitative method – Interpretative Phenomenological Analysis**

The health psychologist Jonathan Smith (1996) first described Interpretative Phenomenological Analysis in a paper titled “Beyond the divide between cognition and discourse: using Interpretative Phenomenological Analysis in health psychology.” IPA is grounded in the participant’s lived experience but acknowledges that the meaning people ascribe to their experience is socially constructed as they try to make sense of it. IPA further acknowledges that as part of the analytic process, researchers also engage in a hermeneutic process of meaning making about the data. This double hermeneutic process draws from the wider corpus of phenomenology in order to empathetically understand through close analysis of the participant’s own interpretations (Smith et al., 2009). IPA moves beyond a participant’s description of an experience to achieve what van Manen (1990) describes as an “elucidation of the lived meaning” of that experience (p. 27). IPA embraces the uniqueness of the individual and uses an idiographic single case analysis approach, followed with “detailed analysis of divergence

and convergence across cases” (Smith et al., 2009, p. 200). In this study, IPA was used to explore the meaning of the unique individual experiences of each person with disability as they negotiated the processes to access healthcare. It also provided a framework by which similarities across participants were explored to allow for a more transferable understanding of people with disabilities’ self-advocacy efforts within healthcare when accommodations are needed.

c. **Hermeneutic phenomenology**

IPA combines phenomenological and hermeneutic philosophical frameworks to understand how people make sense of their lived world. The approach uses a phenomenological stance to deeply examine and understand the individual experience on its own account but then demands understanding and embracing the role hermeneutics has in how both researcher and participant interpret the experience. “Without the phenomenology there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen” (Smith et al., 2009, p. 37). Indeed, van Manen’s claim that “a description can aim at lived experience but somehow fail to elucidate the lived meaning of that experience” (1990, p. 27) acknowledges that merely describing people with disabilities’ discrimination in healthcare is not enough to fully understand how these experiences shape future decisions about how and when to self-advocate. This reinforces the utility of using an interpretive phenomenological approach to examine the meaning of these experiences. Where the social model questions and provides a new understanding of the construction of disability for a person with impairment, and critical theories question the “economic, political and social practices of oppression” (van Manen, 1990, p. 176), phenomenology contemplates the meanings of these lived experiences. A phenomenological analysis also ‘allows’ the lived experience of impairment and other embodied needs of an

individual to be explored to better understand their influences on the everyday choices when interacting within the healthcare context as a person with disabilities.

Identifying the meaning of these interactions requires accurate interpretation of the narratives of individuals' experiences of exclusion during healthcare encounters. In order to study this experience a phenomenological framework explores the "important dimensions of experience and meaning that lead to behaviors" (Daniels, 2005, n.p.) of self-advocating or not self-advocating. A phenomenological lens provides for an inter-actionist perspective of how the social construction of disability and encounters of barriers to healthcare is more than a failed accommodation but may be a phenomenon of significant meaning for PWD.

IPA draws on Heidegger's interpretive approach to phenomenology, referred to as hermeneutic phenomenology as it is a synthesis of hermeneutics - the theory of interpretation - and is dependent on language as the means to individual interpretation. Heidegger believed pure description of phenomena was humanly impossible because it is through language that we describe and language is implicitly tied to interpretation (Smith et al., 2009). Gadamer in *Truth and Method* (Gadamer, 1989) repeatedly describes hermeneutic phenomenology as 'a path of experiencing' through the exchange of words used to interpret meaning and understanding between one person and another. This involves consideration of the "social, cultural and gender processes" that reciprocally co-create interpretations of experience (Dowling, 2007, p. 132). Extending this process to research of issues to disability requires considering the implications and interpretations of living and being in the world as a disabled person (Finlay, 2011; van Manen, 1990). In interpretive phenomenology, this process is described as the hermeneutic circle - the researcher interpreting the meanings of experiences as the participant is describing it - demanding an intimate relationship between researcher and participant (Smith, 2004).

Phenomenology as an approach to explore the lived experiences has been suggested as a means to rework the social model of disability to better “incorporate all the complexities of being disabled” (Hughes and Paterson, 1997, p. 602). This complexity includes the argued inability to separate impairment from disability. Turner (2001) describes phenomenological approaches to disability studies as a “crucial challenge to the assumptions of the medical model, which assumes a clear division between mind and body” that neglects to include the subjective and personal accounts of experience during encounters with others (p. 254). Use of phenomenology, as a methodology to explore experiences of disability is common within the disability research literature (Cassidy, Reynolds, Naylor, & De Souza, 2011; Dhillon, Wilkins, Law, Stewart, & Tremblay, 2010; Harrison & Stuifbergen, 2006; Tighe, 2001) with a growing literature based on discussions pertaining specifically to impairment-disability social construction (Abrams, 2014; Diedrich, 2001; Hughes & Paterson, 1997; Schillmeier, 2007). Toombs (1995) suggests that using phenomenology to explore the lived experience of disability can provide “invaluable information about the everyday world of those who live with disabilities” which help “determine how best to address the personal, social, and emotional challenges” experienced by people with disability (p. 10). Understanding the meanings of experiences and how these meanings come to make sense to a person might occur from the context and language that inform the perceptions of an individual (Smith, 1996). A means to explore this sense making process is Interpretative Phenomenological Analysis (IPA).

IPA was developed in health psychology and according to a systematic review of IPA literature the most common experiences explored using IPA is the study of illness experiences (Smith, 2011). Upon deeper analysis, much of the “illness research” is actually a study of living with disability. Indeed, these studies describe themes such as the experiences of stigmatization

(Dickson, Knussen, & Flowers, 2007, 2008; Murray & Rhodes, 2005) and threats to normative identity (Marriott & Thompson, 2008). Similar themes of oppression and discrimination against people with disabilities have been described in the disability studies literature, indicating that IPA is an appropriate methodological approach for exploring these social constructions.

IPA focuses on a psychological and interpretive examination of lived experience. IPA attends to using interpretation that favors researchers becoming part of the interpretative process through empathetic understandings and reciprocal exchange. It shares common approaches in connecting phenomenology and hermeneutics with work of phenomenologist Max van Manen (Smith et al., 1996). According to van Manen (1990) the empathic process represents “the researcher’s ‘intentionality’ as they strive to know that which is most essential to being” (p. 5). This reciprocal exchange between researcher and research participant corresponds as well to the processes of participatory knowledge production that leaders in the disability community encourage when exploring issues that concern them (Kitchin, 2000; Oliver, 1992).

Finally, my orientation as a disability studies scholar and ally drove my selection of IPA as a method of choice, as it asks researchers to “engage with the personal accounts of those who are always-already” immersed in the lived experience (Larkin & Thompson, 2012, p. 102). According to Smith and Osborn (2007) this process requires a two-stage interpretation – “the individual is making sense of their world experiences and the researcher works to interpret the participants trying to make sense” (p. 53). It is this collaborative approach to exploring the making sense of the world a person with disability lives in that intrigues the occupational therapist and disability studies scholar intersection in me.

d. **Positionality and researcher role**

Given the central role that the researcher plays in the IPA process, it is critical to make transparent what the researcher brings to the process. Indeed, van Manen (1990) suggests that in phenomenological interpretation the “risk is often not that a researcher knows too little of the phenomenon under investigation but that a researcher knows too much” (p. 46). My work as an occupational therapist and as a research assistant exploring the healthcare access concerns of PWD gave me a frame of reference for formulating presumptions and assumptions of why a disabled person would or would not decide to self-advocate for an accommodation in a healthcare setting. My position as provider must be acknowledged both for how my experiences and knowledge inform my belief of disability and also how it might influence the participants. My own experiences in self-advocacy shaped my ideas about ‘what self-advocacy is’ or what it means to decide to self-advocate – but from my own social, political, economic, cultural and able-bodied world. I do not self-identify as a person with a disability and so “do not know the inside experience of being disabled” (Gill, 1994, p. 49). By acknowledging and making explicit my positionality, I purposefully integrated strategies to minimize potential biases at each stage of the research process.

My approach throughout the research is guided by the disability community’s mantra of ‘nothing about us without us’ (Charlton, 1998) and strategies of peer examination and member checking by members of the disability community are embedded through my research design. By really listening to the disability community, I was able to explore the issue of self-advocacy in healthcare for PWD beyond the vantage point of my own knowledge and life experiences and help ensure my findings represent the participants’ experiences (Patton, 2002). One approach

used throughout this research study was the bracketing of presumptions that influence my interpretations (Merleau-Ponty, 1996).

e. **Researcher role**

I entered this research project as a person with a background in healthcare, academically educated in a system with biomedical epistemology biases to the causes and cures of disability void of any input or voice from the disability community (Linton, 1998). I was, and still am drawn to occupational therapy because of its commitment to viewing the whole person, addressing issues of social inclusion, social justice and enabling occupational participation (Townsend & Wilcock, 2004). However, disconnects exist between what my profession identifies as its mission and the medical systems it works within (Frank & Polkinghorne, 2010; Hammell, 2013) that I feel pull me in two different directions. Therapy is restricted to evaluations and interventions that remain internally focused on the individual versus external to the social barriers that prohibit participation and limit capability. Through personal experience of family members with disability, an advocacy attitude infused early in my childhood, growing older and flirting with the disabilities I will confront, and listening to disability advocates, I recognize most client-centered care locates disability in the person and fails to achieve the potential of occupational therapy.

Despite growing understanding that the profession needs to move away from its focus on the individual to address the larger socio-political environments that disable (Kirsh, 2015; Paul-Ward, 2009) the discipline of occupational therapy remains trapped in a world of the medical model. My personal attempts to incorporate interventions addressing autonomy and ownership of the rehabilitation experience in a partnered intervention (VanPuymbrouck, 2014) were fleeting and lost in the systemic demands to attend to G-codes and reimbursable treatment (Doucet,

Woodson, & Watford, 2014). My attempt to include the client's voice in treatment planning led to my discovery of the social model and disability studies.

Over the years, I have developed close working and friendship relationships with disabled people, which exposed me to my own medicalized views on disability. I am critically conscious that I am still influenced by this despite having a better appreciation of its influence on me. I continue to develop a heightened understanding that those that live with disability must be involved in identifying the skills and strategies needed to navigate society and participate in meaningful occupation. I have a new attitude of the causes of disablement and see my new relationship in elimination of the medicalized social construction of disability (Finkelstein, 1980). My location provides me with a unique perspective as both a knowledgeable disability advocate and knowledgeable healthcare provider who understands the need to dismantle the medicalization process that currently exists within occupational therapy. In my role with this research, I embrace my own transformation from a medical expert reporting on the impact of disability to a lifelong "active learner who will work to tell the story from the participant's point of view" (O'Day, 2002, p. 10).

Finally, I come to this research with an appreciation for my position in the larger society and how this influences my role as researcher. I am a white, educated, able-bodied woman. I realize no matter how well I know how to properly transfer, do range of motion exercises, joint protection, or wheelchair management - I do not know first-hand the experience of living in a world of discrimination and marginalization based on disability status. I have and do experience forms of sexism and ageism; I have never experienced extreme poverty, disability and racial discrimination, but I have observed and felt its impact on friends and family.

I am fundamentally aware that each person is the expert of his or her own lived experience. However, I am also aware that my own experiences and preconceptions can bias and influence my research questions, methods, and interpretations in analysis. I acknowledge my positionality will influence my interpretation but my goal is through constant and detailed self-reflection and audit trailing throughout the process I can expose my biases and achieve a greater level of transparency of when and how my interpretations influence the research. With a humility toward others I am focused on listening and learning in hopes to achieve what Kohut (1959) describes as empathy – “a sympathetic understanding of the introspection of another” (p. 463) in all of my work with partners in the disability community.

f. **Bracketing**

Bracketing is defined as the “act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world” (van Manen, 1990, p. 175). Many qualitative researchers contend that suspending one’s biases is impossible and that acknowledging biases is a more realistic tool for enhancing the analytical process (Corbin, Strauss, & Strauss, 2014). I identified three fundamental beliefs that I bring to this research. First, PWD experience oppression within the healthcare system and that systems of oppression are deeply embedded within the social structure of the healthcare delivery. Secondly, the power and hierarchy that providers have in relation to PWD is pervasive. Finally, I believe that PWD may or may not recognize the influences of these processes in their own healthcare decision making, yet these experiences influence the decisions about when and how to self-advocate for an accommodation in a healthcare setting. I further acknowledge that there may exist deeper social, cultural, economic, professional, and ableist biases of which I am not consciously aware.

IPA suggests that bracketing and the use of the hermeneutic circle of interpretative engagement allows the researcher to shift focus, bracketing out the researcher's preconceptions to allow for intense engagement to the participant's description of the experience and how they make sense of it. The researcher then returns to their own knowledge base to guide the interpretation of a participant's description (Smith et al., 2009).

My methods for incorporating bracketing are guided by Tufford and Newman's (2012) that embraces the "multifaceted nature" (p. 87) of bracketing and provides a systematic approach. They suggest that bracketing is "meant to access various levels of [researcher] consciousness ... to the extent the researcher as instrument maintains self-awareness as part of an ongoing process" (Tufford & Newman, 2012, p. 88) to enhance the research process. I integrated bracketing into each stage of the research process: project conceptualization, development of research questions, data collection, data analysis, and during the writing phase.

For this project, I created a series of three reflective journals to organize my thinking. These reflective journals include: 1) a methodological journal to track decisions that shaped my methodological choices across the study; 2) an ideographic participant journal with a chapter for each participant; and 3) a hermeneutic journal to reflect the analytic process of meaning making from engaging with the participant data. At the outset of the project, I started my methodological journal to help me as I deliberated about the research and conceptualized how it might take shape (Denzin & Lincoln, 2011; Ortlipp, 2008). I formulated and revised research questions and interview questions based on written reflections of conversations with mentors and members from the disability community.

During data collection, I created the ideographic participant journals that include my preconceptions of how the interview might unfold, based on what I knew of the person from

previous encounters. I included in this journal memos that I wrote immediately following each interview and any thoughts or concerns I had in the following days. In my own hermeneutic journal, I kept close account of emerging themes or new interpretations that developed from one case to the next. This approach is consistent with the acknowledgement within IPA that “iterative process ideas can develop and change research questions following a previous interview” (Smith et al., 2009, p. 60). During data analysis, I documented in the hermeneutic journal new concepts and how they influenced my coding and interpretations from one case to the next. I returned to the participant journal, to revisit the person in efforts to clear my mind of outside influences of other participant interviews. Throughout the analytic process, I went back and forth between the idiographic participant journals and the hermeneutic journal to ensure that my interpretations were deeply grounded in the individual participant experiences while also attending to the larger themes and sub-themes from across cases. IPA approaches this as the hermeneutic circle of interpretation – “to understand any given part, look at the whole, to understand the whole you look at the parts” (Smith et al., 2009, p. 28). This non-linear and iterative process opened opportunities for the researcher to influence the findings, my rigorous use of bracketing helped me to recognize how my positionality shaped me as the instrument for analysis. My efforts to bracket throughout the process has helped me and hopefully readers to see how the researcher I am might hinder the findings as well as provide new insight into the phenomenon it is exploring.

B. **Study Design**

Interpretative Phenomenological Analysis approaches were used for all data collection and data analysis of this research. Data collection in IPA is based on semi-structure interviews that use an Interview Question Schedule to guide the collection of participant’s subjective reports of their experiences. Data are analyzed using a case-by-case inductive and iterative qualitative

analysis of interview transcripts (Smith et al., 2009). IPA uses an ideographic approach—focusing in on the particular experience and the meanings created by a given person in a given context. Attending to this I used a case-by-case process of data gathering followed by a case-by-case inductive and iterative process of qualitative data analysis. Finally, individual cases are compared and contrasted to identify similarities and difference. Figure 1 provides a flowchart of study activities.

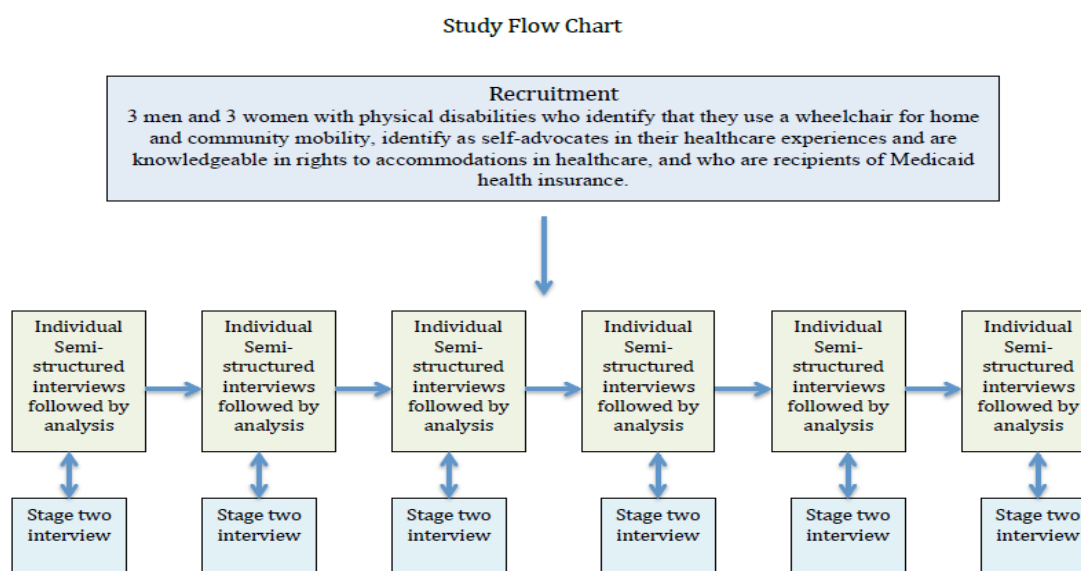


Figure 1. Flow chart of study activities

C. Methods

1. Participant recruitment

IPA research is committed to understanding how a particular phenomenon is experienced and interpreted from the perspective of a specific group of individuals, they “represent a perspective not a population” (Smith et al., 2009, p. 49). Purposeful selection of

participants is recommended to ensure participants identify as having experienced the phenomenon being explored. Due to the detailed case-by-case analysis of each participant interview, relatively small homogeneous samples are recommended - between three and six participants (Smith et al., 2009).

For this study, I considered different demographic factors that could define the homogeneity of the sample such as socioeconomic status, gender, and insurance type. Based on critical reflection and input from people with disabilities, disability studies scholars, and researcher mentors, I identify discrimination experienced within the healthcare system and the need to self-advocate as the critical factor that defined the homogeneity of the target population (Iezzoni, Frakt, & Pizer, 2011; Iezzoni, Kilbridge, & Park, 2010; Pharr, 2013; Phelan, Lucas, Ridgeway, & Taylor, 2014; Shakespeare, 2012; Stuber, Meyer, & Link, 2008).

a. **The role of gender – a secondary consideration**

In their research exploring disability identity and disability rights in employment Malhotra and Rowe (2014) describe that intersections of gender and disability do impact a personal sense of agency specific to practical life decisions - including decisions to request accommodations in the work place. Disability scholars describe how gender and societies' cultural expectations of woman and men can alter the meanings of disability and social interactions (Fine & Asch, 1988; Wendell, 1996). The salience of how gender might impact experiences of addressing failed accommodations lead to the decision to recruit an equal number of men and women in the hope that if gender differences did emerge during analysis the minimum recommendation of a sample size of 3 in IPA research (Smith et al., 2009) would allow gender identified themes to be more thoroughly explored.

b. **Inclusion/exclusion criteria**

This study purposively recruited three men and three women older than 18 years of age, who self-identify as a person with a physical disability who uses a wheelchair as their primary mode of home and community mobility; identify as self-advocates in their healthcare experiences; are knowledgeable in rights to accommodations in healthcare; and who have had a minimum of one healthcare visit in the last 24 months that might necessitate a physical accommodation. choice to focus exclusively on PWD who identify as self-advocates stemmed from the study's overarching focus on understanding factors that influence decisions to self-advocate or not. In order to fully explore the factors that influence decisions to advocate or request accommodations, participants in this study had to understand their right to make the request and perceptions of being a self-advocate. Individuals were excluded if they were unable to participate in an extended interview process of up to 2 hours based on their own subjective report of performance capability and an inability to provide informed consent.

Individuals were also excluded if they were:

- Unable to communicate verbally in English as no interpreter services were available due to a lack of funding capacity;
- Identify as using surrogate decision-makers or guardians on health-related issues as the relationship between the guardian/surrogate and participant may alter the interpretation of the access and accommodation experience; and
- Self-identify as being a person with mental and/or intellectual developmental disabilities as the scope of this current study is to specifically address the need to request a physical accommodation.

c. **Purposive and snowball sampling**

Purposive sampling through gatekeeper organizations and individuals was used to recruit people with shared experiences of healthcare access barriers and the decision-making process to advocate for an accommodation. The researcher contacted clinical and community networks and known connections within the disability and disability studies community. Additional word of mouth and snowball sampling (Taylor & Bogdan, 1998) was needed to achieve the target sample. Potential participants were contacted by phone or email depending on the contact information provided. IRB approved recruitment letters were sent to individuals who expressed interest in finding out more of the study. This letter (Appendix A) asked potential participants to contact the primary investigator by phone or email, to learn more about the study. Eligibility was determined through use of the IRB approved telephone screening survey after the individual contacted the researcher after reviewing the recruitment letter. Appendix B is the IRB approved telephone screen. Seventeen potential participants were identified and twelve contacted the researcher to learn more and were screened for eligibility. Six individuals met the inclusion criteria and comprise the final sample.

Participant demographics are provided in Table I. Participants were assigned pseudonyms that are used for all reporting of study findings. All other background information was provided by the participant during either the initial or second clarifying interview. The symmetry of the ethnicity across men and women occurred purely by chance.

TABLE I
PARTICIPANT DEMOGRAPHICS

Pseudonym	Age	Gender	Racial identify	Acquired Disability
Lynn	58	F	Caucasian	Birth
Marcus	34	M	African American	Birth
Eve	53	F	Puerto Rican	Acquired - SCI
Tomas	56	M	Puerto Rican	Acquired - SCI
Lala	55	F	African American	Birth
Gary	31	M	Caucasian	Acquired - SCI

2. Development of interview schedule

This study's overarching question was: *What are the meanings that barriers to healthcare have for people with mobility impairments as well as the personal and contextual factors that influence decisions to self-advocate for accommodation?* To explore this overarching question, I developed an interview schedule with questions for participant interviews. Within IPA, the researcher is encouraged to keep the primary interview questions broad to "explore both flexibly and in detail the experiences of interest" (Smith & Osborn, 2007). In this research study exploring the meanings of experiencing barriers and a lack of accommodation and decisions to self-advocate, I used broad open-ended initial questions asking participants to describe an experience. These were followed with more pointed second-tier questions as recommended by Smith et al., (2009, p. 48) asking for participants to infer meaning of an experience to allow a more accurate interpretation of contextual influences on decisions to advocate. This provides an opportunity to examine the responses of participants in analysis using the theoretical frameworks of critical theory, critical disability theory, and the social model of disability.

a. **Pilot Interview**

To ensure that the interview schedule reflected the perspectives and input from the disability community, a pilot interview was conducted with a leader in the disability community who identifies as a healthcare advocate and is knowledgeable in the legal rights to accommodations in healthcare. This individual met all of the study's inclusion/exclusion criteria so that the individual experiences might easily translate to those of recruited participants.

Input from this key informant helped 1) ensure relevance of the interview questions from an experiential point of view, and 2) clarify the wording and clarity of questions, including the need for prompts and probes, especially in second-tier questions. This key informant suggested an emphasis on the lasting impact and stressors of negative encounters in healthcare settings and other everyday lived realities of accessing necessary healthcare (Sabin, Stuber, Rocha, & Greenwald, 2015). This interview provided an expert insider perspective and also informed the research questions (Larkin & Thompson, 2012). The changes made to the interview schedule were subtle but significant. An example can be found with examining a question focusing on the factors that influence decisions to self-advocate from before and after the pilot interview:

Before, - *If you know you need an accommodation and know that you have to ask for one what different things influence your decision to ask for one or not?*

After, - *How do your past experiences influence what or how you advocate for yourself when interacting with providers or the staff?*

The pilot interviewee critiqued the pilot interview for not attending to the subtler contextual factors such as how experiences impact self-worth, internalized oppression, and the impact and weight of experiences of exclusion versus original focus on knowledge of civil rights. Both versions of the interview schedule can be found in Appendix D. Two other key informants

from the disability community also reviewed working versions of the interview question schedule. They also recommended a focus on the lasting impact of the experience. One suggestion was to adopt more neutral phrasing of the questions to enable participants to explore both positive and negative experiences. Following this suggestion, I made small but important changes to the questions. The interview schedule is informed by the research questions but do not include the research questions. My interview schedule is broken into three groupings of questions: experiences with healthcare access barriers, experiences with the need for and decision to advocate for accommodations, and how participants interpret these experiences as they impact their own health.

D. **Data collection**

Data collection occurred in two phases, similar to Engel and Munger's (2003) approach in exploring civil rights and PWD. Phase 1 involved semi-structured individual interviews using the interview schedule to address the key research questions. Phase 2 involved a clarifying interview to check on emergent themes and to clarify analysis done by the primary investigator of their individual interview as also a form of member checking. The clarifying interview took place after the analysis of individual cases had provided emergent themes and before initiating the analysis of themes across cases. These two phases occurred across ten months. Table II provides a timeline of participant recruitment and data collection.

This two-phase interview approach was designed to ensure that research participants were partners in identifying the meanings of the experiences reported and analyzed by the primary investigator. This process helped rebalance power relationships between researcher and participants and avoid replicating power hierarchies that permeate mainstream disability research (Heyer, 2007; Oliver, 1992).

TABLE II
STUDY TIMELINE

Phase	Month									
	1	2	3	4	5	6	7	8	9	10
Recruitment	X	X	X							
Phase 1. Individual interviews and analysis	X	X	X	X	X	X	X			
Phase 2. Individual clarifying interviews and analysis					X	X	X	X	X	X

1. **Phase 1: Individual interviews**

Individual interviews were conducted at a place selected by the participant to make it comfortable and convenient for them to engage in the interview process. The interviews lasted between 1.5 to 2 hours attending to participant's need for breaks or more time to discuss the experiences of concern. While knowledge and efficacy on laws and rights is fundamental to my inclusion criteria for participant selection, I did not ask direct questions on this until the end of the individual interviews. Similar to an approach used by Engel and Munger (2003) in *Rights to Inclusion*, I hoped to allow this to emerge naturally without researcher prompts to explore the individual interpretation of how their knowledge on legal rights influenced and influences their experiences of barriers and requests for accommodations. Engel and Munger (2003) encouraged their study participants to describe in detail their "actions or inactions on ADA employment rights and how these experiences influence future decisions" (p. 9) and as a result had transcripts dense with meaning. I believe the decision to follow a similar path in my interview questioning provided this research study with similar outcomes. Interviews were audio-recorded with the participant's consent and transcribed verbatim with identifiers removed. Participants received a \$25 gift card to acknowledge their time and contribution to the research.

2. **Phase 2: Clarifying interviews**

Following the third level of initial transcript analysis, I returned to each interview participant for a clarifying interview. This third level in IPA is the more interpretative process of annotation and assumes the researcher is now returning to and drawing upon their pre-understandings of the phenomenon. At this stage in the analysis, I believed returning to the participants maintained a transparency of the analysis and maintained a respectful appreciation that they are the experts of their lived experience. The semi-structured clarifying interview provided an opportunity for feedback, clarification, and reflection by the participant on accuracy in the emergent interpretations. Engel and Munger (2003) used a similar approach and emphasized how participants' clarifications and critiques of the researchers' interpretations provided for an "additional interpretative layer that enriched the insights of their findings" (Engel & Munger, 2003, p. 16).

Prior to the clarifying interview, the I sent the participant the descriptive, linguistic and interrogative/interpretative codes, emergent themes and associated quotes from the transcript ahead of the scheduled meeting. This enabled the participant to review and prepare for the clarifying interview. The second interview question schedule (Appendix E) was organized by the three groupings of the initial interview questions: experiences with healthcare access barriers, experiences with the need for and decision to advocate for accommodations, and how participants interpret these experiences as they impact their own health. Each participant came prepared to the second interview having read the analysis and my interpretations of their interview. Participants all expressed appreciation for having the opportunity to read the interpretations and eager to offer their feedback. The clarifying interview provided rich affirmations as well as clarification of participants' intended meanings to their experiences. In

some instances, participants reported an increased understanding of the meanings of an experience to their identity and influences on decisions to advocate based on their participation in the study. Divergent concepts or differences in interpretations were documented and attached to the quote along with my initial interpretation. Both interpretations were explored during analysis. Appendix F has a sample of how clarification comments were documented. At this time, any new interpretations of past experiences reported by participants and agreed upon by both researcher and participant as meaningful were included into the data for analysis.

These interviews were also audio-recorded with the participant's permission. Participants were provided with a \$25 gift card for their involvement in the clarifying interview.

E. **Data Analysis: Phases of Analysis**

Data were analyzed using an 8-phase iterative and inductive analytic process. All phase 1 individual interviews were completed prior to initiating analysis of individual cases.

1. **Phase 1: Initial engagement with single transcript**

Initial engagement with the transcript occurred with first simply listening to the recorded interview. No notes were taken during this time. My intention was to reflect on the person I was hearing by listening to their words with no interruption to better understand their perspective of their experiences. I then listened again, taking notes and memoing any questions that emerged or recollections of the interview experience itself. I followed this with a third review as I transcribed the recording, making notes and interjecting them into hyphenations within the transcript, on recollections of body language, impressions of facial or body language, moments of emotion or silence, or questions that emerged as I listened. Following transcription, I read and re-read the transcripts. During this process emerging thoughts on connections between the transcripts and study questions, theoretical frameworks of the study, or my personal lens as

an OT and disability studies scholar were recorded in my audit trail reflections. This initiated early connections to potential theoretical frameworks that might be used to explore themes.

2. **Phase 2: Descriptive, linguistic, and conceptual exploratory comments**

Three readings of each transcript were performed using different perspectives for initial noting of exploratory comments (descriptive, linguistic, and conceptual or interrogative/interpretive). This approach is the most detailed and time-consuming process according to IPA researchers (Smith et al., 2009). Descriptive comments focusing on describing the content of what the participant is saying, what appears to be important but taking what the participant is saying purely at face value. Linguistic comments made note of specific use of language or tone of language, repetitions of key words to reflect hesitation, pauses and laughter or use of metaphor to describe an experience. The final re-reading of the transcript focused on analysis at a conceptual level where what a participant is saying prompts further questioning, prompting me to reflect and question what the participant meant by what they were saying. Through this process, I recognized how much my own pre-conceptions influenced my interpretations. According to Smith (2009), this is an opportunity for a researcher to “sound out the meaning of key events and processes of participants through personal perceptions and understandings” (p. 89). Here the IPA process described as a ‘double hermeneutic’ was followed requiring a researcher to interpret meanings of experiences - as an individual also engages in making sense of the experiences that have happened to them (Smith 2004, 2011).

Following this final layer of analysis, I then moved to combining the comments to explore themes that would link the comments to participants’ statements. Figure 2 provides for an example of the early analysis.

<p>PAR: And that's something I'm always concerned about...hitting that <u>tipping point</u>. Because that's when I've lost control. And I can't let that happen or I not going to achieve what I came to...or I'm not going to feel good about myself.</p> <p>LVP: This is so great thank you.</p> <p>PAR: I had time to think about it...and remember - thinking about <u>'it'</u> is the healthiest thing I can do. To be able to start to understand it to be able to accept it. <u>I don't want to accept it if I don't understand what's going on.</u> For me, that's been a very healthy experience and again, only because I <u>have</u> to do that. So that's why I think I'm a stronger person, as long as I can survive the immediate impact in the <u>long run I'm a stronger</u> person.</p> <p>LVP: It's very philosophical and analytical</p> <p>PAR: Yes</p>	<p><i>Tipping point – spinning head, out of control</i></p> <p><i>Won't feel good about self – self-esteem</i></p> <p><i>Inability – others control her fate</i></p> <p>Understanding provider bias or social construction helps accept less than</p> <p>Loss of control</p> <p>Survivor – what doesn't kill you makes you stronger</p>	<p>Fear of losing control – anger in response to providers?</p> <p>Emotional and psych damage? -disablement?</p> <p>"it" – what is it?</p> <p>Can understand it is bigger than just her- bigger than provider</p> <p>Empowers?</p>
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Figure 2. Early analysis Lynn

3. Phase 3: Analysis across comments to identifying emerging themes

Analysis across all three levels (descriptive, linguistic, conceptual) was done to identify emerging themes. IPA instructs researchers at this stage to focus on turning exploratory notes into “concise and pithy statements of what was important in the comments attached to a piece of transcript” (Smith et al., 2009, p. 92). It was this version of analysis that each participant received for review prior to the clarifying interview. Here I also returned to my original notes and memos and my reflection journal of the interview with the participant to help me to understand nuances in the participant's words or any emotional underlying element that might help better understand the meaning of the experience being described. This is also where I

clearly used presumptions and frameworks from my positionality such as OT and disability studies to help me to explore the meanings an experience might have or why or how a person might be making sense of an experience in the way being described. Table III is an example of emerging theme development.

TABLE III
ANALYSIS OF EMERGING THEMES

Transcript Lynn	Codes <ul style="list-style-type: none"> • <i>description/content</i> • <u>Language</u> • interrogative 	Emergent Themes
<p>Ok, so there can be a lot of variances between different experiences but I'll just describe for you the most recent experience because that's the freshest in my mind.</p> <p>Par: So, um, I scheduled a doctor appointment, I had a couple of issues that were kind of urgent, and um, so I scheduled the appointment. I had found out a few weeks earlier when I was there, that there was an accessible exam table there now, when there had never been one before at this clinic. I'd never been able to find one actually, or I wasn't willing to change doctors to find it. But this time I knew there was an accessible exam table. So when I scheduled it I said "I need the accessible exam table – which is on the first floor – a different floor than my doctor usually is on." And they had no clue what I was talking about – so you know there's that...but I had seen the exam table, I knew where it was so I didn't need to follow up on that. LV: wow.</p> <p>Par: So I said, "Just make sure my doctor knows that that is where we're going to be going after I check in...which is on the usual floor."</p>	<p><i>Experiences in healthcare can be different</i></p> <p><u>Variances – Context matters</u></p> <p><i>Sense of urgency</i></p> <p>What made it urgent? Had she delayed getting something done because of not wanting to go to the doc?</p> <p><i>Discovery – Like it had been hidden away and she discovered it versus being told it was there after not being able to find one in the past.</i></p> <p>Why hadn't she been told it was there? How did she find it?</p> <p><i>Changing docs – weighing pros & cons of changing docs</i></p> <p><i>I need – asserting her accommodation request</i></p> <p>Done in a way that asserts and instructs</p> <p><i>Providers clueless</i></p> <p><i>So you know <u>there's that</u> – lack of provider knowledge on her needs</i></p> <p>She understands that I understand what she means by 'that'</p> <p>Necessity to manage because of past negative experiences?</p> <p><i>Make sure - Instructing – controlling/managing situation</i></p>	<p>SA context specific?</p> <ul style="list-style-type: none"> • Time? • Personality/emotion? <p>Decisions to accept less than</p> <p>Management/Control by default</p> <p>Providers Ignorance (different than knowledge – indifference – lack of concern)</p>

4. **Phase 4: Cross-checking emerging themes with codes/themes identified by data analysis team**

Here, each interview was cross checked with the analysis performed by a corresponding data analysis team member (further described in the next section on developing trustworthiness) assigned to that participant transcript. Validation of themes was the most common finding however, new emergent and divergent themes were identified on occasion and incorporated into the collected themes that emerged for the participant. Any significant difference in interpretive coding between the team member and my own signaled the need to verify interpretations with the participant in the clarifying interview.

5. **Phase 5: Grouping emerging themes into corresponding interview questions to guide clarifying interview**

I collected the emergent themes into three groups relating to the initial interview schedule's conceptual question categories to identify themes to guide the second clarifying interview with participants (Appendix E). Participants were sent my initial analysis with the emergent themes for review prior to the second meeting. During this second meeting the quotes and associated emergent themes were reviewed and themes, questions and concepts were discussed to identify divergence or agreement between my interpretation and the participants' interpretation of their experience. Differences in interpretations were documented into a form (Appendix F) and participants' clarifications were attached to the quote along with the initial interpretation. Any of the participants' new interpretations of their experiences were included into the data for analysis.

6. **Phase 6: Grouping of emergent themes from individual interview**

To identify how emergent themes fit together, each transcript's set of themes were written down by hand onto index cards and laid out one by one, side by side. Like themes were grouped. For example, participant 4 had 4 themes: "concerns over retaliation", "enforcing rights in defense of denial", "selective self-advocacy", and "the approach makes a difference". These were grouped into an individual participant master theme named "right ways and wrong ways to self-advocate". This process proceeded through multiple iterations based on ongoing reflection and included returning to the voice recording or initial transcript and passage of the quote, considering the focus of the dialogue, and reviewing my reflective diary. This process helped determine the underlying intent of the participant's interpretation of their lived experience, and whether the initial code and then theme captured the essence of the interpretation through layers of reduction to come to an "understanding of the essential structure of the experience" (van Manen, 1990, p. 185). This process of identifying patterns across themes was repeated to create an exhaustive list of individual participant master themes and sub-themes. Master themes and sub-themes for a participant were then linked with corresponding quotes from the transcript. Initial noting and identifying search words were used to link back to the number lines of the transcripts to pull out corresponding quotes to complete the analysis of a participant's transcript. During this process, I conducted a thematic analysis of the transcript to ensure I captured nuances in meaning.

7. **Phase 7: Visual concept maps**

Visual concepts maps, linking to the master themes and sub-themes were made for each participant to visualize the links between master themes as well as sub-themes. Smith et al. (2009) recommends that an analyst use a method of "charting, or mapping" to assist in

identifying how the themes fit together (p. 96). I used Inspiration® 9 software to map individual master and sub-themes. Through this process, I identified a total of 39 master themes and 179 sub-themes across all cases. Figure 3 is an example of an individual concept map.

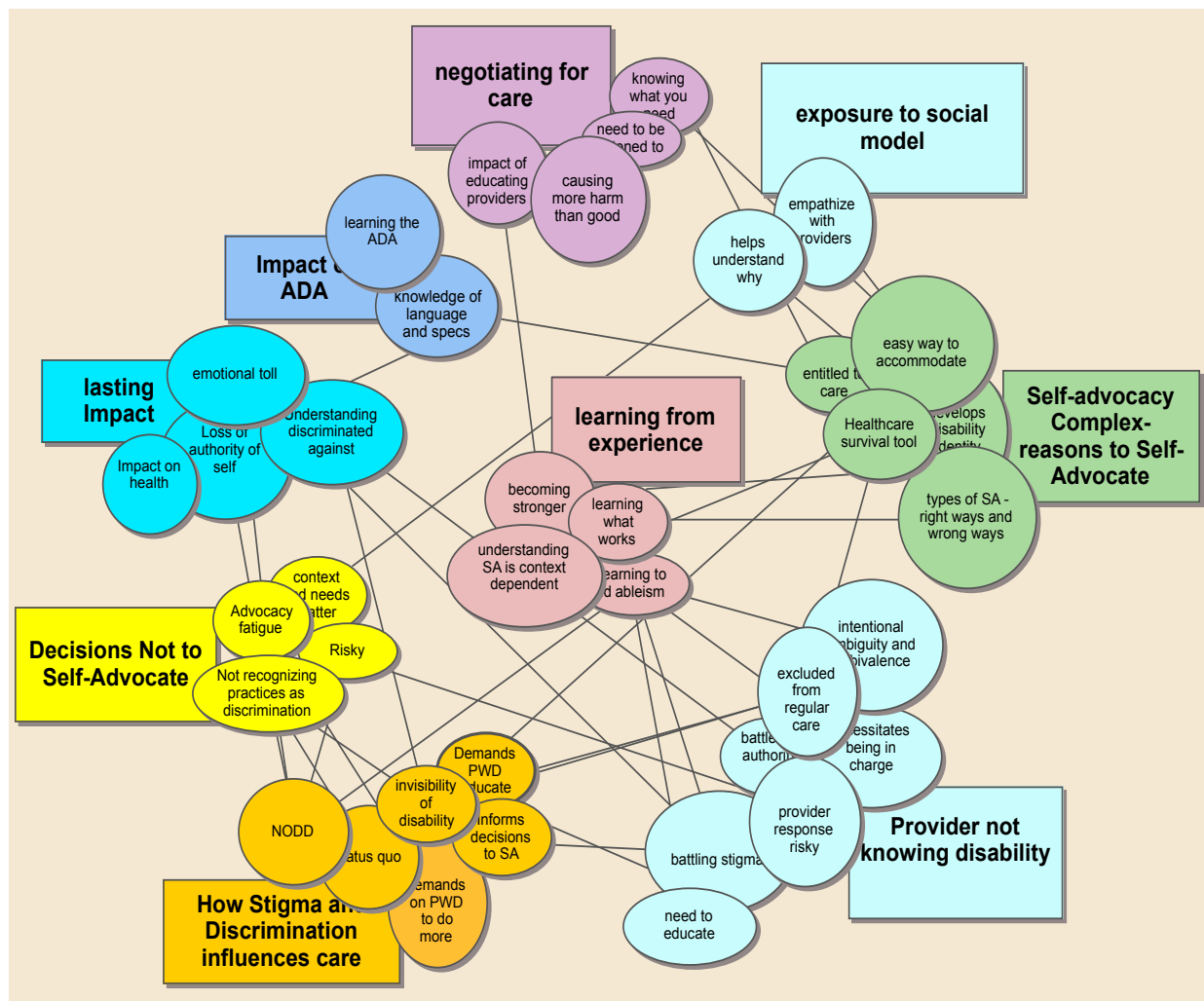


Figure 3. Concept map of themes Lynn

8. **Phase 8: Master themes and sub-themes to super-ordinate themes across cases**

The final phase of analysis involved looking for patterns across cases to identify what are the most potent themes (Smith et al., 2009). Previously, I had focused intently on understanding what the participant was thinking and how their description of an experience defined their given meaning. What appeared initially to be a similar master theme across participants could not be taken at face value and the analytic structure was re-evaluated. Ideographically, the master themes appeared appropriate for the individual given their experiences and interpretations. However, to identify those most potent master themes across participants, I returned to the process of looking across all sub-themes and the grouping of these across participants.

A figure was created, with a corresponding master visual map, using Inspiration[®] 9, identifying all participant master themes and corresponding sub-themes (Figure 4). Similarities between master themes were identified. Themes and sub-themes were clustered based on similarities or removed if meanings differed. This process allowed for re-labeling of master themes across participants and reduced the number of like master themes across participants from 39 to 16, 9 of which were recurrent across multiple participants. Within IPA, a recurrent theme is present in at least a third of the participants (Smith, 2009).

Ultimately nine super-ordinate themes emerged, four with strong sub-themes associated within the larger super-ordinate theme. These are: 1) normalization of disability discrimination; 2) provider lack of understanding disability; 3) knowing what you need; 4) context matters; 5) understanding rights; 6) advocacy fatigue; 7) self-perceived burden; 8) embodied experience/impact on health; and 9) empowerment (Figure 4). To further refine the analysis, the

nine super-ordinate themes were organized into conceptual categories that align with the three research questions. These are: 1) how do people make sense of barriers to healthcare – ‘NODD’, and ‘providers lack understanding of disability’; 2) what factors influence decisions to advocate [broken into factors that negatively influence decisions] – ‘advocacy fatigue’, ‘self-perceived burden’, and [factors that positively influence] – ‘knowing what you need’, ‘knowledge of rights’, ‘context matters’; and 3) the lasting impact of experiences – ‘impact on health’, and ‘empowerment’. These conceptual categories are used to frame the findings in both the individual case analysis (Chapter IV) and in the cross cutting analysis of findings (Chapter V).

F. **Techniques for establishing trustworthiness**

Qualitative researchers, including those using IPA, must implement strategies to enhance rigor to ensure the trustworthiness of findings (Lincoln & Guba, 1985; Krefting, 1991). The following section describes the strategies used to ensure that strategies were used to establish five key components of trustworthiness: credibility, dependability, confirmability, attention to validity and rigor, and transferability.

1. **Credibility**

Krefting (1991) describes credibility as the ‘truth value’ of “discovery of human experiences as they are lived and perceived by informants” (p. 215). Credibility asks researchers to have confidence that what they describe are true to the lived meanings of participant experiences. In this research study, three strategies were used to increase credibility: prolonged engagement, debriefing, and member checking to increase the truth value of the findings.

a. **Prolonged engagement**

The two phases of individual interviews offered greater opportunities for sustained engagement with the participants than a single interview. The process of preparing for the clarifying interview provided an opportunity to closely review my interpretations so I was able to describe to the participants the rationale and reasoning behind my interpretations. The prolonged engagement also provided participants with time and opportunity to reflect on their experiences allowing for the development of more nuanced interpretations of their experienced.

Prolonged engagement also occurred as I spent time with the individual recorded interviews and transcripts during an intense, multi-stage, in-depth analysis - a critical component of IPA transcript analysis described by Smith et al. (2009). I listened to the recorded interviews multiple times, transcribed them, and then analyzed them from different perspectives. I returned

to the transcripts as well as the audio-recordings in determining meaning or identifying theme assignment to a section of transcript. This deep immersion into the interview data was part of the process to understand the participants' view of the world and the experiences they described (Larkin, Watts, & Clifton, 2006).

b. **Use of debriefing**

The original intention was to use a single peer from either a disability studies program or academia in disability studies to debrief following each interview session to discuss the interview process and initial memos and notes with an impartial peer (Krefting, 1991). However, time constraints and adherence to confidentiality concerns made this approach untenable. Following each interview – often within the first hour but always within the first day – I wrote a reflective entry into the participants' reflection journal. I documented my own reactions to the interview, how I believed the interview impacted the participant, as well as my overall impression of the experiences the participant had described. I returned to these reflections often during the analysis of participants' descriptions of experience to understand how my presumptions of the participant might be influencing my own understandings. I also was fortunate to have frequent contact with my dissertation advisor as suggested by Shenton (2004) that allowed for informal debriefing as needed following participant interviews and throughout the data collection process.

c. **Member checking**

The phase two clarifying interviews focused on reviewing the emerging themes with each interview participant. This approach provided a method for member checking and feedback on initial interpretations of the interviews. IPA acknowledges that participants can be actively enlisted as part of the research process (Smith et al., 2009) and this is one manner this

study used to encourage this. This approach also addressed concerns with the truth-value (Krefting, 1991) of my own interpretations of the participants' interpretations of their experiences. Krefting (1991) describes truth-value – or the confidence in the truth of the findings for the participants – as the “most important criterion for assessing a qualitative research study” (p. 216).

2. **Dependability**

a. **Audit trail**

I used a documented audit trail - in the form of the methodological journal - early in the conceptual development phase of this research proposal to record key decisions that inform the study. IPA researchers are encouraged to document each step of the decision-making process so that a chain of evidence could be followed from initial conceptualization to final report (Smith et al., 2009). This documentation includes: considerations involved in development of study design, decisions on research questions, decisions on issues related to selection of research methods, and interview questions. It also includes problems encountered and decisions made in purposive sampling, recognition of emerging themes in a single interview and efforts to bracket these in subsequent stages of analysis, coding procedures and decisions made in coding of the transcripts, and recognition of emergent super-ordinate themes. In this audit trial, I have a historical accounting of emergent themes, master themes, super-ordinate and sub-themes for individual cases, prevalence for themes as well as sub-themes across cases and versions of super-ordinate theme tables (Smith et al., 2009, p. 183). Appendix G offers an example.

I utilized my dissertation advisor as an external auditor in decisions made throughout the research process as recommended for qualitative research (Krefting, 1991; Lincoln & Guba, 1985) to establish confirmability during active research, versus waiting until the final product.

Decisions made in these conversations were recorded in the methodological journal. I also referred periodically to members of my dissertation committee as experts in their respective fields to discuss emerging themes and questions. Notes and feedback from these meetings have also been documented as part of my audit trail process.

To achieve guidance specific to the qualitative approach of IPA, I participated in advanced training and sought out mentorship from national and international experts in IPA. This afforded me the opportunity to receive targeted feedback on methodological challenges in data collection, analysis and writing from an IPA informed perspective. This significantly strengthened the rigorous application of the IPA approach.

b. **Data analysis team**

I utilized a team of data analysis consultants to read and code an assigned de-identified interview after my initial coding to provide for increased trustworthiness and a confirm-ability audit of findings and a check for researcher bias. This team consisted of six (one for each transcript) UIC IRB trained individuals selected based on their experience or knowledge of the social model of disability through participation in an academic program and experiences with analysis of qualitative data. The team members included disability researchers and scholars, occupational therapists and people with a lived experience of disability.

Data analysis team members were asked to approach the assigned transcript at a very exploratory level, maintaining an open mind and noting anything of interest within the transcript. I met with each team member to discuss their analysis and interpretation of the transcript, the intent was not to achieve consensus but to provide new perspectives of the text. The comments and descriptive codes were cross-checked with researcher codes and if different or new perspectives were identified these were included into the final code group for that transcript.

More often than not, there was consistency across transcript analysis. At times, different language was used to describe a concept which encouraged me to explore the different linguistic meanings between the words. In other instances, a different but similar code was used that required closer analysis of the participant's meaning. These subtle but important interpretation differences were used to help frame my clarifying interviews questions.

3. **Confirmability**

a. **Reflexivity**

I used the hermeneutic journal as a journal for reflective self-analysis as recommended by Clancy (2013) - immediately following individual interviews, including reflexive examination of my perceived influence or effect on the participants being interviewed, and impact of my presumptions (and bracketed as such) on analysis throughout the research study. Following the interviews, I recorded all recollections of participant reactions to my questions including non-verbal communication, facial expression as well as how my own presentation may have been interpreted positively or negatively by interviewees. I also kept corresponding individual participant journals that assisted me in reflecting on the ideographic element of the single case and its uniqueness.

I continually considered my role in the construction of this research – attending to ‘where I am coming from’ - my ‘position-ality’ (Cousin, 2009, p. 4) and outsider status as it influenced my own interpretations and the interpretations of participants during interviews. During initial readings of the interview transcripts, notes and memos were included and crosschecked with notes from my reflection journal. These have been used to explore how the researcher's personal

characteristics may have influenced responses of an interviewee.¹⁰ All of these processes were used to “inform the analytic logic and interpretive authority of the final product” (Oliver, 2012, p. 413).

4. Attending to validity and rigor

Smith (2011) warns that an IPA study can suffer from a number of pitfalls reducing a study’s credibility including: when vast amounts of descriptive or superficial themes develop from a large number of participants; when themes are poorly interpreted or poorly supported by extracted script; when no explanation is given for how a prevalence of themes was determined; or, when analysis of data is done crudely or ignores nuances. Anyone of these problems can adversely affect the study but a combination can invalidate study outcomes. As such I attended to the recommendations made by Smith and other IPA researchers on addressing validity and credibility (Osborn & Smith, 1998) by use of this suggested checklist.

Smith’s criteria for evaluating the validity and the trustworthiness of IPA research, include:

1. That the study subscribes to the theoretical principles of IPA; phenomenological, hermeneutical and idiographic in nature;
2. That the report provides sufficient transparency in reporting its data collection and analysis; and

¹⁰ Beatrice Wright in *Physical Disability – A Psychosocial Approach* (1983) describes the problems when a person (the outsider) is observing or evaluating others’ (the insider) behaviors, feelings, or problems as evidence supports the fact that there are important differences in how each person might describe or interpret the context of the situation (p. 47) including the significance and causal factors that are attributed to influence on observable behaviors. Shakespeare, Iezzoni & Groce in *Disability and the training of health professionals* (2009) describe the incorrect assumptions about disability that healthcare providers can have that negatively influence attitudes of PWD. These examples and other readings emphasize the importance of understanding my positionality as an outsider to disability as well as a healthcare professional.

3. There is sufficient sampling from the corpus to show density of evidence for each theme:

For a study with a participant number of between 4 and 8, themes must have extracted evidence from at least half of the participants for each theme, providing an indication of how prevalence of a theme is determined.

Smith (2011, p. 24) furthers the criterion checklist to identify qualities that identify an IPA research study that is of ‘good’ quality:

- The written conclusions must be well focused with in-depth analysis of themes;
- The data are strongly interpretative not just descriptive;
- The paper must provide a measure of prevalence for each theme and narratives should be included with in the analysis; and
- The research provides sufficient space to elaborate on each theme-including any sub-theme(s) identified as significant.

5. **Transferability**

a. **Dense description**

Use of thick description in written reports is a necessary component of IPA to maximize descriptions of participant experience (Smith et al., 2009). IPA research demands smaller sample sizes with purposeful sampling focusing on participants that have similar engagement or expertise with the phenomena of concern. Inclusion and exclusion criteria focused on purposively selecting participants who were able to describe their experiences as a PWD within the healthcare system. The use of detailed ideographic accounts challenges the researcher to dig deep during interpretations of the interview texts to understand “how a given person, in a given context, makes sense of a given phenomenon” (Wagstaff & Williams, 2014, as quoted in Cohen et al., 2007, p. 9). In depth and multiple rounds of data analysis also allows for

the ability to analyze divergent or convergent concepts that emerge of the phenomena within and across cases (Brocki & Wearden, 2006). While thick description of the participants' accounts provides for increased transferability, description is restricted to the perceptions and interpretations of only those individuals that identify as a person with physical disability with similar characteristics as the individuals interviewed. This demands detailed description of each individual, their background, and the contextual elements that their experiences occur within. This occurs in the results section detailing the individual participant interview analysis. Some details are necessarily omitted to preserve the participants' privacy and confidentiality.

V. INDIVIDUAL FINDINGS

IPA is ideographic in its exploration of the interpreted meanings of an experience. There is an “emphasis on the experiential claims and concerns of the person...with the aim to understand their world and describe what it is like” (Larkin et al., 2006, p. 104). However, as the researcher interpreting participants’ interpretations and decisions in the emergence and collection of themes is informed by my academic frameworks for contextualizing these experiences. This chapter provides an exploration of how each individual case’s unique narratives informed master and sub-themes. This provides transparency and understanding of how patterns were identified across cases resulting in super-ordinate themes, and explores how individual interpretations contributed to the substance of a theme.

The master themes are similarly organized for each participant as they emerged within the responses to the categories of interview questions, including: what are the meaning of experiences, what factors influence decisions to request or not request an accommodation, and, the lasting impact of experiences. Sub-themes within any similar master theme across cases expose individual differences, similarities and the complexity of these experiences as interpreted by participants. The categories of interview questions also directly link back to the three primary research questions, which are:

- How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?
- What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?
- Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?

As described in Chapter IV on study methods, during recruitment efforts were made specifically to recruit 3 men and 3 women who identified as having a physical disability. However, recruitment resulted in a similar racial representation across the two gender groups. Capturing how convergent and divergent experiences were informed by the intersection of race, gender, and disability type was explored by examining individual responses to interview questions. Each of the six participants were interviewed using the same interview schedule however, flexibility in the interview approach allowed for the exploration of individual histories and in turn allowed for nuanced interpretations of individual experiences. For anonymity, participants' names are pseudonyms, and any identifying information has been removed.

The structure for describing the findings of each individual case begins with a brief background of the participant - information gathered during the interview process - followed by my reflections on the interview itself. The master themes and corresponding sub-themes are described using an interpretive analysis of the participant's epitomizing quotes to provide transparency on how quotes were connected to each theme and sub-themes as well as any interpreted relationships between themes. Participant cases are reported chronologically as the interviews occurred.

A. **Lynn**

1. **Background**

Lynn described herself as a “woman with disability or a disabled woman – either one” showing that she appreciates the subtleties that underlie word use and the importance of description in disability studies and by the disability community. She describes her disability as progressive, with a gradual transition – through her teens and early adulthood – from walking, walking with braces, using a manual chair, to now using an electric wheelchair for the last 20

years. She identifies as a disability advocate, giving lectures on access and accommodation rights of PWD. Lynn lives in a suburb of large urban setting with her husband, has a large extended family, and a rich network of friends and neighbors.

a. **Bracketing**

I have worked professionally with Lynn and I came to this interview with a sense of having a strong positive relationship with her. I was happy that she was my first interview. This was in part because of Lynn's ever-present projection of calmness, thoughtfulness, and my own comfort and presumptions of her. Our somewhat shared positionality: both identifying as white women, same age, similar economic and academic experiences – all providing a sense of somewhat 'knowing' her. I also presumed her level-headedness, pleasant demeanor, and knowledge would help her to be a strong self-advocate and that her responses to the interview questions would be filled with rich detail and reflective thoughts.

She was promptly on time to the interview and had her signed contract and what appeared to be extensive notes she had prepared on her copy of the question schedule. As we said our 'hellos,' I was hit by the reality that I had assumed I knew what her experiences in self-advocacy were like. I worried how our previous relationship and my assumptions would influence the interview. Before turning the recorder on, we spent at least ten minutes in small talk, laughing together, and her composure and preparedness helped to relax me and settle the scene to begin the interview.

Although Lynn identifies as a disability community advocate, her own agency as an authority in her healthcare experiences appears at times in conflict with her tempered personality. She uses her knowledge of the evidence on healthcare access barriers for PWD and civil rights to

help justify in her mind the times she elects to self-advocate and inform her on the times she chooses not to. How she prepares and presents herself in a provider visit is a major tool she uses in her advocacy in healthcare. She reports efforts to be calm, level-headed, and prepared, which corresponds to how I have seen her in our many past interactions. From listening to her transcript, I understand now the mannerisms she used to relax the environment in our interview are tools she likely uses to calm and manage other contexts. Her master themes and sub-themes revolve around her ability to understand her need for care, concern for self, concern for others, and concern for her community.

The master themes identified in Lynn's narratives were: 1) understanding the need for self-advocacy; 2) decisions to self-advocate; 3) decisions not to self-advocate; and 4) the lasting impact.

2. **Master theme one: Understanding the need to self-advocate: “someday I won’t”**

Lynn understood from experience that when she perceives providers fail to provide competent care, she must assume responsibility in her healthcare visit to assure her needs are met. This responsibility includes understanding her need to self-advocate for an accommodation. She interprets providers' behaviors as stemming from two basic issues: 1) a lack of knowledge, exposure, and training on how to work with PWD; or 2) discriminatory processes that are so common and every day she coins the term “normalization of discrimination”. These two distinct interpretations of providers' behaviors require different responses and form the two sub-themes within this master theme of “understanding the need to self-advocate.”

a. **Sub-theme 1: Providers not knowing about disability**

Lynn recollected a time from her past, prior to using a wheelchair, when the providers took ‘care’ of her and the visit was smooth and effortless on her part, allowing her to concentrate on what her needs were. She has learned that if she is to have a successful healthcare visit she has to take on more responsibility to instruct providers in how to address her needs, which reminds her that her physical needs are different and not understood.

Line 164: Being organized and being in charge versus being supported. Which I felt, years ago, before I was in a wheelchair I always felt supported. I came in, they knew what to do – you know – I really just had to communicate what or why I was there. Um...it’s just SO much more complicated and there’s so many layers...making mental notes for the future, ‘what can I do next time?’, so I can avoid complications.

She described the emotional strain obligation to attend to safety for staff who are working with her. A sense of obligation that is rarely reciprocated.

Line 71: So that’s what I did, I helped her [the nurse] – I um – it’s always good to know, to find out ways to doing things – so I don’t know if that was a negative thing or not because it was just - the me being in charge in the exam room is how I felt...usually it’s the staff that’s in charge and everything is laid out for you.

Lynn described tension between her strategy of helping staff and her disability rights activism.

Line 476: A lot of that has to do with anxiety so I can keep my head on straight. I use methods that work for me. Offering to help, telling them what to do, if I know what to do seems to be very effective especially with people who are unsure of what to do. You know I try to be understanding - and some would disagree with that. You know because this is a right and some would insist and be more demanding but, for me I put myself - I try to put

myself in their shoes, in other words, what if I was completely unfamiliar what to do with a certain person, you know a person with whom I have no familiarity with, and I'm bound to stick my foot in my mouth, and you know? So, I try to put myself in those shoes. That works for me. Understanding, I don't think a patient should be required to be understanding of their providers but it works for me.

Lynn also reported the challenges she faces when providers make assumptions or attempt to overrule her expertise with her body and how it impacts her psychologically. She interpreted providers' disrespectful behaviors as an impetus for learning to be in charge, advocating for her needs and for her respect.

Line 228: LV: *When a provider, or caregiver is not letting you – when you are the only one that really understands the situation because they clearly don't– your reaction is...?*

Lynn: *I realize I'm being disrespected...I'm being disrespected....and I'm not the kind, it's not naturally my personality to come in the room and be the one in charge – it's just not me. And so, it's something I – you learn cuz you have to do it. And so, I, I'm feeling like, um, already out of myself. This isn't Lynn that started out today this is Lynn feeling threatened. Right...that's a different Lynn. And so, again, it's a head spinner. Some of these experiences.*

Lynn depicted with bashful pride how she has learned to speak up when providers approach her in disrespectful ways.

Line 107: *The doctor was very rushed. I had my notes so I knew what I needed to cover that day so...but he was in such a hurry he took the notes from me.... like, "let me see what you have" ... and I said, "Ah ... no, those notes are for me" [said in a firm voice followed by a chuckle to herself].*

Critically important to Lynn was recognizing when a provider's lack of understanding disability and their approaches to accommodation made her physically vulnerable and may actually do more harm than good.

Line 81: *So, they start anticipating what I need ... and I have to I very ... like hardly giving me time. Not even saying 'how about if I go here?' So, I feel like somebody already starting to pull, someone is starting to pull on me this way [lifting arm up and away] ... so then I had ... I'm in danger!*

Lynn's halting description provided a glimpse of the mental processing she does when assessing the provider's knowledge and her understanding of the ramifications that can occur. This reinforced her expectation that each healthcare visit may require her to assume the role of strong self-advocate.

b. **Sub-theme two: Normalization of disability discrimination in healthcare**

Lynn also recognized that disability stigma is prevalent and shapes provider behaviors and attitudes in her care. This recognition helped frame her understanding *why* she's not receiving the care. A knowledge that she uses as emotional armor and helps her to make sense and understand her own responses to these experiences.

Lynn: *I'm so used to discrimination in the healthcare setting being normalized that --- that is what I should have said to one of these questions because the experience of being treated differently is being 'normalized' ... that didn't come out right...they 'normalize discrimination'.*

Intrigued by the importance of the concept of normalization of disability discrimination, during her clarifying interview, I asked Lynn to provide insight into how she would define it. We

reviewed her initial description which she had forgotten but recognized immediately. Lynn affirmed this definition: NODD occurs when discriminatory policies, practices, protocols and behaviors are acceptable and routine – the status quo – what is normal and normally expected to occur. These may even be reinforced by institutional policy and culture in the name of efficiency, fiscal attentiveness, and safety for both the provider and the person with disability. NODD may influence how PWD come to understand their own candidacy for accommodations, and is directly linked to experiences of advocacy fatigue and perceptions of being a burden to providers due to their differently functioning body.

Providers' claims of understanding disability accommodation often fall far short and place the burden on people with disabilities to ensure that their access needs are addressed so they can get their healthcare needs met. Lynn described frustration when dealing with institutional ignorance on how to provide her with necessary services.

Line 21: ...this time I knew there was an accessible exam table. So, when I scheduled it I said "I need the accessible exam table – which is on the first floor – a different floor than my doctor usually is on." And they had no clue what I was talking about – so you know there's that...but I had seen the exam table, I knew where it was so I didn't need to follow up on that.

Line 51: I look at the [accessible] exam table and they've got it pushed against the wall and the side that's available for transfer has got a lamp installed onto it, so you couldn't use it for transfer.... And I said, "Well this is going to have to be moved, I actually transfer better from the other side anyway" so, then the nurse didn't know what to do. She said, "Well this is really kind of heavy I can't be moving this." And I asked if there was another room where the table is in a better position? And she went and checked and

they were all up against the wall to get them out of the way So, I then said “I’m sorry, I can’t get on the table – and if I can’t get on the table then – I had..., my purpose, my purpose for the visit won’t be met.” I had a pressure sore, just to explain why it was so important that I get on the table this time.

Based on her experience Lynn had taken all the appropriate steps to try to ensure access, but the reality of how healthcare systems are organized means that Lynn never feels that accommodations are guaranteed.

Line 75: So now, then I need to transfer. The nurse they promised me would be there, who said she had experience in an ER, which means she knew how to transfer... And [emphasis in voice] she had told me quite a bit about how she knew - when I had come before. She wasn’t there that day. So, these other nurses didn’t know how to do a safe transfer.

Due to her experiences of discrimination in primary care, at times Lynn sought care in alternate settings to ensure that her access needs would be met.

Line 343: Lynn: Emergency room, wonderful places [both laugh], but really in terms of accessibility and feeling normal, I go to a hospital that is fairly new so there’s extra space ... The staff there aren’t prepared for ambulatory people, they’re prepared for people in an ambulance chair.

The failure to incorporate accessible equipment and practice patterns that accommodate PWD was interpreted by Lynn as a sign of an institution’s attitudes toward her and PWD. Prejudice and stigma of disability support discrimination. Dealing with disability stigma in healthcare is emotionally charged and psychologically demanding.

Line 173: *So, there's kind of a dread that I carry with me when I go to the doctor, um, about just attitudes. It's not really my doctor because I'm familiar with him, it's really the staff. If for some reason my doctor is on an emergency call and I get a different doctor, then it's like, the first kind of response is surprise when they see me in a wheelchair. Typically, they blurt out something like 'oh, I'm so sorry' or 'oh, I didn't know you had this kind of challenge' or 'why are you in that?' So, that there's ... right away there's a feeling like 'oh, I'm not what they expected'. And then typically they'll, as they realize how, they're feeling awkward and trying to mitigate that, and I think really trying to not make me feel uncomfortable. Then comes the remark that "Oh, well, you seem to be doing well in spite of yourself!" and "Oh, you really get around good in that thing!"*

Lynn described how the disability stigma conflicts with her lived experience:

Line 185: *I see that there's disappointment. They are disappointed because they feel that not walking is...the medical system didn't work. Whereas in my mind it did, I'm in a wheelchair, I mean my god, I'm in a wheelchair that I work pretty well. But they feel like I've had some disappointing experiences with the medical system because I'm in a wheelchair. That's my interpretation of it.*

Line 201: *So, there's that ... the dread...the sense of dread of what type of communications and feedback and judgments, none of which are meant to be unhelpful but they actually are.*

Lynn conceded that discrimination is almost a status quo and demands constant diligence on her part, possibly to resist its influence through a decision to self-advocate. In her clarifying interview, she emphasized how each repeat experience was a reminder from her past – prior to

having the knowledge and skills to advocate for herself - where she assumed responsibility and self-blame for failing to fit within the processes of care designed for the norm.¹¹

Line 208: LV: *Have you experienced a situation where you attempted to be in charge but maybe because their sense of authority or their control or power that they know better in such a way that they over rule you? If so how is that experience for you?*

Lynn: *Yea, it's frustrating because I've had that experience too many times so that there is an additional level of discouragement, like 'here we go...this again'* [extreme sadness in her voice].

Lynn was vigilant to recognize how processes that normalize disability discrimination influenced her capacity for self-advocacy. The voice Lynn used to describe recognizing her role in perpetuating the process becomes softer and is filled with sadness.

Line 197: *So, I'm often ... I dread that. And I'm always, and this probably adds to my stress that I'm always thinking "how do I make them more comfortable so we can move on" and when I realize that I'm doing that I realize how abnormal this is. I should not be doing this... someday I won't.*

In the clarifying interview, I asked Lynn what she meant by "someday I won't" and she replied, *"that's just the positive part of me coming out...it's the positive manifestation of my personality... and I'm old enough to have seen things change and get better...I have seen things change and I'm hopeful that someday I won't have to advocate because healthcare will be accessible."*

¹¹ Many disability scholars explore the conceptual ideas of norm, normal, normalacy (Davis, 1995; Thomson, 1997; McCruer, 2006), however, using Tanya Titchkosky's (2015) definition of "Normal" in *Keywords for Disability Studies*, provides a foundation for exploring its significance to disability.

Possibly most damaging is the psychological impact that NODD has on its recipients as exemplified in Lynn's word choice when describing her experience:

Line 670: There are so many things going on in that process of normalizing – and there's um, what's happening from the perspective of the discriminator-there's all kind of layers of what's going on with them. And then as the victim of... as the person being discriminated against – I think there's a lot of things behind that realization. LV: yeah, and that decision you make when you decide not to request the accommodation when you believe you should request one for what-ever reason? Lynn: And that is actually the normal response. That 'they' would expect.

Lynn's interpretation of why self-advocacy is needed (due to lack of provider knowledge or due to acts of discrimination) informed her decisions in self-advocacy.

3. **Master theme two: Approaches and reasons to self-advocate**

Lynn described her experiences as learning how to overcome provider stigma and discrimination by learning to self-advocate for care and access using strategies that draw upon her experiential and academic knowledge as well as her identity as a PWD. She described assessing many contextual factors when deciding to self-advocate for an accommodation. Within this master theme are four sub-themes: knowing what you need, understanding entitlement to care, self-advocacy as a survival tool, and ways of self-advocating.

a. **Sub-theme one: Knowing what you need**

Lynn understood that there were times when her knowledge of her needs and her expertise on her body demanded that she self-advocate, assume authority and attempt to educate providers on her needs.

Line 208: LV: *Have you experienced --- it seems like it's important for you to be allowed to be in charge because they can't be in charge, they don't know what to do ...*

Lynn: *...there are times where I've gotten almost emotional and upset and I've had to raise my voice and so my reaction when I'm being resistant on something like that is the more they resist me, the more insistent I become. But for me, for that part of my personality to come into play, means I'm going into anxiety mode. Then it's the fight or flight – if it's the fight, I'm going to get what I need here, and I can't really hear. I lose a lot of what's going on because all I know is I'm here, my one goal is to get this understood, period. That's how I react.*

Lynn was often confronted with providers who resist her claim of being the expert of her body. When providers respected Lynn's authority, she interpreted the experience more positively.

Line 87: Lynn: *I said, "If you could just wait and I need to do a lot of wiggling, that's all... just let me wiggle, and I'm going to need support, like I'm going to have to have you put my legs on the table but if you just wait – you know – I can tell you exactly what to do." Um and then they did, they just stood back and waited and helped me appropriately on the table.*

Lynn described self-advocating as a way of educating providers on their failure to provide equitable care. Her awareness of what she needs and what constitutes equitable care heightened her awareness of the discrimination she experiences. In these instances, Lynn consciously took steps to expose normalized practices that discriminate against PWD.

Line 416: *All I can think of is the need to be weighed. I request it, although I know I'm not going to get it, I just want it to be on the record. 'Here's another request for an accessible weight scale' and I hope it adds up somewhere.*

Lynn discussed at different points in her interview, her style of using rights based self-advocacy to emphasize to providers how their approaches to caring for PWD are discriminatory.

b. **Sub-theme two: Entitled to care**

Lynn provided insight into how she incorporates her knowledge of her legal rights with her understanding of disability models and the power the knowledge that she is entitled to care provides her when as she decides to assert her rights.

Line 493: Lynn: *It seems to me, maybe it's different for others but the ADA, citing the ADA is not too effective. Now...I will use the language of the ADA, to sound intelligent, right? To be assertive, it helps me to be assertive to know the language of the ADA.*

Line 496: LV: *Is there a specific part of the language you find especially powerful?*

Lynn: *Well the general right to accommodation, sometimes I'll bring that up gently. Cuz, that's what works for me right now. Like, well.... 'you do know that the law does require that we be provided equal service, I mean that's just fairly common knowledge.' I don't know ... [frustration in voice] ... specs are very useful. They tell me the exam table is accessible because I have knowledge in the ADA ... and I am often told that they are when they are not, then I can ask, 'oh, can you tell me how low it goes and how high it goes?' Right, and this is very confusing...So, I'll use that knowledge, I know what it means to be accessible and I know that I can't get by with it being an inch or two off. So just having the specifications¹² in my head is very helpful.*

Lynn's use of the Access Board's specifications for medical diagnostic equipment informed her practical decisions based on a clinic's ability and willingness to accommodate her

¹² Under the ADA, DOJ and U.S. Department of Health and Human Services has issued *Access to Medical Care for Individuals with Mobility Disabilities* available at: [https://www.ada.gov/medcare ta.htm](https://www.ada.gov/medcare_ta.htm)

needs. She also used this information to educate providers. Lynn used her knowledge of civil rights - the American's with Disabilities Act - to support her and all PWDs' rights to accommodations.

Line 510: *And, you know, the language of accommodations – reasonable accommodations and just seems to, it makes me feel more empowered because it is reminding me that I have a right so using the language of the ADA or any terminology is helpful to me.*

Lynn described a process of weighing the pros and cons to self-advocating and the value she gives to the role of disability activism.

Line 438: *You are weighing other considerations as to whether you can speak up at that time and what the consequences are....and it goes back to why we have to do this.*

c. **Sub-theme three: Self-advocacy as a survival tool**

Lynn described times when she felt her providers were placing her in precarious situations or using methods that compromised her immediate health. In these cases, she identified self-advocacy as a survival tool, essential for managing her interactions with providers.

Line 81: *I have very poor upper body balance – so then I had to raise my voice and say “STOP –I’m going to fall!” [in loud voice].*

Line 640: LV: *I get a sense from the conversation that you have learned over the years to be a self-advocate ... my interpretation ... you have learned to be in control as a tool that you use. Lynn: It’s a survival tool...I can’t, I cannot be passive or show that I’m uncertain, even if I am. It’s a performance, is what it is. Even if you don’t feel like*

performing it's a performance and I wouldn't have learned that if I didn't have to learn that.

Assuming this “unnaturally” assertive stance was another approach in her self-advocacy tool kit but was something she had to learn through experience.

d. **Sub-theme four: Self-advocacy approaches that work for her**

Lynn recognized that she developed her own style of self-advocacy through what has worked and what has not for her in the past. She has a deep understanding that there are different ways to self-advocating and has developed a flexible set of strategies that compliments her preferred style of interacting with others.

Line 476: I use methods that work for me. Offering to help, telling them what to do if I know what to do seems to be very effective especially with people who are unsure of what to do.

4. **Master theme three: Choosing not to self-advocate**

Being able to recognize reasons for the lack of accommodations was part of the mental process Lynn used when she decides to advocate or not. If she chooses not to self-advocate - she understands why she chooses not to. This was critical for her to stay in control and not lose herself when she strategically choose not to self-advocate, she was doing so because she understands the structures that exist cannot be dismantled in the moment simply by her requests. She also recognized the toll that self-advocacy took her overall health. The master theme of ‘choosing not to self-advocate’ has three sub-themes: context and needs impact decisions, advocacy fatigue, and the social model helped understand why.

a. **Sub-theme one: Context and needs impact decisions**

Understanding how contextual factors influence decision making has been an increasing focus of health disparity research (Hagglund, Clark, Conforti, & Shigaki, 1999; Iezzoni, 2006; Litaker, Koroukian, & Love; Mayberry, Mili, & Ofili, 2000). Andersen's behavioral model (Andersen, 1968) and other healthcare access models (Carrillo, Carrillo, Perez, Salas-Lopez, Natale-Pereira, & Byron, 2011) consider how personal and contextual factors intersect to contribute to access to healthcare. Lynn learned from her previous advocacy efforts how different factors might tilt the scale toward desired outcomes. She described the complexity of factors that influence her decisions to advocate for accommodations.

Line 164: *Um...it's just SO much more complicated and there's so many layers ...that my mind is trouble shooting transportation, and the time I'll get out, how much time has been wasted here and there.*

Sometimes the physical and attitudinal barriers of the environment lead her to decide that self-advocacy would be futile.

Line 317: *So, I haven't been able to get on an exam table for I say ten years, but I think it's much longer than that. So, I don't insist on it. If I go in with an upper respiratory issue, it would be good to be able to get onto the exam table and just have some other things examined because I'm there but I'm not going to insist on it if that's not my main goal...something that doesn't require it. So, it's the urgency of need. And then it's the likelihood of getting it. I'm not going to keep asking the same clinic for an accessible exam table when I know they don't have it. So, then I just don't ask, I don't. For example, I did not, I haven't had a gyn exam for probably 15 years. Because, just the issue of the exam table.*

Lynn described the urgency of her perceived needs as a determinant to her decision. She also acknowledged ways that she rationalizes her choice.

Line 437: *Lynn: So, if I don't request it [accommodation], I've talked myself into I don't really need it.*

Her other internal debate revolved around the concern for providers safety that out way the urgency of her need for care.

Line 332: *They are so uncomfortable, they aren't trained to do it [transfer]. These are nurses, their bodies are being put under strain - period. And so, their stress, I can feel from them not knowing what to do and being afraid for their own safety. You know, I feel that and that helps me, in somehow and way, not just the exam table but – I know they say they could get me on it but – ohh... [shrugs] there's that too.*

Lynn's 'in the moment assessment' of her capacity to battle the powers of discrimination, ignorance, and indifference at a time when she is already concerned for her health was a significant determinant to her decision.

Line 263: *Lynn: It's [self-advocacy] very time consuming and that's very stressful too...I have limited amounts of energy... oh, I wanted to mention that. This whole thing is very draining on my energy. And I have limited amounts of energy period as it is without going to the doctor. Even when it's not too stressful but, I have to be in charge, I have to go in and dictate what everybody should be doing it draws a lot on my reserves.*

The energy drain within one encounter built up across time and experiences to create an overwhelming state of fatigue that became a sub-theme for why decisions are made not to advocate.

b. **Sub-theme two: Advocacy fatigue**

Lynn explained the emotional and mental strain caused by the need to so frequently self-advocate – in and outside of healthcare. The repeated need to remind providers of her rights can at times become overwhelming and result in advocacy fatigue¹³ which influenced her advocacy decisions.

Line 567: *mentally and emotionally it's exhausting um, it requires some ... I think this answer might differ between people that have or don't feel they have mental health concerns and people who do. And I am somebody who does. So, for me, I'm already a little bit vulnerable and so yeah, I feel it is definitely not helpful, it is not in my best interest to have these experiences.*

In spite of informed decisions not to self-advocate, Lynn described how this negatively impacts on her self-identity.

Lynn: *...it goes against my nature to accept 'less than' right? So, when I do accept 'less than' then it's like this isn't really me. Like, 'alright, I'm going to do it [not self-advocate] but it's not really me' so this becomes an unfamiliar area emotionally...I think when you – for me – if I feel that ... then I'm accepting second class status. I don't expect to be 'more than' I just expect to be normal, what everybody else is getting in that particular environment. So, when I decide, I'm not going to even bother then that's not the real me. And I'm letting myself be put in that, that 'other' place, which I don't like.*

¹³ Carrie Griffin-Basas describes “advocacy fatigue as the increased strain on emotional, physical, material, social, and wellness resources that comes from continued exposure to system inequities and inequalities” (2015, p. 39).

c. **Sub-theme three: Exposure to the social model helps understand why**

Lynn's desire to be treated just like everybody else draws from a social justice ideology she embraces. She understood the discrimination and located the lack of healthcare access on society's failure to accommodate people with disabilities' needs. Her involvement in advocacy efforts in disability community organizations and professional work enabled her to use her knowledge of the social model to inform her understanding of the self-advocacy experience. Reflecting on the complexity of the social construction of disability and understanding the larger powers at work helped her frame her decisions.

Line 689: Lynn: ... *thinking about it is the healthiest thing I can do. To be able to start to understand it to be able to accept it. I don't want to accept it if I don't understand what's going on. For me, that's been a very healthy experience and again, only because I have to do that.*

Lynn's decisions not to self-advocate in a given healthcare experience were difficult, at times painful, but always conscious decisions. She based her decisions on interpretations of how contextual and personal factors influence the probability of a positive outcome and on the impact the experience will have on her overall health. There were risks to her health when she does not self-advocate and she understood she may suffer emotionally from damage to her spirit of autonomy. She also understood the care she receives may be inadequate and compromise her physical health, especially if she de-emphasized advocacy related to routine appropriate healthcare. Lynn's weighing of the pros and cons and her active decisions not to self-advocate were as deliberate as the times she elects to self-advocate.

5. **Master theme four: Lasting impact**

Lynn was resolute in describing how routine healthcare visits, that for people without disability could be incidental, become experiences that have a lasting impact. The master theme of ‘a lasting impact’ includes sub-themes of: learning from experiences on ways to cope, becoming stronger, the toll it takes, and developing a disability identity.

a. **Sub-theme one: Learning from experiences on ways to cope**

Despite describing significant discrimination and negativity, Lynn emphasized her desire to look for a silver lining of each encounter to understand “*this experience I am having as a person with disability*” and the need to find ways to cope with the experience so as not to be overwhelmed by them.

Line 252: *But because it's happened a lot in the last 30 years you learn...you try to find the silver lining. You try to find a take away, what, how can I learn from this? Sometimes that just seems ridiculous I'm so pissed off...fuck what I have to learn from this, right? It's what THEY [emphasis in voice] need to learn!*

Line 572: *I find ways to cope with them [negative healthcare experiences] and I try to make the best out of it but I still have to deal with the health issue...It's just another layer of something being dumped on me that I have to work out of. Um, on a day where I'm feeling strong, it's not going to affect me emotionally as much, or mentally as much, um, because I'm able to do things with the experience. But when I'm already low or um, I'm not as able to take care of myself the best way possible as soon as possible. So, it definitely has an impact.*

b. **Sub-theme two: Becoming stronger**

Lynn recognized that her advocacy experiences contributed to her becoming a stronger person. This helped her emotionally manage the injustices that she experiences. However, in the interview she explained the frustration and fatigue that comes from this process.

Line 601: *In terms of feeling stronger, the positive side ... and I've had experiences with this at times. It's that it's made me more creative. It's taught me about the tools that I can use that are available to mediate some of these things. It's taught me, um, it's given me opportunities to test some of the trainings, information and practices that I've learned in order to come out as emotionally intact as possible. So, it can be an opportunity. To be a stronger person. To be more aware, to be more involved... to not be as passive. That seems to be a very good skill that I wouldn't acquire if I wasn't forced to. So that's on the positive side. You know I have to look at it that way because it is so damaging. You can't just leave it alone, you really have to find something useful to do with it.*

c. **Sub-theme three: The toll it takes**

Despite attempting to find the positive in her experiences, Lynn recognized the powerful influence that discrimination has on her physical health. What is less described in the disparities literature, are Lynn's interpretation of how the discrimination impacted her mental and emotional health.

Line 553: LV: *Many PWD request accommodations because they have to just to be able to get basic care so how do you think this impacts a person's physical, mental and emotional overall health?* Lynn: *So, let's take the physical. I'm going to postpone and I have postponed - my treatments have been delayed at times - because I have postponed*

the visit. Because I know it's not accessible – so in my own mind I down play the symptoms I'm having. So physically when you delay the diagnoses you delay the treatment...sometimes it's more complicated than it would have been so I think that's all physically related.

Line 566-581: I think, do I really need this? I'm not a doctor so I can't really make that right decision. I make a layperson's judgment. So mentally and emotionally it's exhausting... I'm already a little bit vulnerable and so yeah, I feel it is definitely not helpful, it is not in my best interest to have these experiences... You know ... I go to the doctor to be helped, so that's not helpful. That part is just not helpful.

d. **Sub-theme four: Developing disability identity**

Lynn's understandings of her experience as a person with disability was grounded in the social model of disability which situates the problem of disability discrimination in society rather than in herself. She was determined to learn from these encounters, reflect on them and critically analyze them to deepen her understanding of discrimination and lack of accommodations.

Line 705: LV: Thinking of if the meaning of all of these experiences if they do have a common theme.... Lynn: To answer that... this has helped me to form a disability identify. To recognize that you're a different group of person. And I think that is empowering. Because that takes it off of the individual. When you realize that you're part of a community having these experiences – that this is an identity - perhaps imposed at some point. But then it is left open for you to choose that identity or not. That can be very empowering. Otherwise...it's just medical. "I'm stuck in the medical model" ... it's just

happening to me. Right, but when you see it from a bigger picture that's happening to a group of people then we're going into the social model. It's very interesting.

Lynn summary: Lynn described wanting to understand philosophically the experiences of disability and she appeared to approach her interactions within healthcare as opportunities for learning. Her analysis of these encounters enabled her to prepare for the next interaction. She has a unique ability to use experiences to learn why others interact with her the way they do. Her transcript was rich with descriptions of her attempts to interpret her experiences and although she related efforts to educate, to be in control, and learn from experiences, she also spoke about the layers of vulnerability (Luna, 2009)¹⁴ that impacted her healthcare experiences. Contextual and personal factors - such as providers' understanding of disability (not impairment), her capacity and the capability to effectively communicate her needs, the urgency of her needs and likelihood they will be met, and the institutional culture of the attitudes, policies and practices toward PWD within a clinic - enabled Lynn to make informed self-advocacy decisions. She also recognized an obligation to advocate for her community and to educate providers on how their failure to offer accommodations are, in fact, acts of discrimination. An obligation she optimistically hopes she someday will not have.

B. Marcus

1. Background

Marcus self-identified as an advocate for the disability community and a disability activist - active in group actions "*speaking up and out on issues of injustice*" that contribute to

¹⁴ Florencia Luna (2009) describes in *Elucidating the Concept of Vulnerability: Layers not Labels* that "layers of vulnerability allow for flexibility to the concept of a person's vulnerability based on the relationship between the person and the circumstance or context" (p. 129). Luna suggests vulnerability is layered because of the "relationship between the particular situation that makes or renders someone vulnerable, the result of the interaction of the particular circumstance and the individuals' characteristics" (p. 129).

the social inequities PWD experience. Marcus is 34 years old and lives with his mother with whom he is extremely close and who assists him when necessary with some activities of daily living. Marcus was born with his disability and described his provider relationships, some of which he has had since childhood, as nurturing and supportive. He talked a lot about feeling extremely comfortable in his relationships with healthcare providers and his ability to openly communicate his needs.

Marcus has only recently become involved at his local Center for Independent Living (CIL) and described strong peer as well as mentoring relationships that have developed through his association with this community. He identified specifically with one older outspoken advocate and says he is becoming a stronger self-advocate by learning from him. He sees himself as the ‘next generation’ of disability community advocates. During our conversations, his passion and commitment to the disability community were evident.

a. **Bracketing**

Initially, starting in the recruitment phase, I had concerns whether or not Marcus had enough background as a *self*-advocate and during the interview this was on my mind. During analysis, my presumptions of what constitutes self-advocacy behaviors were confronted as Marcus’ descriptions offered differing beliefs and styles to strategies in accessing healthcare as a PWD. He clearly self-advocates and brought some differing perspectives to the overall analysis of the diverse expressions of self-advocacy and interpretations of accommodation allowing for a better understanding that enrich the findings. Many of the questions in the interview appeared challenging to Marcus – relying on stories from peers rather than providing examples from his own experience. Marcus explained he understands peers’ fear of speaking up or out against their providers but this was not his situation as he has little of his

own fear of rejection from providers, and feels empowered and positive from managing and advocating for his personal health needs. In his own relationships and interactions with providers Marcus described open communication and collaboration as a natural vehicle for advocating for himself. He perceived a more productive approach to receiving accommodations come from partnering with providers versus demanding access to accessible equipment. Over the course of the study, what emerged was how his exposure to the disability advocacy community and disability activists are shifting his perceptions on his rights to accessible equipment. The themes for Marcus document an evolving understanding on healthcare accommodations as well as expanding knowledge on personal self-advocacy. Four master themes emerged from the interviews with Marcus: understanding self-advocacy as a fact of life, learning to recognize disparity in care that necessitates self-advocacy, decisions not to self-advocate, the lasting impact of experiences in healthcare.

2. **Master theme one: Understanding self-advocacy - a fact of life**

Although Marcus's past experiences with providers were generally positive, he described the need to advocate to receive basic healthcare as a fact of life. Based on a lifetime of experience, he described that in most of his providers' offices and facilities, accommodations were non-existent, and having to "figure it out" as the status quo.

Line 329-337: Marcus: *As a person with disability I think you just have to you have to ... since the day I was born you know and this has taught me well – it has taught be to advocate. And I think this is vital to be able to self-advocate you know - for yourself because if you don't do it, no one is going to do it. If you don't advocate for yourself, if you don't advocate for an accommodation, if you don't do those things it's not going to happen.*

Marcus described needing to advocate in such a matter of fact way that it seemed a natural part of being a person with disability. He identified that his preferred approach to advocating for himself is developing an open collaborative relationship with providers where he can communicate his concerns and problem solve when necessary. By his own account he has grown up in the healthcare system, feels supported by his providers and has a solid understanding of how to navigate through it.

a. **Sub-theme one: Using communication and collaboration as his approach to self-advocacy**

Marcus described learning to self-advocate as a “long process” evolving from being advocated for by his family to achieving independence in being able to speak for himself. He identified his capacity to be his own self-advocate as the prerequisite to independent visits to a provider. This included being able to communicate his needs and the ability to request an accommodation when needed.

Line 341: Marcus: *As a PWD I had to learn this myself I had It was a long process but I can speak for myself when I'm in a doctor's office I can actually speak for myself you know? LV: How did you learn that? Marcus: Just being able going by myself you know, because most of the time when I was going to the doctor appointment my mom was there with me or somebody else was with me. But these days I am sort of going by myself because I know if I need an accommodation I can ask on my own.*

Marcus described the process of assuming authority for his own care. This transition is a major step to adulthood for any child, but for some PWD the parental authority is never conceded or provider authority suppresses the transition (Binks, Barden, Burke, & Young, 2007). For some PWD, low expectations - from parents and providers - for the capacity of medical

decision making becomes internalized, prohibiting this transition (Mitchell, 2015). Marcus recognized that he had the skills and knowledge needed to independently communicate his need to the healthcare team which enabled him to assume greater control over his own healthcare.

Line 348: Marcus: *If there is something I need I can express that to my doctor, and we can work together to figure something out to make that experience a lot better or if there is ...if I'm going for an examination to make sure everything is all set for me. That the process goes smoothly so having ... being a self-advocate is a valuable tool to have especially being in that...in the medical setting.*

Line 356: Marcus: *I sort of remain, one of my survival strategies is to stay calm and level headed. Because when you are going to a doctor all kinds of things run through your head. So, when I go to the doctor one thing I do is I am calm and level headed and I ask a lot of questions. If there is something I need to know, I ask. I think it's simple but in my case...having or learning to advocate for myself has been a huge tool to survive.*

Effective communication and collaborative problem solving were major contributors to Marcus' concept of being accommodated. Having a relationship where he feels he can ask questions and have providers listen to his needs helped him alleviate stressors and rationally assess his situation.

Line 256: LV: *Do you feel he listens to you...as you being the expert of your body?*

Marcus: *Oh ya, oh ya, he does, he definitely listens to me because I think that's what he really wants to know Because you know I'm not really that talkative of a person, in a doctor's office or I'm more of a kind of 'yes' and 'no' kind of person. He says, no, no, no, that's fine but I need more I need a little bit more information here. Once he gets that*

information then he can ... we can go from there... we can work on what needs to be done.

Marcus reasserted the value he attributes to an open collaborative provider – consumer relationship in his clarifying interview describing his overall healthcare management as a “team effort”.

b. **Sub-theme two: Understanding self-advocacy means more**

Marcus has had the benefit of long and supportive provider relationships. He described his primary and specialty doctors as people he has known most of his life. A handful of his providers are entering retirement forcing him to seek out new relationships. He described some anxiety about meeting new providers, especially related to his uncertainty over how they would handle requests for collaboration and accommodations.

Line 239: Marcus: *Cuz I was ok, I'd never been in this situation before you know, I have had other doctors that I've known for a while, LV: your whole life? Marcus: Yes, and this guy I didn't know him and I was like ok, how is he going to treat me and has he ever worked with a PWD ... does he ... If I need accommodations is he Is he willing to do accommodations for me? A lot of things go through, it's really nerve wracking when you're meeting someone for the first time that's when your stress level is like oh....ok. I'm kind of nervous here about what's going to happen and I think once you meet the person and talk to them once you know feel them out a little bit, that stress level sort of lowers.*

Marcus also raised concerns that lack of accommodations would force him to assume a more confrontational form of advocacy that he lacks confidence in using. These concerns may come in part from his interactions with disability peers, many of whom have experienced many and frequent problems with healthcare providers.

Line 216: *A prime example is (peer) who has talked to me numerous times and to others about having that fear of going to a doctor because you know something as simple as a transfer, safe lifting and so I know he's been injured on a few occasions because of nurses' and doctors' negligence when he has asked for an accommodation and they respond with like 'this is the way we're going to do it, we do it this way' not his way and that could cause a lot of stress for a lot of PWD.*

This friend's experience exposed Marcus to the potential negative outcomes of a provider who is not collaborative and the need for strong self-advocacy. When asked about his own healthcare experiences, Marcus described the sense of ease and reduced stress and concern for his own safety when provided with space and accommodation.

Line 291: *You're less stressed when you are going into a room you know...? You know exactly, you don't have to worry about 'hey are they going to... 'how are they going to hurt me today?' 'How are they going to hurt me today when I'm try to maneuver through here you know?' ... Or maneuver onto an exam table.*

Marcus' most recent healthcare experiences have been with an unfamiliar provider trying to receive an MRI screening. He acknowledged that no amount of collaboration was going to gain him access to an inaccessible piece of diagnostic equipment.

Line 133: *I swear it was about 10 people in there, so I was the problem, I was on the exam table now to get me into the tube. They couldn't ... I couldn't do it ... so they had to get – I swear it was 10 people – they had to get me back on the gurney, take me back to where I originally was and then had to get my stuff on and then be able to transfer me over.*

Marcus' interpretation that he was the problem is reminiscent of medical model language that locates the problem of disability within the person versus within inaccessible equipment. Despite having a solid knowledge of the social model and social construction of disability, Marcus made sense of the failure to have his MRI by placing the blame onto himself. His frustration is evident when he described his experience.

Line 157: *It was frustrating because I felt – I wanted to do I [emphasis in voice] –we went through this whole process of getting the MRI set up and it just didn't work out.....you're trying to get me on here and it just wasn't working and my frustration just started to actually boil over as the process went on.*

This experience risked fracturing the sense of calm and confidence he previously experienced within the healthcare system and caused him to endure emotional and physical pain. In his clarifying interview, he discussed his realization that to receive this healthcare service would require that the diagnostic equipment be “*designed with PWD in mind.*”

3. **Master theme two: learning to recognize disparity in care that necessitates self-advocacy**

Marcus recognized the amount of effort or tolerance that is being asked of him to work collaboratively with providers when accessible medical equipment is absent. He also recognized that there was a time and place when self-advocacy is needed.

a. **Sub-theme one: Providers' alternatives poor options**

Line 16: Marcus: *They wheel me in, into the office space and to be weighed. And you know since I can't really get up and be in a ... be weighed at all, they sort of put you on a weighted type of scale. I mean it's kind of fun, for me, cuz you're swinging but it it's sort of a pain because you're being, because you are in the air and*

they are lifting you and you're probably not comfortable being lifted. So that's a lot better than Having a weighted scale is a lot better than being hung up in the air you know...they have ways now for you actually to be weighed. So that comes, having an accommodation like that where you're not in the air swinging or you're not having to try to stand up and be weighed, you now can be weighed in the chair and it's a lot less time consuming, it takes maybe less than 30 seconds.

Line 109: I was supposed to have an MRI and on that day... so, everything is going well, you know everything's been set up, they've got me in the exam room, patient room, open space and so we're like ok, everything is all good. They're helping me out, taking stuff off, everything is all good....so they're like, 'ok we're going to transfer you over to this other...to the...the gurney that's it the gurney yes, and then they bring you over to the MRI tube and they're like 'ok, we're going to do this' and they – as it worked out... it started off with one person. 'OK, we're going to do this, we're going to do this'. SO, they are getting me on there, the problem was with my legs I sit cross-legged most of the time so I'm on the gurney and my legs aren't fully on there and they – we're trying to straighten the legs out and they had to get another person to come in.

In both of these passages Marcus described the discomfort and pain he was forced to tolerate due to a lack of accessible medical equipment. It makes sense to him that providers are attempting to do the best they can with what they have but the “problem” is his body’s inability to conform and potentially an interpretation of the inequity in how his care is received.

Line 163: LV: There were 10 people working to get you onto the MRI table...how did this make you feel?

Marcus: *It made me, it really made me feel different. I was like ugh, like at the point...when I was thinking about it I was like ok, if I was walking this would be a problem ... but I'm not walking so the reality I have to deal with is like I couldn't do an MRI.*

A history of being able to tolerate inaccessible equipment may have been, to some extent an indicator to Marcus that his body was able to perform within 'normal' parameters. This experience created a significant disruption in that narrative and caused Marcus to realize that he may not receive the care he needs unless he more assertively self-advocates for accessible medical equipment.

b. **Sub-theme two: The reality is ... he must ask**

Marcus described increasing awareness that collaboration and communication are insufficient and that to receive care demands stronger or more direct self-advocacy. However, many of the examples Marcus used to describe advocacy experiences are from peers from his disability advocacy community versus his own. He recognized through the multiple stories that experiences of discrimination and substandard care are prevalent and an important target of group advocacy efforts. Despite a foundation of knowledge from his many group advocacy efforts critiquing the built environment, he interpreted his own self-advocacy through a lens of his own independence and capability. Although understanding he has a right to request the accommodation he struggles with what it means to his identity when he makes the request.

Line 175: LV: *You said 'it's the reality of what I have to deal with' what is that reality?*

Marcus: *It's that for certain things I need an accommodation. You know sometimes ... as a person like me... I'm an independent person so sometimes I don't want a whole lot of help.... I don't ... I don't ... sometimes I don't like it but it's something that I know has to be done. That I have to deal with ... that it means to be...it needs to be done for me to be able to do the things that I want to do, you know?*

Marcus' description exposed the conflict he feels between being independent versus needing outside assistance. It also highlighted his belief that requesting accommodations shifted the power relationship and moved him into a more subordinate position.

Line 190: *I have started to become more open about needing an accommodation and you know, people, you know, PWD it's hard to ask because you have this fear that you might get rejected or like you say you might...you feel like you're being treated differently but now as I have been in the healthcare system pretty much my whole life and as I've gotten older I understand that for certain situations I need to ask for an accommodation.*

Marcus' exposure to his center for independent living and disability community has raised his awareness of his right to request an accommodation. However, he understood from his experiences requesting an accommodation he knows is unavailable will highlight his otherness. He equated receiving an accommodation to being treated differently but not so when providers fail to provide him with the same level of care non-disabled individuals would receive. Although he understood his right to request an accommodation, he does not necessarily interpret it from a rights' based claim to equitable care provision.

c. **Sub-theme three: Learning rights to care**

Marcus' emerging awareness from others' stories, now linking to some of his own, of disability discrimination and stigma within the healthcare system, highlighted how

his past healthcare encounters were uniquely positive compared to many of his peers. This difference may stem from his lifelong participation in what might be interpreted as potentially paternalistic but simultaneously collaborative management of his health and wellness. However, as he ages and is faced with new health management concerns, he is confronted by unfamiliar providers. Marcus was the only participant with a congenital but stable health condition which uniquely positioned him as growing up ‘knowing’ his bodily needs as ‘normal’. Despite having a strong knowledge on what he needs to manage his healthcare, he described experiences when providers fail to understand that health – his health - can co-exist with disability.

Line 203: Marcus: *Being stuck in a little tube for hours I don't think PWD are even considered and like you said in some doctor's offices those accommodations like for example having a wider patient room, where a PWD can navigate you know, I don't think that is even thought of when the building process was even happening.*

Marcus understood PWD are rarely considered in the design of medical diagnostic equipment and structures across the healthcare system. Marcus described that this lack of consideration of the disability experience extended to healthcare providers as well.

Line 248: Marcus: *a lot of people, a lot of primary care doctors sometimes, healthcare professionals they're not really comfortable around PWD. You know it's their job but.....*

LV: *I think that's a very accurate statement*

Marcus: *I think a lot of them aren't, aren't, comfortable with a PWD because there might be a set of stressors on them to make sure that they are doing it right, and that you know, if a person with disability needs an accommodation.*

He interpreted the responses of providers as stemming from a lack of knowledge on how to work with PWD and felt that he needed to be sensitive to the stress this caused for providers. Concern about putting providers into an awkward position may prevent him from requesting accommodations that he is entitled to.

Line 402: Marcus: *So, when you come out of there, when you come out of the CIL you understand ok, as a PWD you have, you have a right to an accommodation, you have the right to speak to your healthcare provider about an accommodation. You have those rights.*

Line 467: Marcus: *I feel like here, you know, we fight for our rights, you know, we are at actions we are at different places, you know, fighting for our rights and I don't know if in other places that is there.*

Marcus described a process of learning his rights as a PWD from the independent living movement as transformative—his understanding of being a PWD has not changed but his self-concept as a member of an oppressed minority group appeared to be evolving. His mentoring includes exposure to and developing a knowledge of civil rights for PWD but also to advocacy techniques and activism used in group actions. His reflections suggest he might consider this an important piece to becoming empowered as an advocate for himself.

For Marcus, the ADA legitimized his requests and provided him with the language in making requests, and he surrounds himself when possible with providers who are disability allies¹⁵ or those who have a solid understanding of the ADA. As a result, his experiences in

¹⁵ While often mentioned especially in literature from interdisciplinary scholarship of disability studies the concept of 'disability allies' is explored in a manuscript by Evans, Assadi, and Herriott (2005) within a special issue of the journal *New Directions for Student Services* titled *Developing Social Justice Allies*.

managing his health have been both positive and empowering.

Line 405: Marcus: *As a PWD you have, you have a right to an accommodation, you have the right to speak to your healthcare provider about an accommodation. You have those rights. And once you understand that you can go into an office and you can just, you know exactly what to do and you know exactly what to say. If you do need certain things, you know how to advocate. You know how to do those things. And being like, being in, being in situations where I've had to do that, it gives you a better understanding you know.*

Marcus described how the basics of universal design¹⁶ can make such a dramatic impact on his ability to feel accommodated.

Line 247: *Accommodation means to me—it means being able to...being able to maneuver in a space ... being able to get around, being able to have access to what I need. Like in this room, I have enough space to get in. Sometimes, for me, that's all I ask, having the space to navigate, if I don't have that space it's going to be a problem. Especially when it comes to things like being examined or being checked out you know. That's probably one of the most important things for me. Is being able to navigate in a space.*

Line 306: LV: *Have you ever had a situation where you were in a healthcare visit that was 100% accessible or accommodations provided up front?*

Marcus: *I would say when I've gone to [hospital name] I've never had an issue going there when I see a doctor from there. It's more like when I go to that place they*

¹⁶ A well accepted definition of 'universal design' is: "Universal design can be defined as the design of products and environments to be usable to the greatest extent possible by people of all ages and abilities. Universal design respects human diversity and promotes inclusion of all people in all activities of life" (Story, Mueller, & Mace, 1998, p. 2).

automatically know what to do so ok...they have weighted scales, they have big rooms where I can navigate easily...at least turn.

He clarified in his second interview that universal design is not just about making this easier to get around but that “*he breathes a sigh of relief*” when he sees equipment designed for his use. A sigh of relief that he will not be forced to endure experiences using poor substitutes to accessible equipment and that “*providers care how to make his experience easy*”. He described that for him accessible environments represent that he is welcome.

Line 277: LV: *When you don't have an accommodation what meaning does this have for you? If there isn't an accommodation or you've been told no, sorry we can't, what does that mean to you?*

Marcus: *it means that I'm not welcome, and that I'm not welcome and maybe this isn't the place for me and like, if I'm outside ... like outside of this building if there isn't an accessible entrance ... if those two doors in the front of this building weren't accessible, I'd be like, 'they don't want me here' so why am I here? You want to feel, having an accommodation means that ok, that you feel welcome, ok, we're going to help you as best as we can to make you feel comfortable, That's also what I think an accommodation means is being able to be comfortable where you're at. If you're not comfortable being at a place like a doctor's office being in a dental chair, that's going to be a problem, it's going to be a problem for the PWD, it's going to be a problem for the doctor and so having an accommodation means it...being comfortable as much as I can in that space. You know, physically and psychologically comfortable.*

4. **Master theme three: Deciding not to self-advocate**

What Marcus described from experiences in healthcare have helped him to understand how the context of an encounter can change the necessity or outcome of self-advocacy. He made sense of times when he chose not to self-advocate based on past experiences and his recollection of the contexts that were successful or not.

a. **Sub-theme one: Rationalizing needs**

Line 189: Marcus: *From time to time I do sort of...you know...sometimes I don't ask you know, sometimes it's you know ok, in my mind this is simple, I don't need none of this and I don't ask.*

Although he may not ask for accommodations and prefers to just make it work, Marcus did consider the larger issue of accessibility and how requesting an accommodation is a form of education and possibly even collective advocacy.

Line 190: Marcus: *The problem is - is that if you don't ask, they don't know.*

At the same time Marcus recognized that requesting an accommodation impacted his concept of himself as an independent person. Asking for an accommodation especially in the form of assistance from others versus having equipment that he could easily access and utilize, invoked feelings of dependence.

Line 176: Marcus: *You know sometimes ... as a person like me... I'm an independent person so sometimes I don't want a whole lot of help but when it's situations like that...*

b. **Sub-theme two: Feeling like you're being treated differently**

Throughout the interview Marcus framed his requests for accommodations as pointing to his need for being treated differently, which he resisted. The lack of routinely coming across accessible medical equipment and providers' unfamiliarity with how to use this

equipment when it does exist was interpreted by him as emphasizing his need for special treatment, something extra, and being a burden. This reinforced the likelihood that he may not request the accommodation even if he knows he needs it. Marcus resisted the appearance of being demanding or difficult as this conflicted with his easy-going personality and his preferred collaborative style of interacting.

Line 191: Marcus...*it's hard to ask because you have this fear that you might get rejected or like you say you might...you feel like you're being treated differently...*

5. **Master theme four: Lasting impact**

Because Marcus described his providers as supportive and his healthcare experiences as generally positive, the lasting impact of his experiences are fundamentally empowering as he feels he is part of his healthcare team and is able to manage his care.

a. **Sub-theme one: Successful management is empowering**

Line 208: LV: *So, when you are going to a provider and you have a doctor's appointment, do you find anticipating this or preparing for it stressful at all?*

Marcus: *I would say no, I might be a little nervous about something...I mean it's 'a doctor' you know. You might be going to a doctor or a dentist you know, you're a little nervous just because ya know. But I don't think it causes me a lot of stress because I actually really trust my doctor, doctors. So, going there is more of a relieve for me because they've seen me before, they know my situation and they know what to do when I get there.*

Line 521: LV: *How do you think that the fact that you've had all of these positive experiences, how has it impacted you physically, mentally and emotionally?*

Marcus: *Right, well, physically, let's be honest, I try to avoid the doctor as much as I can too, but even though I go, when I...physically, when I am going to a doctor, I want to make sure I'm in good health, I think that's important for me, is making sure that, at least as in as good of health as I can be, you know, so and physically, ya, I want to make sure that I'm you know, ok Um, mentally, it doesn't really affect me unless.... you're doing an MRI [laughter] other than that, going, my mental state is like okay, I know this is something that I have to do, I go in...And emotionally, I feel I actually do feel empowered, cuz I'm like, this is something that I'm doing to make sure that I live a long life, you know?*

b. **Sub-theme two: Advocacy fatigue**

When asked how it feels to have to ask for an accommodation and be rejected Marcus referred to stories from peers to help him interpret the experience of advocacy fatigue and its impact that can result in decisions not to seek care. Therefore, Marcus through his engagement in the disability rights and disability activism communities had developed a sense of shared disability experience which while different from his own relatively positive experiences, he recognized as both valid and important.

Line 510: Marcus: *You know, they will try their best not to be, you know, to have a doctor's appointment or to visit the doctors because of those situations and I think physically, but mentally this is also a problem. Because it's added stress because I know people that are like.... [big sigh] "Okay, I gotta go to the doctor today" [said with resignation and fatigue in voice] "and I don't want to deal with this, and so many things I have to go through to just have this appointment and you know to be there, to getting there"it sort of piles on you know? Emotionally, I think going in, you know, having a*

visit is - it can bring out a lot of different emotions because of having a bad experience and you know, going to the doctor might trigger, trigger those emotions, and trigger those emotional feelings. So, I think it's difficult. From an emotional standpoint.

c. **Sub-theme three: Avoiding care**

Marcus reported feeling empowered by his relationship with his provider, visiting his provider to manage his health in order to live a long healthy life. He empathized with peers that do not have this type of experience and interprets how attitudinal barriers might impact the health of PWD.

Line 506: Marcus: ... *it effects their physical health because if they can, if they aren't comfortable being in a doctor's office they'll probably try their best not to be at a doctor's office ... And so, even if their health is not in good condition, they know that, okay, they're not going to help me so why should I go there, why should I go and see them. If I know that they're not going to listen to me, they're not even going to help me, you know, they're just going to talk over me, and talk down to me, then I'm not going to do that.*

Marcus summary: Marcus understood that PWD are discriminated against in multiple contexts including in access to healthcare. He had a solid foundation of the ADA and the civil rights language that informed his group advocacy efforts and disability activism. He made sense of much of his own advocacy in health care as being collaborative successes. However, when he reflected on his own healthcare experiences and needs for accommodations both met and unmet, he situated the problem in his otherness or bodily difference, a difference he sought to minimize or at the very least de-emphasize. His collaborations have been centered on working together to 'make do' with equipment that fails to easily accommodate him.

Marcus described having a high level of tolerance for discomfort and endured a lot in his healthcare visits as a matter of fact. His primary providers did not have equipment that can accommodate him but he felt accommodated by them in other important ways, such as their inclusion of his opinion and collaboration in his healthcare management. He described his health management as a priority and he appeared to have a strong sense of knowing what he needs to maintain his health. He did understand and has heard of peers with disability that do not have these positive experiences and recognized that he is fortunate to have assembled a team of providers he sees as disability allies. As a team member, he had high regard and even more importantly high concern for the providers in the challenges they will face in handling his body. The pain and effort that providers endure is a factor he considered in making decisions to request an accommodation.

Marcus viewed his provider-consumer relationship as a collaboration. Without the provider, it is impossible for him to transfer, or get the care he needs to live his long and healthy life. Marcus had learned through his experiences of collaboration that team work is critical. He felt like he has learned together with his providers...missing or a lack of accessible equipment means they have to “figure things out”. He did seem resigned to the fact that accommodating equipment and facilities are a rarity and problem solving and collaboration is the more common and practical approach to getting his needs met.

C. **Eve**

1. **Background**

Eve is a Latina woman in her mid-fifties who acquired a spinal cord injury over thirty years ago. She was born in a small rural town and moved to the city as a child. She described herself as a friendly, approachable, strong independent woman with a good sense of

humor and generosity toward others. Despite experiencing many obstacles throughout her life, she proudly declared successes in raising her son as a single parent, and as a recognized leader in the disability activist community. She described herself as being a vocal self-advocate through her life, speaking up for her rights, especially when she knows she is being wronged:

Line 516: Eve: *I've always been an advocate since I was the age of 18. I think when I filed my first discrimination lawsuit against a company for racial discrimination. At the age of 18... I've always known that when I'm being wronged I'm going to do something about it. So, yeah when it comes to discrimination, when I feel like I'm being discriminated against I'm certainly going to do something about it.*

Eve's identity as a disability advocate on issues of healthcare access is reinforced by her knowledge of her rights to accommodation and repeated personal experiences in successfully confronting discrimination in the healthcare system. She has a rich history of educating and mentoring other PWD on disability rights and strategies and approaches for successfully confronting the social inequities many PWD experience.

a. **Bracketing**

Entering Eve's home allowed me to see the multi-faceted lived world of her intersecting identities. I was reminded that who she is, how she interprets the world, and likely her experiences in self-advocacy is informed by these many parts of her identity. Eve talks about her passion for art and performing the interview in her home, allowed me to get a glimpse at her amazing art collection as well as be introduced in new ways to who she is.

Eve's PA greeted me at the door and helped me with my coat, as Eve offered lunch and a tour of her home. She proudly showed me around explaining and described her art and sculptures and stories of the artists – most of whom were all close friends, all were PWD. Her other art was

everywhere but a large grouping was officially positioned in what she called her gallery. We sat at her kitchen table enjoying the lunch she had prepared for us and chatted before starting the interview.

Eve's interview was filled with experiences of discrimination and different public and private examples of her approaches to self-advocacy. In her clarifying interview, she reinforced her advocacy is not always influenced purely by issues concerning disability - that reinforced my own need to bracket the presumptions that disability identity overshadows other intersections of a person. Eve advocates most strongly for respect and this is informed by those multiple intersecting identities of who she is. The themes; understanding the need to self-advocate, decisions to self-advocate, decisions not to self-advocate, and the lasting impact, are each heavily influenced by Eve's assertion to be respected by the providers she works with.

2. **Master theme one: Understanding the need for self-advocacy**

Eve had a heightened diligence to understanding the need for self-advocacy as a PWD, informed by her own history of confronting feminist and racist acts of discrimination. Although she self-advocated to get her own needs met her primary intentions often appeared to focus more on exposing the injustices that are occurring or to educate providers – or both. Beyond requests for physical accommodation, her energies targeted self-advocating for the respect and dignity denied her because of provider attitudes and behaviors she perceived as influenced by disability stigmas and prejudices. Her purpose for self-advocating was driven by interpreting self-advocacy as a catalyst to change policy and practices that perpetuate these constructions. Three sub-themes were identified from Eve's transcript under this master theme: providers not knowing how to care for PWD, understanding how normalization of discrimination impacts care, and understanding the need to self-advocate determines how to self-advocate.

a. **Sub-theme one: Providers don't know to care for PWD**

Eve interpreted the way providers respond to her body as grounded in how they understand other bodies – those without disability – creating false presumptions on how to care for her. She described how providers attempt to transfer her from her chair using methods they would for a child, not understanding how her body functions differently.

Line 89: Eve: *Most of the time I have to instruct them how to do it. Because they always want to just pick me up from under my shoulders, that's how they lift but they don't realize that I'm paralyzed from the neck down so my legs are not going to...they think they're going to pick me up...like picking up a child where they can just pick them up and then...then there are other factors like spasms. I have spasms so when I'm being moved I tend to stiffen up and my legs are not going to... I'm not going to stand up straight, they'll tend to spasm and then it just makes it really difficult to lift me up that way. So, I have to instruct them to put their hands to grab my legs underneath the knees, to do a what we call a pivot, behind me under the shoulders and the other in front under the knees sort of like in a sitting position and the transfer me in that way. But they always want to come in front of me and lift me like that* [she gestures under the shoulders like a child who can stand up].

Eve sensed providers' perceived authority for her healthcare and how it overrules her own embodied knowledge. These presumptions put her in harm's way and she understood the need for self-advocacy to correct misperceptions about how her body functions. Eve indicated that when she requests an accommodation, she shares the responsibility of the extra work being placed on providers as a means to increase her odds of success in receiving care.

Line 269: Eve: *It's like preparing them is important. I want to make sure that they have the right accommodations because um, learning from the past I know not everything is accessible and I can't take it for granted. I feel that maybe I do or should share some of the responsibility to let them know. Or it's going to be a waste of my time.*

Eve interpreted that within her healthcare encounters she must self-advocate on how to be moved and what accommodations she will need to make the visit easier for her as well as for her providers. She described her ability to assert her authority on her body as a tool that supports her self-advocacy. Eve understood that providers' beliefs and attitudes can reinforce and uphold discrimination that impacts not just her healthcare but that of all people with disabilities. This drive to combat disability stigma is exemplified in the following passage from Eve's clarifying interview.

Clarifying interview: Eve: *At times I get so upset, it might be a little thing, but it's really not. Just the language, and the barriers and just these, the stereotypes that bother me. For example, when I was in the ER, the doctor... I hear him talking to my orthopedic doctor and he's describing me to him and he says, "yes, one of your patients is here – wheelchair bound" – and he's really loud, he was talking the whole night, really so loud, he's so loud, "wheelchair bound!" [she yells the phrase]. And that's the second time I've heard that description in that hospital, from a nurse and from this physician. So, later that day, when he came into the room, and I ... I told him - in a mild manner [softens her speech], "in the disability community, we do not use the term 'wheelchair bound' we prefer "disabled" or "wheelchair user" and yeah, he just had this look on his face like ... 'oh' ... He was so embarrassed and I...it's just a form of re-educating him, that we don't*

use those terms. And he, he didn't say anything back to me, he just had that look on his face.

b. **Sub-theme two: Understanding normalization of disability discrimination**

Eve recognized that provider bias and stigma of disability reduce the respect providers show for people with disabilities and can also lead to assumptions that PWD are not in need of, entitled to, or candidates for the same level of primary or preventative healthcare as their non-disabled peers. Eve recognized the pervasiveness of discrimination against PWD demands preparedness to self-advocate.

Line 114: LV: do you consider yourself a self-advocate or do you feel like when you're in a healthcare setting you have to advocate for yourself?

Eve: yes, because if I don't who? Who?? Yep and you need to ... cuz, it won't.....it just won't....[care won't happen]

LV: What do you think you have to advocate the most for?

PAR: Um ... my dignity.

For Eve, being treated with dignity and respect were highly valued and a major focus of her advocacy efforts.

Line 497: Eve: Accommodation also is ...it can be the attitude of both the physician or technician that is present– that is showing me respect in a way that while yes, I'm a person with a disability but I also expect respect and deserve the healthcare just like anyone else so I would like to be treated in that manner.

Although providers may not recognize their negative attitudes and inadequate approaches when working with PWD as discrimination, Eve did.

Line 40: Eve: *I mentioned that I needed assistance that I ...so they scheduled me to the right room and when I got there I noticed that the scan machine was like the same height as the other...[inaccessible] table. I was like whoa, she had said this scan table... [was accessible] ... and so I thought ok it would be lower! But it was the same height as that earlier table. But the difference was that there were two technicians, two people came to help. I was like ok...so there ya go! There's the difference. I guess the accommodation is getting two people but I thought it was going to be that the table would be accessible...lower you know? But that was a misunderstanding on my part I guess.*

LV: *Why do you think that the tables -- the equipment isn't the thing that is the accommodation? Why is it the added staff that is what they consider the 'accommodation'?*

Eve: *I have no idea, that's something that...it has to do with the designers and the engineers that put those machines and equipment together because you know they're not thinking of the issues like the height and thinking of course people that might use them like people that are disabled. So, I think they are only designed for people that are standing up and then can sit and lie back.*

Eve conjectured as to why she was not accommodated but also interpreted this scenario as the status quo and the providers' efforts the only alternative without appropriate equipment.

However, in trying to make sense of discrimination in a healthcare setting she was appalled.

Line 343: Eve: *There were no bathrooms that were accessible. The whole hospital! This was my recent experience with discrimination. I was there for a fractured femur. I was a patient there for 6 days. Was not able to use the bathroom...the bathrooms were not accessible. None of the bathrooms in the bedrooms even in the [entire] hospital. They*

wanted me to use a bedpan. I'm like 'I'm sorry I can't use a bed pan I'm a quadriplegic that's just way too difficult for me and it's just not going to work' So, I asked, are there any bathrooms that are wheelchair accessible? They said yes there's one in the lobby. So, I had to go to the lobby. To use the bathroom, only one in the whole hospital!

Eve interpreted her experience as discrimination that necessitated self-advocacy. She described understanding the many layers at play in provider prejudices and stereotyping and has learned to use different approaches in how she self-advocates.

c. **Sub-theme three: Understanding the need to self-advocate determines how to self-advocate**

Eve was keenly aware of the level of respect providers give or fail to give her. She is diligent in speaking up when providers failed to respect her as a person, or when she experienced unjust treatment and discrimination. Eve demonstrated a tacit understanding of the hegemonic standards of what a “respectable person” would do in the healthcare setting and through her insights was able to balance the respectability politics¹⁷ of disability activism, self-advocacy and the right to dignity. She understood how disability stereotypes inform provider prejudice and discrimination and used this knowledge as a subtle form of self-advocacy.

Line 464: Eve: *And keep in mind that it also could be how they carry themselves. The PWD that is. How they look, how they're dressed, how, right? They might think that yeah, maybe you're just some Joe Blow down the street hustling.*

LV: *Is there a higher standard for PWD to look um, put together.*

¹⁷ Randall Kennedy described in “Lifting as We Climb”, an essay in the October 2015 issue of *Harpers* magazine (<https://harpers.org/archive/2015/10/lifting-as-we-climb/2/>), the essence of respectability politics and its critical role in understanding biases and responses to these bias, emphasizing that “any marginalized group should be attentive to how it is perceived” by the group that has power over it.

Eve: *Oh yeah, presentable. To look decent. Cuz, if you don't they're going to think you are just some homeless guy downtown. Looking for a quick fix.*

Based on years of experience as a disability activist, she recognized the reality that requests for accommodations are frequently perceived as asking for extra, or how self-advocacy can be wrongly construed as being the 'non-compliant patient', a burden, the "angry cripple" and becomes a balancing act for some PWD in how to best self-advocate for accommodations.

Line 235: Eve: *Because anybody can be a loud mouth and walk around and yell out things with a stick but who's going to hear you? Is it going to accomplish anything? I think um, there's a way, there's ... there's a way to get things done...the right way, the appropriate way.*

LV: *What way is that?*

Eve: *Well, for example, like what I did. Instead of coming out of that clinic and yelling and cursing and barging into his office and making a big deal out of it. I don't think it would have worked in my favor to behave that way. As well as doing it the appropriate way like writing a letter to get his attention. Not only get his attention but to let him see that I am a person ... I am not just a nobody, but I'm an educated woman and I felt at the time I was disrespected and I was overlooked as a woman with some knowledge and strengths.*

Eve's approach to self-advocacy was tactfully used to strip away negative stereotypes providers hold of PWD who self-advocate as being belligerent in the face of authority while targeting providers' discriminatory practices. She used this method as an avenue to address her own needs and turn her self-advocacy efforts into a catalyst for policy and practice change in a form of disability activism.

3. **Master theme two: Decisions to self-advocate**

Eve's strong convictions for her right to respect and equitable treatment in healthcare lead her to self-advocate. She cannot be intimidated and does not hesitate to address discrimination in private or public ways. From her interview three sub-themes emerged from the master theme of decisions to self-advocate: to be respected; deserving of care; and as a catalyst for change.

a. **Sub-theme one: To be respected**

Line 513: Eve: *I speak up for my rights, especially when I know I am being wronged, violated, intimidated or disrespected. I am going to speak up, I will do something about it and I am not going to endure any kind of humiliation or discrimination.*

During the interview, Eve described an experience where her self-advocacy efforts targeted a violation of her dignity.

Line 125: Eve: *The PAs um, were starting to undress me and the doctor was in the room with a medical student. And I was um like 'Hey, wait a minute what's going on here?' And they were like you know, we need to take your clothes off because he's going to be doing some exams down there or something like that. I was getting upset because they were just undressing me right in front of everybody and in front of him and in front of the student. Without asking me or nothing just undress me, they took my pants off, my underwear, everything. I was like so humiliated and the doctor heard me protesting and*

*he um, first of all he didn't even introduce himself or anything... I was so humiliated I was like this [Head down and hands over her eyes].*¹⁸

Although she described feeling disempowered by this encounter, she was determined to expose the degrading practices of her providers. She acknowledged that others may not have the capacity to pursue and follow through with self-advocacy to right the wrong of this experience. However, Eve was resolute in her decision to self-advocate as a form of self-defense to claim her right to be treated with dignity and respect. She described reaching out to mentors, including a provider she saw as an ally to explore strategies for her self-advocacy.

Line 209: Eve: *Oh my god! At the time I couldn't stop thinking about it ... it was like, oh my god, it was so horrible you know?* LV: *Did you stress over whether you should write the letter?*

Eve: *No, what I did was, I went, I talked to somebody right away. I went to J... and I told her what happened to me and she told me what I should do. I told two people. I told a nurse who I knew really well and he told me... [in a whispered voice] "you should tell Dr. X. He would ... if you tell Dr. X!" And then I told J and J was like, "write a letter to Dr. A, he's the medical director and he will...."*

Eve was successful in bringing this abusive practice to light which in turn led to policy change. Her decision to self-advocate reinforced her confidence for future self-advocacy.

Line 186: Eve: *Uh huh, yes that was the first time because that was the biggest that was one of the biggest things that has ever happened to me really. It was so humiliating.*

¹⁸ This is an example of 'public stripping' – an unknown phenomenon to people without disabilities – in which providers "display their patients in front of colleagues, residents, therapists and other professionals" to "facilitate teaching and the exchange of medical knowledge" (Blumberg, 1994, pp. 78-79).

LV: *Would you kind of say this was the ah ha moment where you realized if you were a PWD and ... want to get the respect that people without disabilities get I have to do this?*

Eve: *Yes, because ya, because imagine how many others never get that.*

LV: *Where do you learn that?*

Eve: *I was always like that to defend myself. That's what I felt like – like I had to defend myself.*

b. **Sub-theme two: Deserving of care**

Although Eve chose to self-advocate in response to overt discrimination she also acknowledged advocating against provider indifference. She recognized that the indignities, disrespect and inaccessible care she experienced were likely also experienced by others with disabilities. She questioned if passivity of the disability community contributes to the continued existence of barriers and missing accommodations.

Line 70: Eve: *You'd think that they would be thinking about the people that can't stand and think ahead like that but they're not.*

LV: *Why?*

Eve: *Maybe because they just don't care? And maybe because we're not voicing our needs as much? Because we don't speak up and say anything when it is important. But there are very little of us that are experienced and we're not saying anything. So, they get away with it.*

In efforts to increase community knowledge on rights to equitable care Eve reported feeling responsible for educating others in the disability community through formal mentoring roles and casual encounters.

Line 528: LV: *Do you teach, or you use to be in a mentor program ... do you feel like you have a responsibility to teach other PWD to be self-advocates?*

Eve: *Yes, yes, I feel definitely, if I feel that something's not right that something that's going on with them, I feel that in some ways that it's my duty to say something...like, "I think you should look into this because it's just not, something's not right about this."*

Eve understood self-advocacy as a vital tool that PWD must have to receive the equitable healthcare they need and deserve.

c. **Sub-theme three: As a catalyst for change**

Eve's self-advocacy efforts support her activist agenda to effect long-term change and improve the quality of healthcare that people with disabilities receive. Her knowledge of the ADA, concern for justice, past successes in self-advocacy and disability activism, and her network of community members converge to inspire her to take on major advocacy challenges.

Line 336: LV: *How do you think your knowledge in this area helps you with your healthcare?* Eve: *Well it's good to know, that's for sure. I think that ... here's an example. Not too long ago, a local community hospital was not in compliance with the ADA after it being 25 years ...after 25 years you'd think that they'd have made, have been in compliance with the ADA and um, I'm just a little surprised that they've gotten away with what they got away with and that was very little accommodations for PWD.*

She described joining forces with a fellow advocate from the community to enforce the right to accommodations but expressed frustration that these efforts are still needed.

Line 355: Eve: *... so we both ended up filing a discrimination lawsuit against them. And now because of that they are making a lot of changes in the hospital where ... I have a*

whole list of the stuff that they are going to do: making rooms... that are accessible, beds and then, the parking lot, just a lot, several things that they are going to do. But um yeah, because of what we endured. They are going to make some changes. But it took a lawsuit to do that because they um, totally just ignored the ADA for 25 years. And have gotten away with that. And that made me think about other patients who are disabled what they have to go through. For twenty-five years! [with emphasis]. No bathrooms! Because nobody spoke up.

When asked what factors encouraged her to file and follow through on an ADA legal claim she described her conviction to right this wrong and an inability to turn her back on making this decision. Eve described how successful advocacy for healthcare access and equity contributed to her sense of empowerment.

Line 376: Eve: *I knew that this had to happen I said, NO! This can't be! When I found out about the bathrooms, that none of them were accessible. And then, OMG I was like no way! Come on! It's unbelievable, I couldn't believe it this has to stop! It's bullshit!*

LV: *the outcome was good and how does this make you feel?*

Eve: *Proud, really proud of myself for doing that. Yeah, because now The disabled community will have – if they ever end up in that hospital they will be able to have access to the bathroom and ----you know, some dignity too. Especially when it comes to yeah, using the bathroom in the privacy of their own room. And uh, yeah because I just I just can't understand why they didn't think of this in the first place.*

4. **Master theme three: Decisions not to self-advocate**

Following her stories of self-advocacy successes, I asked Eve whether there were times when she decided not to self-advocate and what the factors were that influenced her

decision. In response to this question you could see her demeanor change. She sank a bit in her chair and appeared sad. Her decisions not to self-advocate appeared to conflict with her identity as a strong self-advocate but she rationalized factors for the times when she decided not to. There were three sub-themes that influence Eve's decisions to not self-advocate. These are: advocacy fatigue; self-perception as a burden¹⁹; and as a form of education - to make a point.

a. **Sub-theme one: Advocacy fatigue – saving her energies and efforts**

In her clarifying interview, Eve indicated that she cannot fight every injustice and at times she was resigned to accept inadequate and inaccessible healthcare due to exhaustion and concerns with her health at the time of the encounter. Any passivity was temporary, as she described it as fatigue due to the never-ending demand to advocate.

Line 301: LV: *Why do you think providers say they can't provide you with an accommodation?* Eve: *I think she just ... I don't know.* LV: *Do you think she felt bad?* Eve: *I don't think so, I just think that she just, cuz I asked her, I told her, I can't get on that table without assistance. Is there anybody to help? 'No, it's just me', and I don't think she really cared. She didn't care and at that time I guess I didn't really care either. I'm not going to force her to ... I can't make her help me.*

Eve also chose to selectively advocate, not bothering to waste her energies and resources to healthcare sites with limited resources of their own.

Line 422: Eve: *Why bother... a lot of these neighborhood clinics, I wouldn't expect them to be [accommodating], because you know they're rental space and they are usually in*

¹⁹ Self-Perceived burden is defined by McPherson, Wilson, Lobchuk, and Brajtman (2007) as “empathic concern engendered from the impact on others of one's illness and care needs, resulting in guilt, distress, feelings of responsibility, and diminished sense of self” (p. 135).

older buildings and you know. They're not designed for [PWD], and there is nothing modern.

b. **Sub-theme two: Self-perception as a burden**

Eve empathized with providers when she needed an equipment accommodation which is unavailable. She understood that providers have to go through extra efforts to accommodate her requests. Her concern for the challenges she posed to providers due to a lack of equipment made her perceive herself as not worthy of the efforts it would require to enforce the request for accommodation.

Line 54: Eve: *I feel like I'm a burden to them. You know like this is just I'm putting them out. Like it's like, oh god, I'm more work for them. I look at them and see them look at us like 'oh man, now we have to really work and help these people'. 'We have to lift them' ... and ya, you know?*

Her self-perceived burden was always related to concern for providers and the processes they must take to accommodate her when equipment was not accessible. Eve understood that if accessible equipment were present each of their challenges would be diminished.

Line 312: LV: *DO you feel like people who are in the health professions are like oh, you're disabled, you're not worthy of the care. Have you ever felt this?*

Eve: *No, but I have felt like a burden like ok like I'm a challenge, how are we going to get her on the table, how are like that are we ... which you know it's I guess a legitimate thing for them to be concerned because there are people that are in wheelchairs that can't stand and transfer. But I just felt awkward and not worthy at the time with that technician. I just felt like she didn't care, there's no one here to help you so...*

c. **Sub-theme three: As a form of education – to make a point**

Eve's unique style in self-advocacy aligns with her personality as someone with a sense of humor, good natured and friendly. She described times when she elects to not self-advocate, almost poking fun at the provider as a way to educate them.

Line 102: LV: *Have you ever had a person who has ... is like 'I know how to do this just let me do it'*

Eve: *Uh, yes, oh god, oh ...they didn't know what to do they didn't know what they heck they were doing and I'm like ok go ahead, let's see, let's see and I just let them and the next thing you know I'm falling and I'm like "oh, but you know how to do it?" [laughter] ... you know what you're doing and I'm falling and like ... "ok, yep do it your way ... it's working out really well!" [sarcastic voice ... each of us follow with laughter]. We laughed about it and yeah, I've had people like that but uh, most of the times I think, in the healthcare system I always suggest ... I always tell them what works for me. Because most of the times they really just don't know.*

During her clarifying interview, Eve emphasized that she understood her position of power to do this advocacy. Eve indicated that she felt fortunate to understand she makes active decisions not to self-advocate. She acknowledged the many PWD may not have the knowledge or efficacy to self-advocate, and used undocumented immigrants as an example of those who may accept 'less than' for fear of what they might lose if they speak up.

5. **Master theme four: Lasting impact**

Eve's experiences reinforced her identity as a strong self-advocate and disability activist. She described herself as a woman who has endured a lot to overcome many obstacles in her life. When describing the obstacles, she did not include her disability but did acknowledge

the disability stigma and discrimination she encounters as obstacles she continually works to overcome. When she was asked how a lack of accessible equipment impacted her health she described negative impacts such as feeling like a second-class citizen, and sensing behaviors as micro-aggressions, and the stress of extra work/extra demands, but also included one positive impact – empowerment through self-advocacy.

a. **Sub-theme one: Second-class citizenship**

Eve's description of the six days she spent in the hospital without an accessible bathroom was an extreme example of the impact of a lack of accommodations in healthcare. Due to the lack of access to basic toileting facilities, she reported experiencing a loss of dignity and respect.

Line 371: LV: *So, what does that mean – what did that experience mean to you?*

Eve: *Oh my god, it was so horrible. I was so uncomfortable, I was miserable. I was like, oh my god I can hardly wait to go home. I want to go home just to use the bathroom.*

Would you believe that?

Eve reported recognizing she was perceived as a second-class citizen²⁰. The consequences that result when healthcare facilities exclude PWD from consideration in the built environment and in the everyday practice patterns may enforce this self-perception and have long lasting negative impact. Eve appeared to have resilience to combat the impact however this doesn't negate the experiences she endured.

b. **Sub-theme two: Sensing micro-aggressions**

Eve understood that the culture of the institution that fails to consider her needs by neglecting to abide by the law of the ADA trickles down to influence the providers'

²⁰ For further analysis of PWD and concepts of second-class citizenship see Eisenberg, Griggins, and Duval, (1982), *Disabled people as second-class citizens*.

attitudes. The extra work that providers must do to accommodate her potentially fuels the prejudices against PWD. These emerge as the behaviors and negative attitudes that Eve felt in her interactions with providers.

Line 57: Eve: *I look at them and see them look at us like oh man, now we have to really work and help these people. We have to lift them and ya, you know?*

Line 456: Eve: *It's what I felt and how she looked at me. I felt like she stereotyped me. Like maybe she thought I was going to fake an illness or something to get some drugs or something.*

The combination of structural and systematic practices that position Eve as a 'second-class citizen' added an additional layer of stress to managing her health. Discrimination and micro-aggressions take a psychological toll and may contribute to advocacy fatigue, which can in turn impact her physical health as well.

c. **Sub-theme three: Stress of extra work, extra demands**

Eve described how lack of accessibility within the healthcare system placed additional demands on her as a woman with a disability.

Line 255: Eve: *It's just that it is stressful, especially if you're not aware that you ... if you have to make an appointment at a different location how am I supposed to know. And not only that but, like I was told that I have to let them know that I'm disabled... so it's like I didn't think it mattered. I thought it would be accessible for all.*

Eve reported that she has learned that she cannot assume access and she must “*prepare them because preparing them is important*” but still is not assured the most appropriate accommodation will be provided. Eve understood that her practical everyday efforts in managing her health required far more planning, organizing and preparedness.

d. **Sub-theme four: Empowerment through self-advocacy**

Of all of the ways Eve described her experiences as impacting her, she highlighted the positive effect of successfully self-advocating. Her description of herself as a strong and powerful woman was reinforced by the experiences she has had in fighting injustice and inappropriate healthcare services. She was proud of her efforts to change policy in how providers will work with PWD. Despite her obvious pride and empowerment, she hinted at how the insults and discrimination have a damaging impact.

Line 180: LV: *Do you think that did your experience, did you feel like you were educating him?*

Eve: *Yeah, I felt good, I felt proud of myself ... yeah, I felt powerful. Because I made changes, I know they made changes in that clinic. The next time I came in the two PAs were like 'hello' [in a shy voice]. I know they were probably reprimanded for that...But after that they took me to a different room to undress me ... but it was for me, a little too late....*

Eve reinforced in her clarifying interview her disbelief and concern for how many PWD have suffered the discrimination of providers, clinics, or hospitals because they were “*afraid to say anything or just didn't know they had the right to*”. She considered herself lucky to have the knowledge, support, and nature to be able to self-advocate in many contexts.

Eve summary: The meanings Eve gave to her experiences in self-advocacy were complex but a prevailing focus was her desire for respect, dignity, and equitable care for herself and others with disability. She came to the disability experience with an established identity as an advocate in overcoming sexism and racism. Her intersecting identities have planted an astute perceptiveness to provider biases and negative stereotyping that inform her self-advocacy efforts.

Over the years she has developed strategies to advocate for her own needs but as importantly to work to point out and supplant providers' biases. She has an underlying empathy toward providers that unconsciously discriminate because of the influences of the medical model toward PWD and little tolerance for providers she perceived as prejudicially believing PWD are entitled to 'less than'. This distinction informs her strategies and goals in her healthcare self-advocacy.

D. **Tomás**

1. **Background**

Tomás grew up in a large metropolitan city, worked in the military following high school, and is married with 2 adult children. Over two decades ago, he and his family were travelling together when their car's tire blew-out, rolling the car, leaving him with a spinal cord injury but the others in the family unharmed. Tomás had been practicing at a law firm at the time of his 'transformation' - a word he purposely chose to reflect the impact of his injury on his career and his life.

Line 52: LV: *Interesting I like the word you use, transformed.*

Tomás: *Absolutely, you know the good thing was I didn't have to re-invent myself. I mean I had to reinvent how I did things but I was in the [hospital] for goodness, 6 and a half months and uh, there were doctors in there with me. One was this podiatrist and he just loved surgery and the fact that he couldn't operate... he was a quadriplegic like me ... he had a very flourishing practice in the southern suburbs but he ended up selling that He was depressed for a number of years. You know I was determined ... and you know had dreams and aspirations for my family and didn't want to see this go by the way side just because I, just because of the accident.*

Tomás was reflective on his accident and his transformation. He had a deeply philosophic analysis of its meaning. His accident shifted his professional focus to make him a leader in the disability community addressing issues of discrimination and disability rights laws.

Line 76: Tomás: *The regulations for the ADA became effective in 1993 and that's the same year I graduated school ... I was born on Dec. 3rd and Dec. 3rd I found out is the International Day of People with Disabilities. The United Nations decreed this back in 1996. So, the same year in which I was injured, the UN declared my birthday to be the International Day of People with Disabilities. I look at all of this and I say it's not a coincidence. That's why I became a disability rights attorney. I try to find a purpose in everything, and I think that's it, you know? Had it not been for the injury I would not I believe be a disability rights attorney and uh the work that I am doing I think is meaningful and helpful.*

I came to Tomás' downtown office for his interview. The front desk staff announced my arrival and Tomás came out shortly to greet me and escort me down the hall to his private office. Before we began the interview and prior to recording he had to leave the room for a client issue, allowing me to settle in and take in the elements of his office – a glimpse into the part of his life he shares with clients. He has the typical photos of his family: his wife and two young children. His college degrees are framed and hung and awards dispersed among photos, legal literature and working materials. On the wall behind my seat, the wall directly insight of his view, is a large framed recent picture of Tomás showing him in a racing wheelchair positioned squarely in the middle of a desolate winding road that disappears up into the mountains.

a. **Bracketing**

I had met Tomás previously at a disability community event but did not know him other than to say ‘hi’. He is well known within the disability community and I see him as having a knowledge and status that made me a bit nervous as I began the interview. Tomás was composed in his answers to my questions and following the interview confessed his nervousness, that it would be – in his words – “*an Oprah interview*” – with my goal being to bring him to tears. I assured him that this was not my style or intent but wondered what issues might have brought him to tears. His answers to the interview questions reflected his underlying persona of a man determined to work toward goals of being a respected person admired for making a difference. Importantly, it is likely that his greatest professional contributions to society are because of his disability, something he acknowledged. His disability exposed him to a community that needed his passion and commitment as well as the knowledge he holds as a lawyer and PWD. I found him incredibly interesting for what in some ways appeared to be a vulnerability – vulnerable in how he deals with the stigma of disability by others. His life contradicts the stigmas of society, and those that do not know him, informed by negative prejudices of disability might be surprised by his family happiness, his professional achievements, his knowledge, confidence, and satisfaction with life.

When I asked Tomás to tell me about himself, being a self-advocate and disability activist was not part of his narrative. His professional career positions him to have the broadest understanding of disability rights and rights to reasonable accommodations but he refrained from incorporating disability advocate or activist into his self-description. From his interview, his ability to understand the convoluted dynamics of the healthcare system, the laws and legal process, and experiences of discrimination provided him an exceptional vantage point for

identifying the need to self-advocate for accommodation in healthcare. This same position afforded him an empowered basis in his decisions to self-advocate. These two major themes and the associated sub-themes within them make up the majority of what was identified from Tomás' interview, joined by interpretations of decisions not to self-advocate, and the lasting impact of these experiences.

2. **Master theme one: Understanding the need for self-advocacy**

Tomás exhibited a deep understanding of the need for people with disability to self-advocate for accommodation in healthcare settings. This stemmed from his personal experience as well as his professional. He had a strong sense of the bodies of law that exist to protect PWD and if complied with - either voluntarily or through efforts such as self-advocacy – would make the lives of PWD better on a day to day basis. As a result, this theme of understanding the need for self-advocacy is copious in its associated sub-themes and narratives. The sub-themes include: 1) normalization of discrimination is the status quo; 2) providers indifference to the needs; and 3) changing perceptions of health with disability.

a. **Sub-theme one: Normalization of disability discrimination is the status quo**

Often it is everyday practices of discrimination that create some of the most significant experiences of degradation. Tomás described barriers to accessing his provider's office that would be a relatively easy accommodation to make but are not considered to be important by the provider.

Line 303: LV: *There seems like there's a lot of things you think about when you're going to a doctor that a person without a disability would never even have to contemplate?*

Tomás: *This never crosses their mind ... it's something they don't have to ever encounter*

or ever experience, or ever think about experiencing as well. Number one, who's going to be there to open the door to get into my doctor's office, because there's not an accessible entrance, or door. They have a little side window, so I tap on the side window, and if there is somebody in the waiting room they'll come but if not it takes a while, you know? You know, I have two dogs at home, and when they want in they sit at a window and they stare. I think about my dogs every time I'm tapping on that side window trying to get somebody's attention, it's like, "damn, I know how my puppies feel" ... you know? I mean it shouldn't be that way. Doc, get a buzzer here, get a doorbell so I can ring it and have some dignity about it when I'm doing it.

Tomás interpreted that his provider lacked awareness of the environmental barrier but simultaneously made him/her accountable, not permitting ignorance to excuse this act of routine and normalized disability discrimination. This example also highlighted how seemingly small experiences reinforce social exclusion and compromise the PWD's dignity. While this description represented failure to comply with the ADA, Tomás provided an even more expansive interpretation of compliance failures.

Line 431: Tomás: *They said that they were accessible and are listed under their directory as saying that they are accessible but when patients with wheelchairs or scooters try to get in, they either can't get in through the door or can't get into the examination room, no lift equipment, no height adjustable exam tables, no weight scale and so how can you provide comparable, clinically appropriate care if you're not examining somebody out of their chair for things that they need to be transferred out of the chair for?*

Tomás stopped short of interpreting providers' claims of accessibility as intentionally deceptive, however, he did suggest a level of intentional ignorance or indifference, that reinforces the normalization of disability discrimination in healthcare practice.

Line 550: Tomás: *Most doctors in healthcare systems and in clinics that I talk to I think, overwhelmingly they are doing cost benefit analysis... and somewhere within the administrative body they know what their legal requirements are under the ADA but again if they're not compelled to do that they're not going to spend the money to get that done.*

The failure to incorporate accessible equipment often requires the disabled person undergo treatment in conditions that can compromise dignity.

Line 265: Tomás: *For the first 14 years I've had a chair that was as rigid as the chair that you're sitting in [wooden slatted office chair].... imagine sitting in that chair and getting that dental work, even a cleaning, or some sort of treatment like a root canal or a cavity, right? So, I've had, it's painful on many fronts; number one, the procedure, but, number two just the position having to hold your head back in that stiff chair.*

Tomás reported the need to be vigilant to everyday acts of discrimination when deciding how to interact in healthcare settings.

Line 521: Tomás: *You can see it in their eyes, you see who's comfortable and who's not comfortable, you know. You know I try to be a good reader of body language and you can see it...the eyes tell you so much. Right? And how they approach you.*

Tomás detailed his conscious recognition of the derogatory verbal and nonverbal snubs that define the micro-aggressions or inequities in care delivered by providers on a routine basis.²¹

Line 524: Tomás: *It's like ok, what is going on here? So, Doc you know a spinal cord injury is not contagious, I know that the pneumonia is not contagious, it's just a small little spot they found on my lung, uh so, are you this way with all of your patients? You know, then I have to talk to him and, I don't know, I don't know with that guy, I, I think his first reaction is, "Shit, not me, uh, does someone else here want to take care of him?" I think that is the first reaction. I think it is the absence of seeing...you know patients on a regular basis that have a disability, kind of contributes to that.*

Tomás provided insights into the different behaviors and practice patterns of providers that are routine experiences of discrimination so much a part of everyday that they are perceived to be normal.

For Tomás, the obvious signs that helped him understand the need for self-advocacy are both lack of physical accommodations as well as or behaviors and practices that he identified as discrimination. He has learned from experience that efforts in self-advocacy may be ignored or if heeded, the accommodation offered is a poor option at best. These experiences alert him that provider's indifference to the needs of PWD be considered in understanding steps to take in self-advocacy approaches.

²¹ Derald Wing Sue (2010) defines micro-aggressions as "the 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" in *Micro-aggressions and Marginality: Manifestation, Dynamics and Impact*, (p. 3).

b. **Sub-theme two: Providers indifferent to the needs of PWD**

Knowledge of one's rights to accommodation, and confidence in strategies to self-advocate may still not be sufficient for a disabled person to have access to available accommodations. Tomás' chronical of an experience in a local hospital detailed the levels of indifference to his attempts to self-advocate and how he interpreted its impact.

Line 100: Tomás: *I went to urology and, explained to them that I couldn't transfer independently and asked for lift equipment. Cuz, I knew they had lift equipment ... but they couldn't find it for whatever reason and there was an urgency to get me onto the table and get the procedure done so um, security guards came in and lifted me up. And I said not to lift me, and before I was able to get the – 'don't and here's why' – uh, you know I had these guys grab me from under my arms and my legs and just throw me onto the table.*

Line 107: *I was, part of my injury I had suffered, I suffer some shoulder pain uh, and so that made it just that little bit worse being lifted that way...I told them not to ... leave me alone, I said "please put the guardrails up" but there was no guardrails on the examination table. I told them if I spasm I'm going to fall off the table. Uh, and just everybody left, they just ignored what I had to say and just left. And I did spasm but luckily, I was able to stay on the table but it was you know, you know, just by pure luck that I didn't fall off the table.*

Tomás endured the pain and potential risk for significant injury yet what impacted him the most was the providers' lack of respect and concern for his well-being.

Line 119: Tomás: *It was degrading, how they lifted me and going against my wishes uh, was degrading, I mean to me it's, they didn't care about me as a person and they didn't*

respect my preference and I always think why is that? Is it because I'm a person with a disability and the answer is obviously yes, at that time, and also, they didn't care for my safety. After I told them, look please don't leave me alone, you don't have any straps to secure me I mean if you don't have rails then stay with somebody - stay with me.

The last two sub-themes under this master theme, 'understanding the need for self-advocacy' stem from how stigma and prejudices of disability inform how providers treat PWD. Tomás also recognized that his convictions, that basic health has little to do with disability, may run counter to beliefs of providers and demand self-advocacy.

c. **Sub-theme three: Managing your health while dealing with provider invalidation of your authority**

Tomás interpreted that health with disability or the healthy disabled²² create a conundrum for most healthcare providers.

Line 534: Tomás: *I think initially if I come and show up un-announced - that sort of thing, they're thinking, "like, what do we have here and how do we fix it?" Again, trying to fix the disability not knowing that I'm not there, I'm there for a reason other than my disability. I have an ear infection or an eye infection or something else going on that's unrelated to my spinal cord injury.*

While a person can be healthy and disabled, one can also be disabled and have an illness in need of treatment. Tomás described how his physical disability at times distracted providers from competent healthcare. The provider's behaviors perplexed Tomás. His repetition with "*I don't know*" indicated attempts to understand the cause of the provider's behavior beyond outright discrimination.

²² *Questioning Continuum* by Carol Gill, 1994, p. 50, explores ideologies of health with disability.

Line 133: Tomás: *That's one of the downsides of SCI, you know a cold can turn into pneumonia real quick. So, I was running a high fever and so we went to [Hospital], but the doctor didn't know how to interact with me. And so, I was there for 5 days [and] it took until the 3rd day that I could convince him that he could stand close to me. I don't know, I don't, I don't know, there wasn't an infectious disease issue what so ever it was just a small bout of pneumonia. I was trying to explain to this doctor ... that I felt more comfortable with him next to me as apart from his being at the doorway talking to me.*

Tomás shared what happened when his providers failed to acknowledge his authority over his basic health maintenance routines.

Line 142: Tomás: *I have a routine bowel program like every other night and when I got to the hospital they decided - it was a night where I was supposed to have my bowel program - and they decided to skip it for the night. They decided, so the next night when explaining...LV: did they ask you?*

Tomás: *No, no they said it's probably best that we don't, to figure out the infection. So, they were, they're rationale seemed OK at the time but then on the 3rd or 4th day I was finding myself trying to educate them on the importance of me having a regular bowel program.*

Tomás' interpretation was that this experience was caused by the provider's presumption of authority, or incompetency in working with a person with a spinal cord injury – or both. He felt providers failed to acknowledge disability and health can co-exist. He recognized that self-advocacy includes needing to educate providers on issues of basic health management, but because providers may fail to hear his voice they may fail to relinquish authority.

Line 222: Tomás: *I think that in general we're more in tuned to what is going on with our bodies, um, but the problem is that we may know it but trying to convince others that in fact we do know is where the struggle comes in...I, if there's a crease in my sock you know, my foot will start to spasm and I know something is going on, something unusual is taking place and we got to try to figure out what's going on with it, so ... yeah, I think the longer you've had a physical disability uh, the more in tuned to those things um, but again, it's really about trying to convince and tell others that in fact that you know that.*

Tomás recognized that lack of disability competency among healthcare providers create barriers to preventative and primary care which can perpetuate a repeated cycle of emergency care services.

Line 244: Tomás: *If they want us in general to be consumers of preventive care, then we need to be made felt welcome. And we, we want preventive care, we don't want to go to doctors only because we absolutely have to at the point, at that point it's too late. At that point, we're being admitted and we're there for a couple days – in a place where we don't want to be, you know, but so, so if they want us to be consumers of healthcare, in the preventive sense, then this paradigm has to change, and so our voice needs to be heard.*

He realized the need to self-advocate for care but re-emphasized the need to change providers understanding of health with disability in order to create guidelines or standards for care for substantive change to occur.

Line 602: Tomás: *If [emphasis] we have at least one case where a judge has determined that the standard of care is to examine somebody for a physical examination out of their wheelchairs and onto an examination table that's going to be great ... It'll be a game*

changer...but the problem is, the challenge is, finding a doctor who's willing to opine 'here's the clinical standard of treating somebody with a physical disability who can't independently transfer out of their wheelchair'. So, when is it clinically appropriate to examine me in my chair, and when is it clinically appropriate to examine me outside of my chair where you have to move me? We're trying to find docs that can say that.

Tomás understood the necessity and benefits of self-advocacy. However, there are factors that influence whether he advocates in a given context. His background lends him more often than not to elect to self-advocate.

3. **Master theme two: Decisions to self-advocate**

Line 292: Tomás: [If I] *don't have the doctors and the nursing staff do what they can do and should be doing then it's going to make it more difficult for me the next time, um, -- and --- it's going to make it difficult for someone that comes behind me that doesn't have the voice or the strength to speak for themselves. So, it's hard and it's a challenge.*

Tomás' decisions to self-advocate consistently had dual purposes, his own care needs/concerns and activism to educate providers on rights to accommodation, equitable care, and when actions discriminate. This master theme has four sub-themes: understanding approach makes a difference; self-advocacy as education; using the ADA to self-advocate; and, to promote a paradigm shift.

a. **Sub-theme one: Approach makes a difference**

Tomás' decision to advocate was followed with choices in how to self-advocate. His experiences informed him on methods that might close off providers, putting them

on the defensive, and lead to animosity and poor outcomes in care. His experiences have taught him the style he uses to communicate his rights can be the determinant of success.

Line 705: *Right, self-advocacy is NOT [emphasis] is not necessarily, you know, 'the ADA says this', 'the Rehab Act says this', 'you have to do this, because I know what my legal rights are'. That's not self-advocacy. That's trying to forcefully ... you know educate someone who might otherwise have been receptive to you but the approach makes a difference.*

Tomás appreciated that providers may be more open to understanding if information is provided respectfully, avoiding the tendency for providers to label PWD as belligerent or angry. His sense of the respectability politics informed him of the potential ramifications of alienating his providers.

Line 313: Tomás: *Um, but look you know, I don't want to [emphasis] upset my doctors. Because if I think my care is substandard now, what happens if I complain and so I can't complain, I have to educate. You know, there is a difference and the approach is different.*

b. **Sub-theme two: Self-advocacy as education**

Tomás described how he approaches interactions with his providers as opportunities to educate them on his right to care as well as to breakdown stereotypes of disability. He comprehends that lack of representation of PWD in healthcare both as providers and as part of clinical education means a lack of understanding of the disability experience.

Line 170: Tomás: *You know the problem is that what I find is that there are very few people with disabilities in the health care profession to begin with, there are very few doctors with disabilities uh, and in medical school they don't teach and focus significant*

amount of time on caring for PWD so doctors are taught in a triage sense, I'm going to help the people I can fix immediately. And when they see me, they see my disability... I don't need you to help me walk – I'm not there for that, I'm there for something else but it's hard for, I think it's hard for doctors to see that and to get by that. And so that's something we still have to work on.

Overcoming the medicalized perceptions of disability can be overwhelming and Tomás understood the efforts of PWDs are often ignored.

Line 242: Tomás: *... and believe me, there [are] people trying to communicate the best they can what's taking place and what they think is going on with their body um, they're just not being listened to.*

His legal knowledge pushed him to concede that providers may not respond to claims of inequity in care, but may react if educated that discriminatory treatment approaches could be claims of neglect.

Line 604: Tomás: *The fact that I'm not being examined below, or on the lower half of my body, or on an examination table, or examination chair, and they're just guessing is malpractice. There is no way around it. It is negligence uh, and if something were to occur, they'd be exposed ... so we try educating them.*

Tomás was cautious about extending the conversation to malpractice and negligence. During the interview, he went into great detail to explain the complexity and how a lack of standards of care for treating PWD impact these claims. When discussing legal claims and civil rights he believed claims based on Section 504 of the Rehabilitation Act (The Rehabilitation Act, 1973) and the ADA have greater enforceability.

c. **Sub-theme three: Using the Americans with Disabilities Act to self-advocate**

Tomás was careful in how he used his knowledge on the legal justification to requests for an accommodation, and felt strongly that there is a time and a reason to use the ADA.

Line 444: LV: *So, how does it [knowledge of rights] play a role in your decision when you are in a situation that you have to educate your provider, or do you pull out the ADA or when do you use that language?*

Tomás: *I use, the answer is yes ... it instructs me as to how far I can go to talk to somebody and explain what I need done ... it's only when I see them resist me, repeatedly that I say, 'look you have a legal duty and here is your legal duty and that's when chapter numbers, the ADA, the Rehab Act, the Affordable Care Act etc. With my close providers, I don't have to do that, because all I have to do is just remind them ... here's the things we should be doing, I don't have to tell them what the law is.*

Strategic decisions in how to use the knowledge of rights to accommodation were an important component to success in Tomás' toolbox of self-advocacy. He understood his accommodation requests will more likely be a success if open communication and collaboration occurs versus making providers guarded in working with PWD.

Line 455: Tomás: *At the moment that you walk in and say, 'here's what the law says' you're going to meet a roadblock and an obstacle there. I think that is where they shut*

down. In terms of trying to communicate with you and wanting to communicate with you and wanting to keep you as a patient. Right?

Tomás' purposeful decision-making process is evident as he followed this last statement with a qualifier to use of the language of the ADA:

Line 456: *...but the law IS [emphasis] there and when needed again, after repeated conversations and they still don't get it, then I specify what the law requires and what their exposure is.*

d. **Sub-theme four: To promote a paradigm shift**

Tomás recognized his self-advocacy and professional and volunteer activism are necessary catalysts to change perspectives of provider.

Line 685: Tomás: *I consider myself to be very healthy, very healthy, and I don't see my spinal cord injury as affecting me or detrimental to my health on a daily basis. It makes me vulnerable to certain things, like I'm more readily to catch a cold or catch pneumonia than anyone else is um, but, again I consider myself to be healthy ... what's going to keep me healthy and keep people like me healthy is making sure that doctors are aware of what their legal requirements are but don't VIEW [emphasis] them as legal requirements but as a way to receive more patients. Right, and then at the end of the day they're going to make more money – we have insurance – we pay with Medicare or Medicaid or third-party insurance you know, we want to be a consumer of their services but we need to know that we're going to be welcome there.*

Tomás is a realist and recognized that healthcare policies and practices are guided by the material forces (Oliver, 1990) from primary and preventative care. He recognized that greater self-advocacy efforts must come from within the disability community, PWD, families, and

disability allies to enforce a necessary paradigm shift. His approach of educating and enforcing civil rights represent his foundation for persuading providers that the disability community be included as valued consumers of preventative and primary health care. Tomás acknowledged that before providers conceptualize healthy disability, PWD must be persistent in self-advocating for accommodations to primary and preventative care.

Line 557: Tomás: ... *if nobody is insisting on their rights and if we continue to enable them by doing or ignoring it or bringing somebody else to do what they are supposed to do then they're not compelled to comply and if they're not compelled to comply then why comply?*

4. **Master theme three: Decisions not to self-advocate**

Tomás was very reflective on the times he chooses not to self-advocate, explaining these instances are often in response to practical matters concerning time or extra work demands for either himself or the provider. Lack of accessible equipment prohibits equitable care for even the most knowledgeable of self-advocates.

Line 484: Tomás: *The worse I feel, the less I'm going to advocate for myself, because I need assistance immediately and I need care immediately. At the same time, when I step back and look at it, regardless of how I feel I still need to take the same advocacy approach but typically the worse I feel, you know, the worse I'll speak-up and say something for myself.*

a. **Sub-theme one: Too much work**

The efforts Tomás goes to in order to avoid asking for provider assistance or accommodation is notable. He described strategies to circumvent providers perceiving him as a burden and interpreted this benefiting everyone “*if I can avoid having to have them do that*

then that's, then that's good for me, right?" His practical approaches emerged in part because providers lack time or concern for detail that complicate the entire process of his visit.

Line 281: Tomás: *I tried for the longest time, to schedule my doctor's appointments in the summer time. Because when I go in the winter, when I leave my house I'm bundled up, to be warm. When I leave a doctor's office, there's no telling what condition I'm going to be in. As much as I ask them to 'please assist me with my coat', 'please button up', 'please zip it up', it's always...it's not with the same level of care and attention as it is done like when I leave my house so...to minimize the things that staff has to do with me, I try to get my appointments all in the summer cuz I know I'm not going to need help getting dress, undressed, etc. And, so it's those things that you think about, okay.*

Tomás chose to control the context rather than leave to chance if his accommodation request would be honored and performed to his satisfaction. When asked for an example of when he chose not to ask for an accommodation despite knowing he needed one he offered this description:

Line 335: Tomás: *I went to go see my doctor at his office, and it was a very, very, cold day and, I didn't feel like taking everything off, although I needed to because it was a prequel for me getting hospitalized for pneumonia, and I should have asked the staff to get me ready, to take my coat off, to take my sweater off, cuz I had layers. So, it's a coat, it's a sweater, it's a scarf, it's a shirt, you know, take everything off to get there, um but I also then had a client appointment later that afternoon and I didn't want to look disheveled so I, so I thought, 'ok, I'm not going to ask' so as a result of that he [physician] did the best he could, you know, I lifted my coat up in front....So, I opted to get examined in my chair while I had every single layer of clothes on and I knew better*

that I should have asked them to take it off and relied then upon them to get me dressed. But again, it was a concern, that they wouldn't do it correctly, I, and sometimes when staff comes in to help you out, it's in a rush, it's, it's, they're not listening to what you say you know. I ask them, 'I can move forward on my own, you don't have to push me forward, etc.,' and those things and so...just to avoid all of that I just, I had him examine me with everything on...That's just a minor issue but again it's something, I deliberately decided not to ask because, I don't know what condition I'm going to be in when I leave.

Tomás' overall interview indicates rights to accommodation and rights to equitable care permeate his way of thinking in so many ways including during his own care provision. When he decides not to self-advocate – infrequent as it is – he grabbles with how convenience or illness factor into his decision-making. He also appeared to struggle with understanding that by accepting less than he compromises both his health and identity as a self-advocate. He also recognized how his failure to advocate undercuts the activism efforts of the disability community.

5. **Master theme four: A lasting impact**

The sub-themes that emerged within this larger master theme of lasting impact are developing a disability identity; self-advocacy and activism empower; poorer emotional and physical health; and advocacy fatigue. One significant impact Tomás' healthcare experiences have had are in shaping his understanding that providers see him as his diagnosis or more broadly a PWD and fail to see him as an individual with basic healthcare needs.

a. **Sub-theme one: Developing a disability identity**

Line 205: Tomás: *When I, when I first got injured and getting out of the (hospital) and then going to different doctor's offices and clinics, eye care clinics, and*

dental clinics, I, I thought I'd be at home, that I'd be welcome and that you know, that, this is the one segment of the population that would get [emphasis] me! And that is certainly far from the truth and that's what lead to my, to my work in this particular area. To get that changed, so, ya.

LV: *Do you think it's the population that gets you the least?*

Tomás: *It is, that's what I've found out ya, I don't know why I was naïve to think that I'm welcomed here because I'm certainly not. Not by design, not by how they set their clinics, and hospitals, and the equipment is not and the lack of training they provide.*

His experience in healthcare interactions, interpreted as discrimination, inform his work and his activism efforts in the disability community. He expressed significant pride of the impact his activism efforts have on shifting the paradigm.

Line 158: Tomás: *Today it's still a challenge. I look back to where I was 20 years ago, and it's a little bit better now, it's a little bit better at certain institutions now, simply because of the work that we've done with those institutions like [hospital] but others that we haven't touched yet I think it's still, there's still things we have to try to get addressed.*

b. **Sub-theme two: Self-advocacy and activism empower**

Tomás was empowered by his activism and the changes he has been able to affect. He was able to identify how these changes and his self-advocacy and activism have changed his experiences and can impact his health for the better.

Line 253: Tomás: *You know after we've been able to communicate that [legal requirements] then I, you know, then doctor's offices ... welcome me with open arms and I don't feel um, I don't feel rushed, I am listened to, and I'm given prompt care and ...it's worked out.*

Tomás had directly experienced the differences in behaviors following provider education and understood changes have occurred over the last few decades because of activism efforts.

However, he realized, as he tempered his enthusiasm while describing the changes, that he and the disability community have a long battle ahead to fulfill a true paradigm shift.

c. **Sub-theme three: Poorer emotional and physical health**

Until the changes in access to healthcare, programs, and equipment are universal, Tomás realized the disability community will continue to have disparate outcomes in health.

Line 650: LV: *Do you think these experiences have a long-term impact on your own health? All of this?*

Tomás: *Without question, without question it does, the good or the bad, either way it's going to have a long-term impact on my health, not so much on my emotional well-being, but it actually, just the physical well-being. You know the less that we have to fight, if the amount that we have to fight and educate people reduces on a daily basis um, the efforts, if we can get to the point we no longer have to do that...but we're a long [emphasis] way from there.*

d. **Sub-theme four: Advocacy fatigue**

Tomás' interview had various examples of the extra effort he went to when planning to visit a provider and possibly request an accommodation. These constant efforts and the associated stress had a lasting emotional impact that wear him down and at times influenced him to not self-advocate.

Line 624: LV: *How do you think these experiences that you've had how do you think these experiences impact the emotional as well as physical health of folks?*

Tomás: So, I mean... advocating for myself ... if it's not received well or if it's resisted or ignored, it's frustrating um, but knowing that I have to go into a situation where I know I have to advocate for myself the minute I get through the door uh, creates a level of stress that I think should not be there. It creates a level of anxiety that I think shouldn't be there. I shouldn't be reluctant in any situation, to go anywhere for fear of how I'm going to be received but I constantly am. So, that's true at doctor's offices as well.

That a strong activist and legal scholar be reluctant or in fear of how he might be received at a provider's office showed the power of providers' attitudes and behavior. As a healthy disabled person Tomás understood he must use strategically presented self-advocacy approaches to access the care he is entitled to.

Tomás summary: It has been argued that the primary concern for the disabled community is exclusion from the economic and social elements of society (Oliver, 1996b, p. 127). It is therefore, striking to note that someone of Tomás' social and economic status experienced the same vulnerability as a peer from the disability community who may not have these same resources in accessing primary and preventative healthcare. Despite a solid knowledge on the rights to accommodation and a dedication to educate providers on unjust care delivery, there were times when contextual and personal factors influence his decision to not self-advocate. More importantly, his perceptiveness of provider behaviors that negatively stereotype him because of disability stay with him and remind him of how much more work the disability community has to achieve the goal of a paradigm shift in healthcare delivery for PWD.

E. **Lala**

1. **Background**

Lala was born with a rare condition that causes significant fluctuations in her levels of energy and stamina. It also makes her susceptible to frequent seizures and contributed to her having had multiple strokes. As a result, the muscles throughout Lala's body are weak and uncoordinated, including the muscles controlling her speech. To compensate, Lala uses American Sign Language and during strategies such as spelling out words versus saying them as she talks. In conversation, the listener must adjust only slightly to be able to hear her as she entwines her strategies and verbal utterances fluidly.

Lala was enrolled in special education programs while attending public school and recollects having note takers assist her in classes and being mainstreamed in high school. She described having no awareness at the time this was the result of the Education of Handicapped Children Act²³ that had passed when she was just entering her middle school years. She talked about only becoming aware of her civil rights as a person with disability, and the ADA, when she was introduced to leaders in the local disability community and Center for Independent Living (CIL).

Lala frequents her healthcare providers to manage her health condition and quiet often this includes urgent visits to a local emergency room. She is familiar with the ER staff because of years of consistency with these urgent care providers versus the rotating door of the Medicaid clinic's primary care providers. Her advocacy skills grew from a need to have providers understand her, which requires providers slow down and take the time to listen. It also requires providers understand her clinically because of the uncommon nature of her underlying health

²³ The Education of Handicapped Children Act was passed in 1975 and through amendments was renamed the IDEA (Individuals with Disabilities Education Act) in 1990.

condition. When both of these basic elements of competent care fail, the misunderstandings have caused her to be institutionalized. Lala's fear of not being understood and the long-term ramifications, is the primary reason she advocates. She empathized with others at risk of misunderstanding and has expanded her advocacy efforts to disability activism.

a. **Bracketing**

I was excited going to see Lala as we have a growing relationship that began over 3 years ago. I have been with her enough to see the fluctuating impact of her health. At times, she is full of energy and you can easily communicate with her. In down times, her entire body seems sapped of energy and her speech is effortful. I was concerned how this might impact the interview and selfishly hoped she was having a good day. Including her insight into the narratives was important as I hoped her experiences might deepen the understanding of healthcare experiences.

The day of our interview was an early warm spring day and neighbors were out walking dogs and exercising. Lala greeted me at the door using a tripod cane and I'm shocked. I've never seen her standing before and am simultaneously elated to look up to her (she is easily 4 inches taller than me) and also slightly concerned as to whether this should make her ineligible for my research. Lala confirmed in the telephone survey that she uses a scooter primarily for community and home mobility and I have always seen her only in her scooter and I'm confused by this. I hug her and confess that I'm surprised but happy (and I really am) to see her upright and she proclaims it's one her unusual good days. I'm glad she is strong and is having a good day – and begin to better understand how her fluctuating capacity might confuse providers.

Her home looks bright with sun flowing in and both back and front doors are cracked open to allow the warm fresh spring air to breeze through. I hear loud music coming from her

kitchen and realize how much she must be enjoying her morning. I am grateful for her taking time out of her day for me. Lala started the interview strong, emphasizing key points of experiences that she's had over the years in requesting accommodations and confronting provider discrimination. As the interview progressed she had more halting speech and difficulty answering some of the questions. It seemed the more connected the conversation was to negative emotional experiences the more fatigued she became. I wondered if asking her to revisit her experiences, coming now with a stronger knowledge and identity as an advocate, may have made her recognize experiences that were significantly discriminatory and harmful to her. Or was she simply getting tired? I sensed the tension that her providers potentially experienced in questioning what her 'abilities' were. We moved through her interview efficiently and although all of the questions were asked and answered there was little time to linger on experiences to delve more deeply. In her clarifying interview, Lala was able to revisit her answers and brought in some of the important richness to the experiences we had missed in the first one.

Through the process of categorizing her master themes into the four guiding categories her commitment to self-advocacy became apparent. She has strong sub-themes within 'understanding the need to self-advocate' and 'decisions to self-advocate' and few within 'decisions not to self-advocate'. The category of 'lasting impact' provides insight into her now intersecting identities and experiences with how differing layers of stigmas inform her self-advocacy.

2. **Master theme one: Recognizing the need to self-advocate**

Lala's need to be understood by providers and the amount of effort involved on her part is difficult to fully grasp. She knows from her experiences that if she is ill her ability to communicate verbally will be reduced, requiring a communication accommodation. If barriers to

this request occur, obstacles will escalate in her efforts to request accommodation for other needs, many physical accommodations. She understood the need to quickly self-advocate as famed by the four primary sub-themes: provider's failures/inability to understand; loss of authority/providers just take over; context matters; and learning from others.

a. **Sub-theme one: Provider's failures/inability to understand**

Line 353: LV: *What do you look for in a primary care provider when you are looking for a new one, what's the most important thing to you?*

Lala: *Understanding, understanding your patients. Like I said every person is different.*

Lala's medical condition is rare enough that many providers do not immediately recognize her symptoms and do not understand. Despite her own expertise in listening to and understanding her body's symptoms there are times when she is unable to convince providers of her need.

Line 325: LV: *Do you have very many doctors or nurses that are empathetic towards you....?* Lala: *uh.....um, unfortunately not I'm actually in the process of finding a new primary because I had the last situation where my levels fell. I was just explaining.... please give me a treatment. And they refused to give me a treatment and they said 'well look just go home and will give you a call' and next thing you know I had to go to the ER and my levels was so low that I had to be admitted.*

When Lala sees providers, there are times she is physically stronger and times she is weak. When she's strong she may be able to transfer from one surface or seat to another. When she's weak she may need total assistance. This fluctuating functional level complicates how providers interpret her requests for accommodation. She interpreted that her needs aren't justifiable in their eyes.

Line 53: Lala: *I wish they would get a better understanding because, even though you look at a person's past and everything and of course you're going to look at their medical history but at the same respect you need to take what you know and then look at each situation, each situation, each visit separately but they tend to not to do that. Many of them ... they just don't want to take the time and they don't, they don't care.*

Providers' unwillingness to listen to what she needs pushed them to make erroneous clinical judgements. She recognized that past presumptive and judgmental documentation may taint their view of her need for assistance, creating a battle between her word and the recorded authority of the medical record.

Line 66: Lala: *Instead of trying to give me any type of assistance, I'm like excuse me, the nurse is like 'here we'll sit you in the hall' and here it is I'm barely able to sit up and I just wanted to lay down.*

LV: *Was this in an Emergency Room?*

Lala: *Yes, yes it was in the Emergency Room, and um, and the main thing was ... sometimes I am able to transfer but I always need assistance. But ... they are like, shooooo ... "oh ya, there's nothing wrong with you" but my apraxia affects my physical as well as my verbal.*

Lala described the need to be hypervigilant to pick up on judgements and labels providers use to explain and justify denying her care. When asking her, in her clarifying interview, why she believed they said such things she felt providers' limited time prohibits their ability to explore her condition and find it easier to place the blame on her.

Clarifying interview: Lala: *One of the biggest problems is that instead of doing the work they think it's mental.*

Lala described in detail overhearing a provider describing their judgements.

Line 164: Lala: *... one time when I was in the hospital and I was sick and I guess the, the doctor was doing his round and I guess he had you know students with him. He said, the first thing that he said, cuz he'd seen me numerous times before, and I was having trouble speaking and walking and then they stepped out of the room, after my examination. And the first thing he said was 'there is nothing wrong with her, she's just a drug addict'. Yep, that was, yep ... I wonder you know, like I say, [I was] crying ... okay, excuse me, hmm ... okay.*

Line 169: LV: *That's ok. That's really upsetting.*

The dismay spurred questioning in Lala's mind on how and why any provider would make this statement of her. She realized the ramifications of provider labeling to her self-advocacy efforts.

Line 171: Lala: *Yeah, yeah but I don't understand, but I have to think he, he's like, I just guess ... he thought, I just, I think that these doctors just don't care or don't believe, because my condition is so rare, 'oh ya, she's just' ... and I wondering, one thing that stays in my mind because I become apraxic, what if I wouldn't have heard him? I wonder how many times, this is one thing that stays on my mind a lot, I wonder how many times have I um, not heard this and it went in my record?*

Lala's need to prove her candidacy for care demands she make providers listen to her to understand her medical issues. As a result, her self-advocacy includes educating providers when she senses they might be willing to listen.

Line 384: Lala: *You would think and especially by me having that rare condition and they, they don't want to take the time to understand and, and each time, each time I talk to them I try to let them know. If you don't understand because, like you say especially*

with my condition uh, if you don't understand -- just ask me! I'm not - look...I'm not offended, I - I actually would think it's much better if you did then we can have a rapport and everything like that but if you're not and you're just going to um, if you're embarrassed or big headed or whatever you know? But you don't understand ... so instead of getting that understanding you just want to push me aside, then – please, we both loose. We both loose out. You know? Uh huh.

Lala described a deep desire for providers to offer some level of appreciation for her embodied knowledge. Without this, her care will be compromised and the provider will have missed an opportunity to understand what care is appropriate.

b. **Sub-theme two: Loss of authority-they just take over**

Lala recognized the need to self-advocate to combat provider authority over many concerns related to her care needs. The factors she considered important were immediate concerns about receiving the most appropriate treatment and care. She also experienced instances where providers used their authority to institutionalize her.

Line 156: Lala: *One bad thing is- because of the accident [pointing to her shoulders] - I have trouble at night ...when I ask for assistance - they will get to yanking you around and physically hurting you and everything like that. I'm like look here, here is the best way, look I know what I'm doing and okay please', but they won't listen.*

Lala had a desperation in her description of how provider influence and prescriptions have snowballed and pushed her into institutional care when providers failed to understand her.

Line 345: Lala: *Before [she had knowledge of ADA] and, and I've been, I told you ... we're talking about physical disability ... I don't know, when you're put into a mental institution that's another thing... I think I may have told you that I ended up in the group*

home. But just different situations and everything. Talking about physical, physical, physical and emotional. They of course intertwine and play a part with each other but you just have to stay strong. You have to.

Her steadfast intent to always self-advocate came from her experiences of having her authority completely removed. This experience of total disempowerment has had significant physical and long-term emotional consequences.

Line 223: LV: *What do you fear, or what are you afraid might happen if you get some doctor in there that just won't listen to you?*

Lala: *Just, uh, they just take over, I'll get so weak and just then get bed ridden and then my ... you know it gets so [her emphasis] bad... [long pause and difficult to hear her efforts to talk, hard for her to talk here].*

c. **Sub-theme three: Normalization of disability discrimination - context matters**

Frequent healthcare utilization has given Lala an opportunity to observe different clinical environments. She recognized that discrimination is affected by the attitudinal environment, the culture of the clinic, or the presence of support systems.

Line 106: Lala: *One thing they will do, is, like this is bad but, it was, I was in a manual wheelchair, they tend to act much different when they see that you have family or friends coming...they won't push you and they won't bring you anything but all of a sudden, it's like 380 degrees it's like "oh can I help you?" [said with sarcasm in voice] and you're like, 'Ya, right!'*

Lala shared an experience that gave her insight into providers' lack of concern for her care needs but also - as she interpreted it a lack of respect for her as a person.

Line 79: Lala: *I'll call [the nurse] and the next thing you know is that they'll turn it off and you can hear them in the background saying look... "I don't know why she's constantly calling". They don't want to come in, and it's like ok, and see what happens is that they forget, sometimes they turn it off, but sometimes [they don't] and I hear, they are like, 'I'm having my lunch I'm not going back there' and they say 'oh I don't feel like going back' but they forgot to turn the call light sound off and I've heard that stuff numerous times, like that.*

Her understanding of provider's behaviors revealed how institutional discrimination and normalized practices of disability discrimination might be fostered within a healthcare environment.

Line 133: Lala: *Um, I've actually seen one nurse, they tend to take on the attributes – um, for lack of a better word – of their co-workers. Because I've actually had one nurse up here at [A hospital] ... at that hospital they didn't care, you can call and call and everything - but you know, they treat their patients really, really, bad. But I went um, I changed to [B hospital] and the same exact nurse was there and had a better rapport – because there they have a better rapport and everything with their patients... the whole, her whole attitude changed. ...you see that stuff a lot... They take on, they take on the personality of the establishment. And I've seen that a lot.*

LV: *Why do you think they take on the culture of the hospital or nurses station?*

Lala: *I don't, I don't understand it's like they just want to basically fit in, it's best to say it like this, the, the less respect they need to give you the less respect they do.*

LV: *How do you make sense out of this or how do you come to peace or do you with situations like that nurse that she will in one situation she will treat you with respect and then in another situation she will treat you with – as How do you make sense of this?*

Lala: *Like I said basically um, um, it's kind of like ... the only explanation is that they only do what is expected out of them or basically what's surrounding them.*

3. **Master theme two: Decisions in self-advocacy**

Just as different factors informed Lala that she will likely have to self-advocate for accommodations to be understood and receive equitable care, she also explained the factors that influence when and how she self-advocates. She reiterated that she believes she must advocate to be understood in all healthcare encounters. However, she reflected upon influences that make the decision and her approach to self-advocacy easier. These included the context (as described in understanding the need to self-advocate this also informs her on how difficult it might be); her expanding knowledge on her rights to care; what she has learned from others; and a pathway for respect.

a. **Sub-theme one: Context impacts the effort involved**

Lala self-advocates for accommodations and to be understood, however, having social supports bolsters her confidence to confront provider behaviors she perceived as disrespectful.

Line 370: Lala: *I see a big difference though when I have someone with me, like say I have a friend with me. You know that amount of respect that they think that they will give me. Cuz they're going to give me my respect but they try to give me [shows a tiny sign with fingers and thumb]. It's like, uh uhnot here. Like I said when my brother was there and my friend...they were like do you need me to speak, and I'm like no, no, here ...*

you go to the cafeteria, look, I'll handle this. And they actually try to over talk me to them. And my brother is like look, look she's right here. Right, I'm glad you know brother, you tell them...good brother.

Lala recognized having allies within the medical community helps her claims to advocate and leads to more positive outcomes. This context offers an alley in overruling any medical doctrine that has wrongly labelled her and reinforces the appropriate methods for giving her the care she needs.

Line 58: Lala: *I may see, I'll see a nurse or a doctor that knows my history from years ago maybe 10 years ago that, 'oh okay this is what happens' and then they'll be like, 'Oh, okay!*

b. **Sub-theme two: Confidence and knowledge of rights to care**

Lala indicated that her growing knowledge of the ADA and her rights to accommodation are increasing efficacy of self-advocacy efforts. She described events where she has used the language of her civil rights to enforce her right to communication accommodation as empowering.

Line 175: Lala: *And, that's why each time I have, I physically ask for the I-VAN. I have, by law.... Now, we had a big confrontation because they tell me, that by law I don't I shouldn't, I don't have the right to have it. And I have and I actually had to have administration come down and it was, it was a while ago, but like I said I don't let them stop me. I got to keep it going.*

Although Lala recognized how the law offers her the power, she was disheartened that discrimination continues to prevail in her healthcare experience.

Line 340: Lala: *I'm like I have a right to this or even a right to an interpreter and then you start to see them doing the 360 degrees sometimes, but it's sad that you have to bring up the law. You'd think it would be automatic.*

She was empowered by these self-advocacy experiences and reinforced by her knowledge of civil rights.

Line 417: *Thank you! and that's why it's so important to say a word that ... that you learn that .*

She reflected on her past and understood that her experiences with institutionalization may have been avoided if she had the knowledge then that she does now. This drives her to reach out to others who may lack the ability to self-advocate.

Line 235: Lala: *I hear a lot of people saying, you hear people talking about becoming intimidated you know and everything, and I'm like here, you have a right to this. Many people don't know their rights and stuff like that.*

c. **Sub-theme three: Learning from others**

Lala has spent her entire life in the healthcare system and has been institutionalized more than once. Only recently has she become aware of her civil rights and how disability discrimination has excluded her from both society at large and in receipt of appropriate and equitable healthcare. She acknowledged the impact of this knowledge and recognized her power to enforce her rights has grown out of new relationships and mentoring.

Line 319: LV: *Do you feel like, one of the things I'm starting to see is that people that are good advocates seemed to have learned it from someone.*

Lala: *um, uh... many, many people cuz, like I said, there have been many that have you know ... [CIL] plays a big part. And you all [academic partnerships] ... a big part.*

Learning how to self-advocate within healthcare, even for small things, occurred by watching her strong mentor allies advocating for her needs.

Line 310: LV: *Have you brought people with you?*

Lala: *No, well they... it's mainly like when they come to visit me in the hospital, [my family member] you can't tell, she is like "Look!" "Look, she needs your help!" It can be anything. I can remember during eating time...they brought everybody something to eat but me. And you know, maybe they just forgot or whatever, but I bet I ate better that day because she was like look, literally hawlering and had them physically come back into the room. And then it was like 'here you go, pick what you want [laughing] ok, I was like 'yes mam' and give me....and she actually got a meal out of that too! [laughter].*

d. **Sub-theme four: Pathway for respect**

Lala's need to be understood is related to her need for respect. She made sense that one comes with the other. Her sense of empowerment in advocating for accommodations appeared to empower her in advocating for treatment with respect.

Line 185: Lala: *I actually, when I went back several months later, um, the same doctor came into my room and everything like that and I ... um, 'get out!' I literally kicked him out! [laughing] I literally kicked him out. I'm not seeing him, I'm not seeing him. I made sure, I did. I'm like look, and they're like 'look, you might have to wait a little bit longer to see another one, a little bit longer in this room' I'm like, Ok, fine, here, I'll wait in the room, I'll wait a little longer but I'm not seeing this man! He's got an attitude and here....see you. Right. Uh, huh, I sure remember that, nope, not today.*

Lala interpreted that her capacity to self-advocate and experience with rejecting discrimination protected her from providers she believed were perpetuating the labels she knows providers have

given her. She understood her decision to self-advocate for her rights can change the experience significantly.

Line 193: LV: *Did you ever see him again?*

Lala: *No, not as a patient no. uhhuh, no.*

LV: *Did he know why?*

Lala: *Oh, yes! And I made sure oh, and like I say, I can get a little vocal sometimes and I...and you say drug addict? I'm not a drug addict. And one of the nurses that's been knowing me for 20 years she's like, "girl!" and I'm like 'that's ok, I'm just letting him know, you know' and I made sure.*

During the clarifying interview, I asked Lala if she ever felt like her requests were a burden to providers. She was surprised that I might have interpreted any experiences in this way and forcefully rejected providers attempts to make her internalize disability discrimination.

Clarifying interview: LV: *Do you feel like you are bothering them?*

Lala: *No, no, go back. **They** try to make me **feel** like I am bothering them, but I'm like look ... [I don't feel like a burden] and if they start to act condescending or just disrespectful then...let me speak to your supervisor.*

4. **Master theme three: Decisions not to self-advocate**

Rejecting provider discrimination and disrespectful behavior pushed Lala to self-advocate even when she was in distress and emotional pain. Any desire not to self-advocate were overruled by her knowledge of the potential consequences of staying quiet.

a. **Sub-theme one: I may cry as I advocate but stopping – no**

Line 212: LV: *... are there some situations where you'll just be like, I know I should advocate for myself but I'm just not going to do it today?*

Lala: *No, I, I, it would be a situation where I am so frustrated where I, I, but, I may cry as I advocate but stopping, uh uh, no because like I said, you know.*

LV: *What do you risk if you don't do it?*

Lala: *Like, not getting the proper care, going back to the nursing home, just not, not having whatever needs met, whatever medical needs that I have not being taken care of because, having to be sent right back and just becoming worse worsening, uh uh, just worsening. Like I say, I have to advocate you know, for myself, I don't care, physically, I have the right. Because 'you will understand!' [emphasis].*

The only way Lala sees as a safe manner to not self-advocate is making the decision to avoid the discriminatory healthcare setting which is in itself a form of advocacy.

b. **Sub-theme two: Avoiding harm**

Line 363: Lala: *I actually have an appointment with my, my um, my previous primary maybe in about a week. I refuse to go. Because this is the one I was telling you about that refused to even [see her].* LV: *Well you ended up in the hospital because of that.* Lala: *Right!*

5. **Master theme four: Impact of healthcare/self-advocacy experiences**

When asked what she believes are the lasting impact of her experiences in healthcare Lala described two powerful realizations as she interpreted her experiences. She recognized the negative impact of her past experiences of extreme and subtle healthcare discrimination. She also interpreted how her knowledge of her civil rights and her efficacy for using the language empowers and helped her to develop a disability identity.

a. **Sub-theme one: Loss of dignity**

Lala's past experiences were often interpreted by her as disrespectful and discriminatory but her institutional experiences are interpreted as stripping her self-dignity.

Line 22: Lala: *I'm sitting up here and needing help to you know get around the room, or try to go to the restroom, the nurses will refuse to come and I've actually fell numerous times...I didn't want to have an accident and so I am here just with a walker and I'm sitting up here standing and that's boy, boy, talk about, talk about fru..frustrating and that it's just frustrating but you just have to keep going on, um....there are times when I become so weak where I've had to crawl around and I've had to do that numerous times I've had to physically crawl from room from room. But I'd rather do that than fall.*

She reinforced in her clarifying interview how the lack of care left her crying and emotionally distraught. These memories reinforced her passion to advocate at all costs even when she feels overwhelmed and fatigued.

b. **Sub-theme two: Advocacy fatigue**

Lala acknowledged the effort of self-advocacy and disability activism has on her energy levels. She recognized that times when her physical strength is low, she understood may be the times most critical to her to self-advocate. She described strategies that help her regain her strength and simultaneously rally an ally.

Clarifying interview: You do get tired – When I get too tired I will ask for a pastor or a priest to come in. Just try to understand – understand my condition and [that] it does cause epilepsy and apraxia.

Frequently throughout her interview Lala appeared to be giving herself, possibly others, encouragement, “*you just have to stay strong, you have to...*”, a pep-talk to resist succumbing to the fatigue.

c. **Sub-theme three: Impact on health**

Lala was able to explain how providers’ attitudes and authority can overrule her own authority in caring for her health. She reported constant battles with providers who compromise her health leading to the onset of seizures and strokes.

Line 326: Lala: *And they refused to give me a treatment and they said go home ‘well look just go home and will give you a call’ and next thing you know I had to go to the ER and my levels was so low.*

In the clarifying interview, I asked Lala if she ever was concerned for her life in these situations and she replied “*in the past maybe ... but no not now*” as an indication that her confidence in self-advocacy corresponds with an increased confidence to manage her health.

d. **Sub-theme four: Fear for self – confidence to protect self**

Through exposure to her local CIL and mentorship from disability leaders, Lala has increasingly been involved in disability activism and has increasing success in advocating for her own needs in healthcare encounters. She drew on recent experiences in visits to providers that she interprets would have gone drastically in the wrong direction if she lacked this growing confidence.

Line 404: LV: *What does it mean to you that you are a self-advocate?*

Lala: *It means a lot to me because like I said, uh, I’m able, you know to speak up for myself, I’m able you know, what if I was in, you know? There are many things, situations*

that have happened that would have been much worse. And everything. It's just being an advocate for myself, I mean it means a lot.

Her ability to request and receive communication accommodations increased her opportunity and capacity to have her other needs understood and met. Lala's successes built upon each other to help her have the confidence to confront explicit and implicit provider bias and disability discrimination that affects her and others with disability.

Lala summary: Despite living with disability her entire life, Lala described only recently being confident in her ability to request the accommodations she needs in order to receive the healthcare she requires. She attributes this confidence to learning from others in the disability community about disparate care, negative provider behaviors and overt discrimination and strategies for managing her healthcare encounters. She now sees her negative experiences within the healthcare system as part of a larger system of discrimination against people with disabilities. She was the only study participant to emphasize the need to self-advocate at all times, never choosing silence or accepting less than she perceives she needs. Despite this, provider authority can still overrule her and put her at risk for oppressive provider encounters and worse, prescriptive decisions that put her health in jeopardy. Her personal experiences with these outcomes strengthen her commitment to self-advocate and advocate for others and empower her growing disability activist identity.

F. **Gary**

1. **Background**

Gary grew up in a working-class city in the mid-west of the United States. He described "*maturing overnight*" when a dirt bike accident resulted in quadriplegia at twenty-one. The past ten years have been a "*struggle and a journey*" for him, but his move two years ago to a

large urban community has changed his outlook on life drastically. He described feeling content and passionate about living, where he lives, movies, baseball, and his friends. He credited this change to his expanded disability community and to the city's accessibility. He spends two or three times each week cycling along the city's bicycle trails with his best friends. As he talked about cycling you can hear his passion for the sport and what it provides for him; *"I love being on my bike, it gives me a sense of freedom."*

After his accident, Gary initially lived in his rural hometown with his mother. His description of the first four years of being a person with disability revealed how difficult this time was for him.

Line 201: Gary: *I don't know, for me I, I just kind of like, struggled to make it. And then eventually it wasn't struggling. And it became easier right? But there's definitely a hard transition where you kind of have to sort through yourself and decide on what ... are you going to be the one that speaks up or are you going to, you know, hide and play video games like I did for 4 years.*

In his clarifying interview, he explained the protection and support received first by therapists, friends, then from his mother was smothering. His decision to move to the city and live on his own was a major contributor to reviving his outlook for his future. I asked him how he learned to live on his own and care for his health and his reply suggests the importance of learning from mentors.

Clarifying interview: Living on your own with paralysis? Being in a community of wheelchair users is the best thing you can do for yourself, just for your mental health. Being in the hospital or supportive environments doesn't help you learn to live with disability.

Although Gary has and understood the need of self-advocacy in his healthcare encounters, he didn't embrace doing it and did not see himself as a disability activist, stating "*I definitely want to hide and be behind the scenes*". When it came to his health, he recognized the utility of self-advocating in order to ensure providers '*get it right ... because most providers have no idea*'. He felt he has a strong grasp on his healthcare needs, but expressed frustration with not yet having a complete grasp on how best to educate providers on these needs.

a. **Bracketing**

I had never met Gary prior to our initial interview making him the only 'unknown' participant for me. We met at the time and place established in the telephone screening. I was very surprised to see Gary using a manual wheelchair. During our phone conversation, he had shared his spinal cord injury level and based on my clinical background, I immediately categorized him as a person who would use a power chair. My assumption highlighted the 'struggles' (a word he uses multiple times) he has with providers as he learned to become the authority over his healthcare needs and how these compete with diagnostic categorization.

Throughout his interview, it became apparent that advocating is something he felt uncomfortable with and is still learning to do in visits with providers. He described "*learning to know what his needs are*" as a first step, and then "*learning how to advocate for them is the harder step*". During his clarifying interview, Gary was enthusiastic and animated to expand on a lot of the experiences he had first described in the initial interview. It was as if reading his own words provided him with greater understanding of what the experiences mean. Having another's interpretations – affirmed as accurate – helped him to understand that he was actually being discriminated against and not just a 'feeling' he has of being a burden or 'asking more' of

providers. Although he acknowledged still learning strategies of self-advocacy he clearly recognized the need and the barriers that make it necessary, but a challenge. At the end of our initial interview he shared his own analysis of the impact of provider authority over people with disability that revealed his growing recognition.

Line: 506: Gary: *The docs are the top of the food chain and when they recommend something or refuse or rebut you, all it does is remove the progress you've made to assume authority over your body ... making you second guess or be less confident.*

Gary's understandings of his need to self-advocate for accommodation and his experiences in making decisions reflected this growing appreciation for his own authority and knowledge on how to manage his health.

2. **Master theme one: Recognizing the need to self-advocate**

Gary is a young, white male and prior to becoming disabled may have rarely been on the receiving end of discrimination. He likely rarely experienced the inability to access or participate in society because of environmental or social barriers. Likely, seldom had to self-advocate. Recognizing the need to self-advocate follows recognizing that your needs, wants, or desires are being denied by others who have the power to do so. Gary had little background to base what is and is not equitable healthcare for a PWD. What he had learned came from experiences when his care had been compromised by providers who claim to understand his care needs but may fail to understand the experience of living with disability. The sub-themes under this master theme came from Gary's description of his process of coming to understand his need to self-advocate and include: learning stigma and disability discrimination influences care; lack of provider understanding of disability and health; and assuming authority.

a. **Sub-theme one: Learning stigma and disability discrimination influences care**

When I asked Gary to tell me about a time when he needed an accommodation he replied with a bit of embarrassment that he had to call his mother to remind him of some of his earlier experiences. He said it was strange how many memories she reminded him of and in retrospect he realized now how unaccommodating they were. At the time, he took it as being “*super awkward*” realizing something was not right but being unable to make sense of why. He explained the experience of getting an MRI when the equipment was unable to accommodate him and staff were not trained in how to work with PWD.

Line 28: Gary: *I needed like a total assistance to get flat and then they had to like strap me down because I was real spastic, and it really turned into an ordeal. But, I mean they actually said ... that they didn't recommend that we don't come back, I mean 'don't come back'. They said that! “We don't, we don't, we're not suited to handle this kind of deal”.*

At the time, Gary did not realize exactly what the staff meant by ‘*this kind of deal*’ and now, recalling the experience with his mom, after ten years of being a PWD, he realized that awkward feeling as one of his first experiences with being discriminated against. Prior to this experience he had worked with providers within his rehabilitation hospital versus in public clinic settings. He had assumed medical facilities naturally would all be accessible in all ways.

Line 70: LV: *Did your doctor tell you or did anybody give you a heads up that... well maybe you should tell them you're in a wheelchair?*

Gary: *No, no, I guess, I guess, everything was assumed or under the assumption that you know that, they are sending me, I figured that they are sending me there, they're seeing my files, I don't know if I ... I don't know. I didn't.*

Throughout the interview it seemed as if Gary was reflecting on his experiences from a new perspective, interpreting the failure to be accommodated as something other than being his fault.

Line 429: Gary: *Because I'm hard on myself about a lot of things and you know, I don't know why...blaming yourself for things that are totally out of your hands, but still, you're like "mannnn, I am like such a problem!"*

Gary questioned the subtle behavior of a provider, interpreting what this behavior represented, recognizing the fact that he was still thinking about it the next day is significant.

Line 431: Gary: *You know and then again if they make it seem like it is to... it's like 100 times worse, any ... it's like the smallest gesture ... and, and,... you realize what they think, and then I'm thinking about it the next day ... like, 'man that guy was like' ... So, why am I bothered by this one person that like just breathed real heavy, you know, where you noticed it, seriously?*

Gary haltingly described this experience, repeating the interjection of 'and', 'and' as he interpreted "*realizing what they think*" as becoming more conscious of and trying to make sense of the disability stigma he remembers experiencing. He had little experience with discrimination, prejudices, and biased behaviors and initially was unable to readily identify the act for what it is. As he described this experience he interpreted how other provider's rejection or negative responses to requests were more than an isolated experience.

Line 445: Gary: *So that just feeds on my you know, cuz, it's like....ok that....and then the dentist, and then the you know, and you are like ... it's like, kind of a common thing and so then you are like.....man I am REALLY [emphasis] a problem! At least I sure feel like one!*

Gary processed his experiences for what it is, and how perceptions from others, and from society toward disability bleed into all parts of his identity.

Line 439: Gary: *No really, and I mean, I'm speaking out loud about a lot of things. But I have ... like with relationships ... I mean I feel like it all ... like I, like all these things kind of build-up and they, and you are like, I don't know, who would even want to be interested in someone who is such a problem. Right? And I mean, and it like really.....* [long silence].

Gary confessed provider behaviors impacted him and impact his confidence in being able to self-advocate. His strong sense of being a burden conflicted with knowing he needed to receive care. He displayed a growing understanding that in order to be accommodated he has to act against his nature, outside of his comfort zone, and self-advocate despite provider responses.

Line 22: Gary: *... it was super awkward because sometimes when you go into these situations you're like, you know, you're like 'do you think that I would, if you think that I would ask this if I, of you?' it's like making it more awkward just from like the subtle like.... 'uuughhhh' [imitating a long sigh from provider] ... like the little 'huh' [with a rolling of eyes] or like, or kind of like you know, like this [facial expression of imposition] and so, and so they made a deal out of it because they pretty much [are] saying that honestly, normally they don't deal with people in wheelchairs.*

Gary increasingly recognized providers' everyday acts and behaviors as influenced by stigma that impacted his confidence for self-advocacy. He also had a growing understanding of the influence of provider authority. He described experiences where his convictions on what he needs was overruled by providers. He interpreted this process of losing authority, being disempowered by providers' 'expertise' on living with C5 quadriplegia.

Line 105: Gary: *...because you're a C5 quadriplegic this is definitely **the** problem. And, and, and so then, me, and they [providers] know I'm uneducated of it [issues with care of body], obviously to their knowledge you know, I've following their guidelines since day one because I have NO idea." I felt like the doctors were putting pressure on me to do something that I really didn't know anything about you know. And the therapists. I had many therapists that I had worked with for a long time and I asked them, I asked all of them because I did not know. I did not want the hockey puck in me. I'm like I don't want this.*

His sense of guilt for being 'the problem' added to the pressure to surrender to the authority of providers. Gary acknowledged the damage this might have to him psychologically as he knew he should self-advocate but chose not to.

Line 111: Gary: *Like, this is on me as it's happening and so I just go with it and I know that, that is totally wrong, I know that's wrong, but when you're in it, you're like 'I just want this to be over with as fast as possible and make it just as easy as possible for everyone.*

b. **Sub-theme two: Most providers don't understand disability**

As Gary was learning his new and different needs post injury he began to sense more than awkwardness from providers. He was use to trusting that providers' knowledge would help him care for his healthcare needs.

Line 220: Gary: *Yeah, my, I had a urologist in town, [hometown] and, when I was first injured we kept having incontinence issues like non-stop and it was so insane you know, because I'd get so dysreflexic, I mean I'd be sweating and we'd keep, he kept treating them as UTIs and so I was like, I mean for 4 years ... I think I was prescribed Macrobid*

every other month, for 4 years! Eventually we decided we needed to reach out to someone else [urban provider]. And all it was it was my bladder is so spastic from the spinal cord injury I that we just, he just [new provider] said, 'oh no you just need to double up on the medicine that you're already taking for spasticity' - totally took care of it.

Gary told this story with a tone of dismay in his voice that his provider could have been so inaccurate in understanding the normal functioning of his spinal cord bladder. He also experienced the paternalism of providers when he tried to educate.

Line 223: Gary: *And all that is, is just the knowledge of the doctor here. I went back and told him [hometown provider] and he was just like 'oh, ok' [mimicking a non-apologetic voice]. You know I mean we were just treating something that - I mean if your bladder is also paralyzed – it's always going to have bugs so you test it and it's going to be dirty and so yes and we came up here [city provider] and it was like wow, okay!*

Gary interpreted this experience as a major learning experience in multiple ways. He learned more about how to care for himself but as importantly he recognized that providers can be unfamiliar with PWD and lack a foundation to prescribe care to optimize his health.

Gary used this experience to appreciate that when seeking healthcare, he needed to ensure that providers have experience working with PWD or are open to listening to his expertise. However, during his interview he discussed other experiences where provider's lack of accessible equipment meant that he had to accommodate the provider to receive care.

Line 155: Gary: *The dentist um, we called and the one thing that they had to do – they actually modified one of the doorways to make it [accessible] ... which it was pretty cool.*

LV: *How did that happen or come about did you talk to them about it?*

Gary: *Well we called because I was, I was with them since I was a little kid and so I don't know, it may have already been in the works but it was something that happened within the transition from when I got insured and when I went back within a year they, the door was widened and But ... I can't get in the dentist's seat without ... but you know ... I can bend my head back pretty far and so then I just stay in my chair.*

While he appreciated that the provider widened the door for access to the clinic, he realized providers did not fully understand what was needed to provide equitable services. Gary described this scenario in a way that suggested he should be grateful to the provider for their efforts. Because he felt indebtedness, Gary initially tolerated this lack of equipment. During his clarifying interview, he voluntarily expressed a shifting perspective as he re-interprets this experience as unfair.

Clarifying interview: *Sometimes it's just simple stuff – pretend you're me, your fused, do you think you could do this [he tilts head way back with his mouth wide open] while they clean your teeth, or would you even put up with having to do this?*

Gary described his resistance to provider's efforts to prescribe an intervention for his spasticity. He resisted, becoming more aware his knowledge surpasses providers'.

Line 111: Gary: *I did not want the hockey puck [abdominally implanted baclofen pump] in me. I'm like I don't want this. And I am active, and you know I was doing sports, playing rugby all sorts of things and I was worried it was going to interfere, and all of them told me to do it. They all said, 'it will make things so much easier' blah, blah, blah, and I ...*

LV: *Did anybody provide for you any other alternative?* Gary: *Um...no.*

c. **Sub-theme three: Becoming his own authority on health needs**

Gary described his lack of preparation for being the authority over his body. He used the metaphor ‘perfect bubble’, for his transition from living in rehabilitation to home.

Line 202: LV: *How did you learn what you needed?* Gary: *Ya, LV: just in trial and error?* Gary: *Yes, I think so, I mean I was really lost, I mean, and like it was ... you’re in rehab and you’re in a bubble, cuz I was on like the 7th floor and I loved it, you’re in like this perfect bubble, you’re around all of these other – sadly – but you’re around all these other young male and female people and you can all relate to each other and then you go home and there’s no doctors, or therapists, or friends. You know, you don’t have any of these people anymore and so it’s like then you’re, then the bubble bursts and you just*

Gary described living at home with his mother fairly isolating.

Line 269: Gary: *Before I moved here and before I was around, I was very sheltered and I didn’t want to be, [I was] in my own little world, I didn’t want to be out.*

He decided his move to the city primarily to be closer to providers who understood his care needs. However, he described how living on his own provided opportunities to become his own authority, to take risks, and to become expert over his body.

Line 284: Gary: *Yeah, I think....I feel like ... I feel like there’s always going to be that line that therapists know that they can’t ever cross, that sort of thing. I mean you can’t go out and do certain things with patients that they need to have done to them. Like patients ... I would throw somebody on the ground the very first day. I’d be like --- depending on their injury, I’d be like “you need to fall and you need to learn to get up” ... [laughter]... I mean you need to, that’s how I learned, when I first moved on my own, I didn’t tell my*

mother I mean until months later that for the first weeks, I was falling all the time! On the ground! And eventually I learned and I didn't fall anymore and that's probably not the best way but it was the way I learned and you just have to, you have to be not afraid to, you can't be afraid to fall. You know, you can't. Because you're going to fail and you are going to struggle and it's going to be horrible, horrible.

Gary interpreted how to care for himself as empowering and his expertise and authority over his care as substantially increased.

Clarifying interview: Relearning like a baby, your skin is different, your tissue is different. I watch what I eat. Ever since I've taken control of my body ... I feel better.

Gary's confidence in understanding his body's needs translated to his confidence to self-advocate. Having the conviction that he knew what's best for his health was coupled with an embodied knowledge of moving and living in his world. He understood that providers' lack of this form of knowledge and makes it more critical that he advocate for himself.

Clarifying interview: Gary: For the last 5, probably the least 5 years, I've been trying to get set up for a new wheelchair and they always tell me "you need this, and you need this" At first it was power [wheelchair], and first of all power only makes you fat. You're not going to gain anything by using power and so, and so I majorly just ... we kept leaving because they wouldn't give me what I wanted and I, finally when I went back this last time and said, "this is how it is – I'm ten years post injury, I know, I KNOW [strong emphasis] what I want and need and I had, [friend] was with me... they gave me the wheelchair set up that I wanted – Finally! ... I mean they are telling, they are making people have great posture and all this, and I mean you're sitting me up and I look beautiful and perfect posture but I can't reach the floor anymore, so when I drop stuff I

cannot pick it up, and I can't even go down the sidewalk because I have no balance [in that kind of chair] and I'd fall over. I mean...why does it matter to you?

Gary's experiences over the last ten years helped him understand that provider's approaches to working with him were influenced by their lack of knowledge of living with disability. Providers questioned his authority making it necessary for him to self-advocate. He continues to learn his own strategies for self-advocacy and when making decisions on whether he advocate or not his concern turns to some extent on how his requests will be perceived and this remained an important influence on his ultimate decisions.

3. **Master theme two: Influences that exclude self-advocacy**

Gary also demonstrated an awareness of his trajectory for learning how to self-advocate. He was able to interpret the many factors that excluded self-advocacy from being an option for him. The sub-themes for this master theme focus on the four primary factors that influenced his decisions: not in his nature; self-perceived burden; negative experiences of advocacy; and, concern for backlash.

a. **Sub-theme one: Not in his nature**

Innately, Gary felt uncomfortable self-advocating and reflections of experiences, especially those early after becoming disabled, were interpreted by him as lacking necessary strategies for advocacy.

Line 30: Gary: *They said that, they said, try, I mean it was almost like the doctor should have known better than to have us come to this [clinic]...and so like I said I was with my mother at the time and we were just like, well um, well like ok, you know, it's like I don't know I'm not, it wasn't so much like I was embarrassed but it was like you know, it's really just uncomfortable and I'm definitely one of those people, I have a hard time like,*

really saying like “come on this needs to happen for me to make this easy” like I can’t, I don’t know, you know ... it’s fine because as outspoken as I am about somethings and then when it...it’s like an awkward pressure or something you know.

Gary knew he needed the accommodation but had no foundation at this point for advocating for it. He lacked experience in how to advocate for something he readily received prior to being disabled. He had only basic knowledge of his civil rights and lacked the strategies for using the language of rights to accommodation in healthcare. He had a difficult time interpreting why he wouldn’t be able to advocate in this context when in others he can. He appeared to wrestle with understanding this novel and foreign experience, trying to deduce the cause or where to place the blame.

Line 46-55: LV: *At the time that you were in that situation ... when it was happening did you did you think, ‘I’m being discriminated against’? Did you interpret it that way or was it just a pain in the ass?*

Gary: *Ya, ya, I, I, I look at it like, I mean again, it’s almost, I almost look at it like it’s my fault. You know what I mean? Like, this is on me as it’s happening and so I just go with it and I know that, that is totally wrong, I know that’s wrong ... but ‘I don’t want to be a problem’ obviously I’m ruining your hour cuz you want to get home. I don’t want to be ‘that guy’. You know?*

At that time, Gary did not consider that factors in the healthcare system might be the basis for the problem.

Line 75: LV: *Did you learn a ‘lesson’ [signaled finger quotes] from that experience.*

Gary: *Ya, not to go back there! [laughter] I mean honestly, I um ya, just ... I don’t know that I did really. Sadly, you know what I mean, I mean because, would I have changed it*

in another situation? I don't, can't say that I would ... I would hope that I would you know?

He believed asking for an accommodation was asking the provider to go the extra mile. By his own account he perceived an accommodation as a request for a convenience versus his right.

Line 312: Gary: *I feel like again, it's hard for me because I don't want to be a problem, I don't want to be an issue in any situation, and I know that I would just be asking for a simple thing but you're really inconveniencing them, is how I look at it.*

b. **Sub-theme two: Self-perceived burden**

Gary described his own questioning why self-advocacy in healthcare was so difficult for him when he knows “*how outspoken I can be about somethings.*” He interpreted a lot of these experiences as his natural inclination to ‘not stand out’ or ‘not wanting to be a problem’ but underlying these phrases he interjects understanding this rationalization is inaccurate.

Line 313: Gary: *I know that I would just be asking for a simple thing but ... it's like, and it's, I mean it's like making me sick just even saying it right now cuz, I know it's totally wrong. But when I'm there, I just am like, you know what, I can deal with this for an hour if we don't have to go through all of this and make ME [his emphasis] an ordeal.*

Gary would rather accommodate his providers than request an accommodation. Even when his providers offered to accommodate him, through assisting him in a transfer to the dentist chair, he interpreted that process as a burden.

Line 158: Gary: *Sure, I mean I have gotten in there and you know they totally offer any assistance, again, it's more on me I think, thinking like I'm like, this is really a pain or like I don't want to take up, it's going to take time to get situated and I so, I mean, sadly,*

I just go the easy route, just like no, no, this is fine [leans head way back] totally comfortable [sarcastic voice ... laughter]. Yep...see you in 6 months!

c. **Sub-theme three: Negative experiences with self-advocacy**

This sub-theme was subtle but important to understand some of Gary's interpretations of his experiences with barriers to care. He described encounters, outside of healthcare, when he's advocated for accommodations and his requests have been rejected.

Line 78: Gary: *But then, like the times that I have spoken, up its turned into an anger thing rather than you know it's like, it's like when I'm getting mad about something and it's like 'come on!' and then it's like not constructive ... I couldn't sit at the bar and they couldn't even open up one table and it was really, we ended up saying something and then we just left. And then, and then it was like, you know we kind of ... cut into them and then anyways, they ended up apologizing for the whole situation but anger isn't really what ... you know ... I don't want to be that guy either.*

When faced with overt exclusion, Gary became someone he didn't want to be – angry and out of control. Gary's reflection on this experience precluded him from self-advocating in healthcare for fear that a similar scenario would playout in a provider's office.

d. **Sub-theme four: Concern for backlash**

Gary's perception of being a burden when contemplating requesting accommodations related directly to his perception of how providers and staff would respond if he made the request. Gary interpreted asking providers who are already 'tasked' with his care, as asking for special treatment. He was concerned with being rejected by providers, especially those he wants to keep because they would see him as too much work.

Line 337: Gary: *You know it's again, yea, especially if it's someone that you have history with you don't, you don't want to cause any problems. You know, even though it's not a problem.*

Gary sensed that his request would have long-term impact on his relationship with his providers and feared that, like in his earlier experience with his MRI, he would be told 'they're not really set up for working with people like him'.

Line 336: LV: *Um, how do the people that you go see, that you work with like the doctors and ... do you think they'd be like 'you know what, let's get you up here' do you think their attitudes influence your decisions, or do you think that if they would offer up front that you'd still be like no that's ok?*

Gary: *Sadly, I probably be like, no, it's okay. I mean ... I mean, cuz, I don't know why really because it really, I mean honestly if they were mean about it, it would make it even worse, if they were – I mean not mean, but if they made it awkward like 'HUH?' Cuz I feel like if I said it they would totally do it of course, 'of course we'll help you, okay' but ya it's just the fact that I, plus I know that, I don't want to, cuz I'm going to be coming back again, and I don't want them to be like ----oh man.*

During the interview, Gary frequently described his perceptions of being a burden, not wanting to be 'the guy' or to 'not be a problem' to providers. However, he was conscious that these experiences are discrimination and understood that his lack of advocacy contributed to the continued oppression of people with disability.

Line 372: Gary: *I think I keep saying this [his inability to advocate] ... but I feel like it makes it so much worse on us as a group, disabilities, that we are you know ... that we*

are uncomfortable to say something even though we know totally what we have the rights to it just like any one.

4. **Master theme three: Learning/choosing to self-advocate**

Weighing the pros and cons of self-advocacy and advocating for accommodations in healthcare requires realizing more is at stake than receiving or not receiving equity in care delivery. It requires understanding how different contextual and personal factors might impact and be impacted by decisions to advocate. The decision-making process can be enhanced by understanding the underlying causal factors for a lack of accommodation – including the normalizing ideologies that fail to consider the needs of PWD. Gary’s path to learning the many contextual variables to take under consideration when deciding or not deciding to self-advocate is part of the journey he interpreted being on. The sub-themes in this master theme represent Gary’s experiential learning to self-advocate as both a recursive and reflective process. They include: confronted with his body’s needs; learning from others; you need to ask; and, using his own advocacy style.

a. **Sub-theme one: Confronted with his body’s needs**

Gary described being told “from day one of rehab” what he needed to do to care for his body. He also described instruction in how to direct personal assistance on how to attend to what his body needs. However, following his discharge he described how his inability to direct care givers and self-advocate for appropriate care directly impacted his health.

Line 241: Gary: *Yeah, it’s, I mean it’s embarrassing really. I, I, I was embarrassed and the thing is, I knew – cuz I ended up, I had a sore, and I, and the thing for me is I knew what it was because they had ... that’s like one thing they teach you a lot when you’re in rehab. And you know it’s like, you don’t, that’s not going to happen to me, but it*

happened in my first, two years out and it was, it was like, I didn't want anyone to know because, I don't know, I don't know, I didn't want to face it you know?

Gary understood that to care for his body, he had to assert that his personal assistants be diligent in his healthcare. The process of his coming to understand his responsibility and control over his health established a mindset that likely extends to other providers.

b. **Sub-theme two: Learning from others**

Gary discussed learning how critical it is to closely monitor his personal assistance as they attend to his body's needs and decisions to advocate when care delivery is inadequate. He also has learned from others.

Line 261: Gary: *I mean the best way that I've learned is just being involved with other quads or being involved with people with paralysis. My best friends are two paras. M and another guy A. And so, and I feel like that's what was the deal breaker for me... was when I moved here and I was in a community of quadriplegics or a community of wheelchair users ... and I don't know any other way, honestly, I don't know because when I was, before I moved here and before I was around I was very sheltered and I didn't want to be, [I was] in my own little world, I didn't want to be out. And so, yeah and so, once I started meeting these guys, I was like 'holy cow' and it was neat because I feel like with people with disabilities, at least the ones I've met are like totally open to anything. I mean a-n-y-t-h-i-n-g... any conversation you want to have you're like ... whoa! I mean like, and I'm all for it so, please you know. So that's like major gains have been made with that.*

Gary's confidence in caring for himself and emerging understanding of being part of a minority community helped him to recognize that he had the power and responsibility to make requests for accommodations.

c. **Sub-theme three: Learning you need to ask**

His earlier experiences detailed tolerating inadequate care from not necessarily understanding his right to accommodation. In descriptions of more recent encounters, he recognized that accommodations will only be provided if he requested them.

Line 182: Gary: *I think if it came down to something that I knew was going to happen like it had to be, I definitely would speak up, and you know, most of the time it's you know tone like, you said, the way you project, look this is not going to work. And you know, a lot of times you know a lot of times I've found that if I've asked for something, that it's like pretty obvious that I need it, I can't, they're like almost embarrassed sometimes, it's like 'oh my gosh of course! Why didn't we have that?', or 'Of course why didn't I think of that?', you know?*

d. **Sub-theme four: Using his own advocacy style**

Gary did not have a strong knowledge on the ADA and tended to decide against requesting accommodation in provider visits. His learning in advocacy and decisions to advocate have to deal much more with confronting provider authority and control over his health and healthcare decisions. Gary's battles with providers over decisions concerning equipment prescriptions illustrates his progress toward becoming a strong self-advocate in his healthcare.

Clarifying interview: *My doctor suggested that I think about power again, like in a power wheelchair. I immediately didn't want to have anything to do with it, because I knew, I didn't see this as being the best thing...He looked at me and said, 'I am not the one that*

needs to be convinced here’, that’s what he told me, ‘Why are we arguing, because I am right.’ That moment has stamped in my brain and I reflect on it all of the time because that’s the most motivation I can ever find. And I think, YOU ARE [emphasis in voice] the one that needs to be convinced because this is – I don’t know what you want to call it but it’s just taking everybody who’s in this paralyzed world and lumping them into one and we are not all the same. And you’re not listening to what people want clearly! Because I have never, not ever wanted that. But it somehow keeps coming up.

Gary understood he will not receive the equipment he wants unless he confronts the authority of the provider. He used strategies to get to this point by reflecting on whether his provider’s decisions or his are right, bringing allies into the conversation, and looking to friends for examples.

Clarifying interview: *I have so many friends that have done so well in their lives with simply with pushing a w/c.*

Each of his experiences in advocacy, whether it be advocating for diligence in personal assistant care or confronting provider authority have had a lasting impact in Gary’s journey to develop his disability advocacy strategies and disability identity.

5. **Master theme four: Lasting impact**

Gary’s interpretation of his experiences of advocacy in healthcare illustrate a progression from having no understanding of the different variables at play in access to care to understanding some of personal factors and many contextual factors for consideration in decisions to self-advocate. His reflections on experiences revealed his understanding that disability stigma and discrimination are part of these factors. His confidence to self-advocate corresponded to his embodied confidence in everyday life.

Line 196: Gary: *I mean it took me forever just to feel comfortable paying someone with money or handing someone, just because my hands are not very function-able and so, you know it's like small things like that, like just having the confidence you know of knowing what you need.*

He acknowledged the lasting impact of his experiences influence his emotional health but also have pushed him to be more confident in choosing the times he will advocate and that when he does he has available strategies for doing so.

Line 411: LV: *How do you feel like, overall, how do you think that your health generally is or has been impacted by a lack of accommodations or a lack of providers knowledge on your need for accommodations for good care?*

Gary: *I don't know if ... if, um ... hmmm ... I mean, I feel like, as far as like going to the dentist and the eye doctor and the things like that, it's ahh, it doesn't, it's not as much as it affects my health, it's more, like that it's super inconvenient for what I'm doing ... honestly you are kind of like, I don't know ... not depressed about it, but ...* LV: *So emotionally it affects your emotional health?* Gary: *Ya, no ... ya, it definitely does. And I've been like, you know, like it's, where it's like, embarrassing and then you go home and it ruins your day. You know what I mean, it's like "that sucked!" And then that feeling transitions to the people around you, sadly you know?*

I asked Gary how his care had been impacted by providers' failure to offer accommodations or alternatives to prescriptive treatments. He replied by giving an example of his discovery of a non-traditional, new aggressive approach for dealing with his spasticity – an alternative to the 'hockey puck' providers pushed onto him 'to make things much easier'. He was proud in describing how he had pursued this approach on his own, without provider input.

Line 115: Gary: *I did, and then when I went to go transfer back I was like ... “I have control!” and I was like able to transfer. It was only for like ten minutes that day but you know, flash forward and now you know, and* [smiling and gestures his body into extension].

Gary’s statement of being in control represented more than having control over his spasticity - but include understanding his own authority to control healthcare decisions through self-advocacy. He ended his telling of this story by saying:

Line 118: Gary: [you have to] *speak up and be your own advocate about these things ... because it’s all important.*

Gary summary: Gary demonstrated a growing understanding that he must self-advocate for accommodations within his healthcare encounters. Across the study period from the initial interview to the clarifying one, a distinct difference can be heard in his words. Whether participating in this study had an influence on this evolution is difficult to say but the progression was striking. However, his enthusiasm for identifying new strategies and experiences of successful advocacy in his clarifying interview exposed an elevated confidence as well as recognition of the positive impact self-advocacy can have within his healthcare encounters. He demonstrated a growing understanding of the power dynamics that providers and society use to control his healthcare, ignoring his individual wants and needs and instead categorize him based on his diagnosis. Gary increasingly recognized his experiences as discrimination that stem from his belonging within the minority disability community, a membership he also appears to increasingly embrace. This embrace of disability identity coupled with an involvement in the disability community was a critical step for Gary to develop increasing agency in healthcare self-advocacy.

VI. FINDINGS

Each of the participants in this study had significantly different intersecting identities, background experiences of living with disability, and health management styles. The research questions were used to organize emergent themes from each individual case into four broad organizing categories to allow for closer analysis of interpretations of experience across the diverse participants. These organizing categories are: recognizing the need for self-advocacy; factors that influence decisions to self-advocate; factors that influence decisions not to self-advocate; and, the lasting impact of experiences. Interpreted meanings identified as super-ordinate themes have a frequency of occurring across at least half (3) of the participants. There are two super-ordinate themes in the master theme of “recognizing the need for self-advocacy”, three in the master theme of “decisions to self-advocate”, two in “decision not to self-advocate”, and two in the master theme of “a lasting impact”. Each of the master categories will be a separate section within this chapter to provide in depth analysis of the super-ordinate themes using epitomizing quotes from participants.

- Recognizing the need for self-advocacy
 - Super-ordinate findings: NODD/providers don’t understand disability and health
- Choosing to self-advocate
 - Super-ordinate findings: knowing what you need/entitled to care/context informs approach
- Choosing not to self-advocate
 - Super-ordinate findings: advocacy fatigue/self-perceived burden
- Lasting impact
 - Super-ordinate findings: lasting fatigue-impact on health/empowerment

A. **Recognizing the need for self-advocacy**

Recognizing the need for self-advocacy is a broad conceptual category that emerged from the research question, “How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?” Each participant described self-advocacy as necessary part of their healthcare experience. Each of the participants interpreted the social structures that influenced choices on construction and equipment design and individual attitudes and behaviors as the broader causes of the status quo. Two powerful participant themes appeared across five participants: normalization of disability discrimination (NODD) and ‘providers not understanding disability and health’. Recognizing that discrimination was occurring, as well as understanding that providers lack the knowledge to deliver care surfaced as primary reasons why participants recognize self-advocacy be considered.

1. **Super-ordinate theme: Normalization of disability discrimination**

Critical legal theory and critical disability theory provide a framework for understanding and recognizing the need to self-advocate for accommodations and for understanding experiences of a person with disability in healthcare encounters. The ADA enshrined into law that PWD are “entitled to the full and equal enjoyment” (§302[a]) of healthcare services, yet discriminatory practices and policies throughout healthcare demand that a PWD recognize when self-advocacy might be needed to receive equitable care (ADA, 1990).

All of the participants in this study described experiences of everyday clinical policy or provider practices that exclude, marginalize, degrade, disrespect, and put them at risk for inadequate - or - incompetent care. Eve related her distress of being trapped in a healthcare setting without access to a bathroom and the response from providers.

Line 343: Eve: *There were no bathrooms that were accessible. The whole hospital! ... I was there for a fractured femur. I was a patient there for 6 days. Was not able to use the bathroom...the bathrooms were not accessible! None of the bathrooms in the bedrooms even in the [entire] hospital. They wanted me to use a bedpan! I'm like 'I'm sorry I can't use a bed pan I'm a quadriplegic that's just way too difficult for me and it's just not going to work'.*

These everyday discriminatory practices are so normalized, participants described providers often do not even recognize them. Tomás' description of a barrier to entry into a medical office highlights how these practices are interpreted by PWD as being exclusionary as well as dehumanizing.

Line 303: Tomás: *This never crosses their mind ... it's something they don't have to ever encounter or ever experience, or ever think about experiencing as well. Number one, who's going to be there to open the door to get into my doctor's office, because there's not an accessible entrance, or door. They have a little side window, so I tap on the side window, and if there is somebody in the waiting room they'll come but if not it takes a while, you know? You know, I have two dogs at home, and when they want in, they sit at a window and they stare. I think about my dogs every time I'm tapping on that side window trying to get somebody's attention, it's like, 'damn, I know how my puppies feel' ... you know? I mean it shouldn't be that way. Doc, get a buzzer here, get a doorbell so I can ring it and have some dignity about it when I'm doing it!*

Lynn coined the term 'normalization of disability discrimination' (NODD) to describe this type of exclusionary practice which resulted from the failure to enforce access, equitable care, and equitable equipment design for PWD in healthcare environments. Participants also identified

small gestures of discrimination and micro-aggressions connected to NODD, explained in the following quotation from Gary:

Line 22: Gary: ... *it was super awkward because sometimes when you go into these situations you're like, you know, you're like 'do you think that I would, if you think that I would ask this if I, ... of you?' It's like making it more awkward just from like the subtle like.... 'uuughhhh' [imitating a long sigh from provide] ... like the little 'huh' [with a rolling of eyes] or like, or kind of like you know, like this [facial expression of imposition] and so, and so they made a deal out of it because they pretty much [are] saying that 'honestly, normally they don't deal with people in wheelchairs.'*

Recognizing NODD was a vital step in having the agency²⁴ to self-advocate. Some participants described, as Tomás does in this passage, that their ability to recognize discrimination developed over time through multiple cumulative experiences.

Line 519: Tomás: *You can see it in their eyes, you see who's comfortable and who's not comfortable, you know? You know I try to be a good reader of body language and you can see it...the eyes tell you so much. Right? And how they approach you.*

How participants interpreted and made sense of NODD appeared to impact behavioral and emotional responses and informed participant's decisions to self-advocate for accommodations. Lynn provided insight into the significant role NODD plays in how providers approach and interact with PWD and how this is experienced by PWD.

Line 670: Lynn: *There are so many things going on in that process of normalizing – and there's um, what's happening from the perspective of the discriminator-there's all kind of*

²⁴ According to Paolo Freire (2000) recognizing one's socio-political economic position of power in comparison to others through reflection serves as a catalyst for development of personal agency.

layers of what's going on with them. And then as the victim of... as the person being discriminated against – I think there's a lot of things behind that realization. LV: yeah, and that decision you make when you decide not to request the accommodation when you believe you should request one for what-ever reason? Lynn: And that is actually the normal response...that 'they' would expect.

Lynn acknowledged how NODD shapes provider relationships in healthcare. The “normalized” approaches in provider practices that discriminate contribute to “normalized” responses from the PWD. Recognizing discrimination is the first step in shifting PWDs perspective from accepting the status quo to the response that is a determined act of self-advocacy agency within the healthcare system.

The lack of physical accommodations in a clinical setting is only an outward indication of institutional policy and practice standards that ignore the needs of PWD in part due to entrenched ableist ideologies. For example, Eve's strong activism background helped her understand the lack of accessible equipment stems from choices made by people within the healthcare system that fail to contemplate her needs as a potential service user.

Line 60: Eve: *It has to do with the designers and the engineers that put those machines and equipment together because you know they're not thinking of the issues like the height and thinking of course of people that might use them like people that are disabled.*

The majority of participants made sense of a lack of accommodations by understanding the layers of decision-making that occur throughout healthcare structures and at times excused immediate providers' failure to accommodate because these too are constructed by upper managerial choices. Tomás interpreted with his keen legal eye, these choices are driven by the

lack of enforcement of the law, complacency with the status quo, and fiscal concerns from the business side of healthcare.

Line 550: Tomás: *Most doctors in healthcare systems and in clinics that I talk to I think, overwhelmingly they are doing cost benefit analysis and that is, and somewhere within the administrative body they know what their legal requirements are under the ADA but again if they're not compelled to do that they're not going to spend the money to get that done... if they're not compelled to comply then why comply? If nobody's complaining.*

Participants also interpreted experiences of provider stereo-typing, prejudices or biased behaviors as representative of these larger institutional attitudes toward PWD. For example, Lala identifies how an organization's culture can nurture and perpetuate negative attitudes, disability stigmas, and provider biases.

Line 90: Lala: *Um, I've actually seen one nurse, they tend to take on the attributes – um, for lack of a better word – of their co-workers. Because I've actually had one nurse up here at [A. hospital]. At that hospital, they didn't care ... they treat their patients really, really, bad. But I went um, I changed to [B hospital] and the same exact nurse was there and had a better rapport – because there they have a better rapport and everything with their patients and everything like that. The whole, her whole attitude changed. And stuff like that and you see that stuff a lot... They take on, they take on the personality of the establishment...it's best to say it like this, the, the less respect they need to give you the less respect they do.*

Normalized discriminatory attitudes and practices within the healthcare system, can have significant impact on PWD. For example, Tomás described how provider attitudes influence treatment.

Line 501: Tomás: *I'm a firm believer in that how you see somebody is how you treat them, and often how you treat them is how they become, at least in your mind, right so? Okay, so [in the provider's mind] the person is disabled and they can't speak for themselves, he's not educated, he's etc. and you'll try to dictate terms and try to be autocratic and not respect what they have to say, thinking I don't know any better.*

Each of the study participants made sense of their healthcare experiences by understanding the lack of accommodations as the norm, the status quo. For example, Marcus while choosing not to label his experiences as discrimination does acknowledge that lack of access is part of living in a world where differently functioning bodies are not integrated into the everyday. Although the same underlying features would qualify this as NODD, Marcus provides a different lens to perceiving the experience.

Line 330: Marcus: *As a person with disability I think you just have to ... you have to ... since the day I was born you know and this has taught me well – it has taught me to advocate. And I think this is vital to be able to self-advocate you know - for yourself because if you don't do it, no one is going to do it. If you don't advocate for yourself, if you don't advocate for an accommodation, if you don't do those things it's not going to happen.*

Marcus recognized the need for self-advocacy but his perspective its causes was unique. Marcus' interpretations for self-advocacy and accommodation requests focused on his role as part of his healthcare team. However, Marcus came to this with a strong sense of collaboration and reciprocity with his life-long providers not shared by the other participants.

Line 333: Marcus: *If there is something I need I can express that to my doctor, and we can work together to figure something out to make that experience a lot better.*

The other participants each interpreted NODD as an explanation for why accommodations fail to exist and why providers interact with them in the way they do. They also identified NODD as a barrier to self-advocacy. Gary's evolving recognition of NODD occurred when he reflects on his repeated exposure to discriminatory providers and how they caused him to see himself as a burden to providers.

Line 445: Gary: *So that just feeds on my you know, cuz, it's like... ok, that [access to a table]... and then the dentist, and then the you know, and you are like ... it's like, kind of a common thing and so then you are like.....man I am REALLY [emphasis] a problem! At least I sure feel like one!*

Participants felt that a conscious recognition of the many factors – including NODD - that create the need to self-advocate is critical to being fully informed in making the choice to self-advocate or not.

2. **Super-ordinate theme two: Providers don't understand health and disability**

Institutional and educational mechanisms that support NODD also contribute to providers not understanding health with disability. Participants describe this directly impacts the care they receive, also making them recognize the potential need for self-advocacy. This is the second super-ordinate theme that emerges when participants make sense of a lack of accommodations and experiences of barriers to healthcare. The majority of participants in this study recognize they might have to self-advocate to circumvent providers' limited knowledge or experience in working with PWD. Only Marcus felt that his provider truly understood his needs as a PWD, having providers who had worked with him for most of his life, enabled collaborative efforts to address his primary and preventative healthcare needs.

Line 210: Marcus: *I actually really trust my doctor, doctors. So, going there is more of a relief for me because they've seen me before, they know my situation and they know what to do when I get there.*

The other participants reported stress, indignity, lack of respect, fear and frustration in provider visits because of providers not understanding how to care for PWD. These participants each shared a description that echoes Gary's impression that: "*you have to advocate so doctors get it right...because most providers have no idea.*" The participants detailed the challenges they faced when providers did not understand health and disability, that resulted from inadequate and uninformed care. Participants described provider's lack of knowledge impacted them physically as well as psychologically. Lala clearly articulated how lack of provider willingness to understand the needs of PWD through ignorance or arrogance – hurt everyone.

Line 385: Lala: *If you don't understand -- just ask me! I'm not - look...I'm not offended, I - I actually would think it's much better if you did then we can have a rapport and everything like that but if you're not and you're just going to um, if you're embarrassed or big headed or whatever you know? But you don't understand ... so instead of getting that understanding you just want to push me aside, then – please, we both lose. We both lose out. You know? Uh huh ...*

This passage highlights a sub-theme within this super-ordinate theme: resisting or rejecting provider authority. Participants recognized a critical factor that drove their need for self-advocacy was when provider authority tried to overrule their own on decisions in care. Resisting and rejecting provider efforts to acquire or maintain authority was a primary reason for these five participants to consider self-advocacy independent of accommodation needs.

To avoid stressful confrontations and awkward reactions from providers in requesting accommodation, Eve and Lynn described the efforts and extra mental work they go through to make providers more comfortable exemplified in the following quotation:

Line 269: Eve: *It's like preparing them is important. I want to make sure that they have the right accommodations because um, learning from the past I know not everything is accessible and I can't take it for granted. I feel that maybe I do or should share some of the responsibility to let them know. Or it's going to be a waste of my time.*

Eve prepared the clinic staff for her benefit as well as theirs by offering upfront information on what she requires for her visit to be a success. Lynn conceded, however, that such extra efforts are not enough to ensure access, and in fact are burdensome and exact a physical and emotional toll on her.

Line 165: Lynn: *Before I was in a wheelchair I always felt supported. I came in, they knew what to do – you know – I really just had to communicate what or why I was there. Um ... it's just SO much more complicated and there's so many layers ... making mental notes for the future, 'what can I do next time' so I can avoid complications.*

The wasted time and the complications these women describe are examples of why participants self-advocate upfront for accommodation needs and what they hope to avoid if deciding to do so. They perceived, from experience, it prudent to assume providers will not understand disability or equipment needs.

A common discussion from participants was what they endured when providers failed to consider different bodily needs. Both Gary and Tomás provide similar distinguishing depictions of the extra demand on their bodies due to a lack of accommodation at their dentist's office.

Line 265: Tomás: *For the first 14 years I've had a chair that was as rigid as the chair that you're sitting in [wooden slatted office chair] ... imagine sitting in that chair and getting that dental work?*

Clarifying interview: Gary: *Sometimes it's just simple stuff – pretend you're me, your [neck is] fused, do you think you could do this [he tilts head way back with his mouth wide open] while they clean your teeth, or would you even put up with having to do this?*

Three participants discussed the lack of knowledge and lack of concern providers have for how to transfer a person with respect for both their safety and dignity when providers fail to attend to participant instruction.

Line 107: Tomás: *Security guards came in and lifted me up. And I said not to lift me, and before I was able to get the – 'don't and here's why' – uh, you know I had these guys grab me from under my arms and my legs and just throw me onto the table...and then I asked, 'please put the guardrails up' but there was no guardrails on the examination table. I told them if I spasm I'm going to fall off the table. Uh, and just everybody left, they just ignored what I had to say and just left. And I did spasm but luckily, I was able to stay on the table but it was you know, you know, just by pure luck that I didn't fall off the table.*

Line 89: Eve: *Most of the time I have to instruct them how to do it. Because they always want to just pick me up from under my shoulders, that's how they lift but they don't realize that I'm paralyzed from the neck down so my legs are not going to...they think they're going to pick me up...like picking up a child where they can just pick them up and then...then there are other factors like spasms.*

Line 75: Lynn: *So now, then I need to transfer. The nurse they promised me would be there, who said she had experience in an ER, which means she knew how to transfer... and [emphasis in voice] she had told me quite a bit about how she knew - when I had come before. She wasn't there that day. So, these other nurses didn't know how to do a safe transfer.*

These experiences created a conundrum for the participants – they know they need to be examined out of their chair – they also realized the real danger of being moved by untrained staff. Participants also described how providers' lack of understanding of disability directly impacted their health. For example, Gary's experience with his hometown urologist is similar to experiences others report when a provider fails to understand disability.

Line 222: Gary: *All it was it was my bladder is so spastic from the spinal cord injury that we just, he just [the new provider] said, 'oh no you just need to double up on the medicine that you're already taking for spasticity' - totally took care of it. You know I mean we were just treating something that - I mean if your bladder is also paralyzed – it's always going to have bugs so you test it and it's going to be dirty and so yes and we came up here [city] and it was like wow, okay!*

In Gary's case, the provider assumed his body was ill, and in need of cure, and thus failed to consider a full range of differential diagnoses. In fact, Gary was healthy albeit in need of a simple solution to support and manage his healthy body. Gary and the other participants learned from their experiences to assess provider knowledge and the need to self-advocate. They recognized that providers' medical authority was a potential barrier to advocacy efforts and health maintenance. Participants felt that their exclusion from primary and preventative

healthcare stemmed from providers' lack of awareness and competence. Participants had a strong sense that providers focused on their disability rather than their health.

Line 192: Lynn: *I see that there's disappointment. They are disappointed because they feel that not walking is...the medical system didn't work. Whereas, in my mind it did, I'm in a wheelchair, I mean my god, I'm in a wheelchair that I work pretty well. But they feel like I've had some disappointing experiences with the medical system because I'm in a wheelchair. That's my interpretation of it.*

Tomás made the most explicit connection on how providers' lack of disability competence caused people to delay care.

Line 245: Tomás: *We, we want preventive care, we don't want to go to doctors only because we absolutely have to, at the point, at that point it's too late. At that point, we're being admitted and we're there for a couple days – in a place where we don't want to be, you know, but so, so if they want us to be consumers of healthcare, in the preventive sense, then this paradigm has to change.*

Tomás recognized structural issues need to be addressed to facilitate this paradigm shift. As a lawyer, he had a unique perspective of the need for practice standards as well as equipment standards. He asked this rhetorical question: *“when is it clinically appropriate to examine me in my chair, and when is it clinically appropriate to examine me outside of my chair where you have to move me?”* He suggests this question is far from being answered but also suggests providers might begin by asking the authority – the client with disability; not as a substitute to medical knowledge but to validate and integrate PWD's embodied knowledge.

a. **Sub-theme: Resisting or rejecting provider authority**

Line 218: Tomás: *I think that in general we're more in tuned to what is going on with our bodies, um, but the problem is that we may know it but trying to convince others that in fact we do know is where the struggle comes in... I, if there's a crease in my sock you know, my foot will start to spasm and I know something is going on, something unusual is taking place and we got to try to figure out what's going on with it, so ... yeah, I think the longer you've had a physical disability uh, the more in tuned to those things um, but again, it's really about trying to convince and tell others that in fact that you know that.*

Each of the participants had a strong understanding of what their bodies need to be healthy. They also interpret that providers' beliefs are informed by medicalization, disability stigma and bias that do not allow for health and disability to co-exist.²⁵ The impact this has can be traumatic. For example, in the following passage Lynn described how the care she receives is acquired at a cost to her dignity and emotional health.

Line 202: Lynn: *The realization that I'm going to the doctor to get better, but I come out often feeling, ok, I'm on the path to getting better this way but now I have to deal with processing and understanding in a healthy way what just happened.*

Tomás offered a similar reflection to the meaning of these experiences.

Line 120: Tomás: *It was degrading, how they lifted me and going against my wishes uh, was degrading, I mean to me it's, they didn't care about me as a person and they didn't respect my preference and I always think why is that? Is it because I'm a person with a disability and the answer is obviously yes.*

²⁵ Judith Butler (2011) questions how social practices such as those in healthcare “uphold the precarious higher status of non-disabled people through processes of rejection” (p. 243).

Eve shared a powerful example about how degrading practices like public stripping (Blumberg, 1994) are institutionalized under the guise of medical education that teach providers that patients bodies, especially those with disabilities, are theirs to control.

Line 126: Eve: *The PAs were starting to undress me and the doctor was in the room with a medical student. And I was like “hey, wait a minute what’s going on here?” And they were like you know, we need to take your clothes off because he’s going to be doing some exams down there or something like that. I was getting upset because they were just undressing me right in front of everybody and in front of him and in front of the student. Without asking me or nothing! Just undress me, they took my pants off, my underwear, everything. I was like so humiliated and the doctor heard me protesting and he um, first of all he didn’t even introduce himself or anything. He just said well if you were in another clinic...or something to the effect that this all should be expected.*

For Eve, these practices were not only inexcusable and disrespectful but represented discrimination against PWD and disregarded their authority of their care. She felt devalued as a person by the provider on the basis of her disability. This diminished status, sensed by many of the participants as second-class citizenship, stripped them of authority over their bodies’ health.

Participants described that providers’ attempts to manage and regulate their bodies were often in direct conflict with their experiential knowledge. The knowledge of how to self-advocate and resist medical authority often takes years of trial and error.

Line 142: Tomás: *I have a routine bowel program like every other night and when I got to the hospital they decided - it was a night where I was supposed to have my bowel program - and they decided to skip it for the night. They decided, so the next night when explaining...LV: Did they ask you? Tomás: No, no, they said it’s probably best that we*

don't....So, they were, they're rationale seemed ok at the time but then on the 3rd or 4th day I was finding myself trying to educate them on the importance of me having a regular bowel program.

Line 384: Lala: *I had the last situation where my levels fell. I was just explaining... please give me a treatment. And they refused to give me a treatment and they said 'well look just go home and will give you a call' and next thing you know I had to go to the ER and my levels was so low that I had to be admitted.*

Line 111: Gary: *I did not want the hockey puck in me. I'm like I don't want this. And I am active, and you know I was doing sports, playing rugby all sorts of things and I was worried it was going to interfere, and all of them told me to do it. They all said, 'it will make things so much easier' blah, blah, blah, and I ...*

The learning process on how and when to resist provider authority was described by each participant but with considerable variations. Gary felt that rehabilitation while a “perfect bubble” removed his authority - or his sense of having the authority - to know what his body required.

Line 105: Gary: ... [The doctors think] *because you're a C5 quadriplegic this is definitely **the** problem. And, and, and so then, me, and they [providers] know I'm uneducated of it [issues with care of body], obviously to their knowledge you know, I've following their guidelines since day one because I have NO idea.*”

Overtime he learned to listen to his body and reclaim authority and control over his body and its needs. He expresses a sense of victory when he described his long-fought battle of pushing back against provider prescriptions for his wheelchair.

Clarifying interview: Gary: *For the last 5, probably the least 5 years, I've been trying to get set up for a new wheelchair and they always tell me “you need this, and you need*

this” At first it was power [wheelchair], and first of all power only makes you fat. You’re not going to gain anything by using power and so, and so I majorly just ... we kept leaving because they wouldn’t give me what I wanted and I, finally when I went back this last time and said, “this is how it is – I’m ten years post injury, I know, I KNOW [strong emphasis] what I want and need and I had, [friend] was with me they gave me the wheelchair set up that I wanted – Finally!

Lala’s story was filled with examples of providers asserting their authority over her, battles she continues to fight. She is frequently challenged by providers’ bias and prejudice formalized through the medical record. Each provider visits is clouded by the judgments and discrimination from past providers.

Line 164: Lala: *Yeah, yeah but I don’t understand, but I have to think he, he’s like, I just guess ... he thought, I just, I think that these doctors just don’t care or don’t believe, because my condition is so rare, ‘oh ya, she’s just’ [a drug addict] ... and I wondering, one thing that stays in my mind because I become apraxic, what if I wouldn’t have heard him? I wonder how many times, this is one thing that stays on my mind a lot, I wonder how many times have I um, not heard this and it went in my record?*

Each of the participants described recognizing their own authority as a pre-requisite to advocacy and vital to their ability to manage their health. Even Marcus, who has had exceptional care providers whom he described as disability allies and knowledgeable in how to offer appropriate care to PWD has had enough exposure to other providers to understand that it is critical to be wary of providers taking over control.

Line 352: Marcus: *Because if you don’t [self-advocate] most doctors are going to just assume what is best for you. They will just assume what they know what’s best for you*

and if you don't say anything "[like] this is my way" ... you have to be able to do this for yourself, it's important.

Acknowledging the connection Gary said: *"Ever since I've taken control of my body ... I feel better."* The participants found provider ignorance more tolerable and easier to address than arrogance and assumed authority. Lynn states it quite simply, *"If you just wait – you know, I can tell you exactly what to do"*.

The ability to control one's body and healthcare was a driving force behind the identified need to self-advocate. The everyday normalized processes and practices of discrimination interact and influence with a lack of provider understanding of disability and health and provider authority over the disabled body. The participants use this knowledge to make sense and give meaning to the barriers they experience in healthcare. They described how any one of these on their own might rouse them to consider self-advocacy. These three distinct themes work to create variable contextual issues that demands weighing the costs and benefits before choosing to self-advocate. Participants' agency in self-advocacy can be understood by exploring the meaning they give to the contextual and the personal variables in the moment and their understanding of the implications of their choices.

B. **Factors that influence decisions to self-advocate**

How each participant interprets what is important enough to self-advocate for varies depending on multiple intersecting contextual and personal factors. Each new experience of confronting a healthcare barrier is informed by past successes and failures in accessing care. Recognizing normalized processes of discrimination in the healthcare system and provider's limited understanding of disability and the impact these have on access to care establishes the background for factors that influence decisions to advocate. Experiences were interpreted to have

different influences on participants' understandings of strategies and reasons for self-advocacy, such as the necessity of having mentoring (Gary) and advocacy as a survival tool (Lynn). There are more similarities than variances across the six individuals in factors that influence their choice to advocate. Three super-ordinate themes were identified related to participants' decisions to self-advocate: knowing what you need; understanding rights to care; and, context informs self-advocacy strategies. 'Knowing what you need' was a shared interpretation across all participants. Knowing what you need is a process of integrating what providers teach and individual experiential understanding of healthy disability - described by Gary as a prerequisite for knowing how to self-advocate in a healthcare context.

Line 469: LV: *So how do you describe um, or how would you define self-advocacy for yourself or generally?*

Gary: *um.....I mean, just know, know what you need, and know the best way that someone can help you with it. Right. I mean it's simple because it goes, it starts off with the things they embed in your head when you are injured from day one, where when you go home you need to advocate for, with, your caregivers and how they can take care you, you know, until you can do it yourself, and so, you just, I think it starts with that really. And then ... be brave, and you know, I don't know... that's hard, that's hard. Especially when I can't even, I can't even advocate really for myself.*

His phrase to 'be brave' suggested that for Gary, advocating to caregivers required a level of fearlessness and confidence he was unsure he possesses. Gary had to learn what he needed for his health, that advocacy is a vital component of self-care, and that inter-dependence is a necessity of life.

For many of the participants, advocacy was motivated by more than a need for accessible equipment or access to services. Participants frequently reported choosing advocacy to confront a lack of respect stemming from provider prejudices and discrimination during healthcare encounters. Eve's definition of accommodation exemplifies the critical importance that threats to dignity have as a catalyst for advocacy.

Line 497: Eve: *Accommodation also is ... it can be the attitude of both the physician or technician that is present – that is showing me respect in a way that while yes, I'm a person with a disability but I also expect respect and deserve the healthcare just like anyone else, so I would like to be treated in that manner.*

1. **Super-ordinate theme one: Knowing what you need**

Knowing what you need to maintain and manage health is a life-long process. Participants learned through observation, through exposure to role models, and through trial and error. Even when participants knew what they needed they reported challenges to convincing providers to listen. As described by Tomás:

Line 141: Tomás: *... then it took a significant amount of time for me to convince him to initiate an intervention immediately cuz my blood pressure was shooting up and I knew what was taking place.*

Paternalistic power structures within healthcare can be challenging to confront and can make participants/PWD second guess themselves. For example, Gary was relatively new to self-advocacy and described the impact that provider authority has in diminishing the process of becoming his own expert.

Clarifying interview: Gary: *When they recommend something, and refuse or rebut you all it does is remove the progress you've made to be in control over your own body ... making you second guess or be less confident.*

This statement underscores the importance of Gary's confidence in knowing what his body needs as a prerequisite for him to be able to self-advocate for those needs. Gary wavered between advocating for what he intrinsically understood he needed and listening to his provider's expertise. In contrast, Tomás displayed a confidence and understanding of when and how to self-advocate.

LV: *If you're in a situation where you're in the room by yourself and the doctor's saying I think we should do this and he is potentially has a bias against PWD, and you just feel bad and are anxious or worried, do you think you could get yourself in a situation where you'd be vulnerable [not advocate]?*

Tomás: *No, I would never put myself in that, I'll fight at that point it's not to the point where I just abandon all sense of self-advocacy and defense and allow them to do what they think is right for me. I'll raise my voice selectively, but on some things, I just won't push it.*

Other participants described how acute, in the moment needs, pushed them to strongly advocate when providers failed to provide accessible care.

Line 127: Marcus: *And we're really trying to get my legs on here [into MRI] and at this point I'm kind of in pain, cuz of my legs are being stretched out more than usual and so – they finally got my legs on there...we manage to get them on there...the problem is my legs...I'm like in more pain and you know I finally said we're not doing this ... I can't do this.*

Line 81: Lynn: *They start anticipating what I need... not even saying how about I go here? ...I have very poor upper body balance – so then I had to raise my voice and say “STOP –I’m going to fall!” [in loud voice].*

Lala’s experiences were unique because of her history and forced institutionalization created a sense of urgency and a strong commitment to decisions of advocacy.

Line 212: LV: *Are there some situations where you’ll just be like, I know I should advocate for myself but I’m just not going to do it today?*

Lala: *No, I, I, it would be a situation where I am so frustrated where I, I, but, I may cry as I advocate but stopping, uh uh, no because like I said, you know...?*

LV: *What do you risk if you don’t do it?*

Lala: *Like, not getting the proper care, going back to the nursing home, just not, not having whatever needs met, whatever medical needs that I have not being taken care of because, having to be sent right back and just becoming worse worsening, uh, uh, just worsening. Like I say, I have to advocate you know, for myself, I don’t care, physically, I have the right. Because ‘you will understand’.*

Many participants described the need to self-advocate to counter treatment decisions based on stereotypical and/or incomplete understandings of their disabilities. For example, Tomás’ rejection of providers’ expertise is revealed in his description of outliving his prognosis.

Line 685: Tomás: *When I was injured it was explained to me that life expectancy for people with spinal cord injury of mine which is C5-C6 is maybe 15 to 18 years post injury. So, and here I am, at the 23rd [year] and I consider myself to be very healthy, very healthy, and I don’t see my spinal cord injury as affecting me or detrimental to my health on a daily basis. It makes me vulnerable to certain things, like I’m more readily to catch*

a cold or catch pneumonia than anyone else is um, but, again I consider myself to be healthy so I don't know who came up with these life expectancy clocks. It bothers the hell out of me, and every 5 or 6 years they revise that.

Tomás' statement emphasized an unwavering pronouncement of his health - as he understood from experience few providers would see him as healthy. Gary recognized the dangers of this prognostication as well.

Line 102: Gary: *Um ... well I feel like that a problem a big problem with things in the hospital experiences that I've had ... is they're always like clumping everyone together, right? So, so when I was having these problems with whatever, spasticity, and blah blah blah, it's like, like, they're like, well... because you're a C5 quadriplegic this is definitely the problem.*

The commitment to having providers understand their individual needs in order to determine appropriate care plus their individual rights to accommodation was voiced across all of the participants. Marcus and Tomás described choosing self-advocacy to educate providers of their specific care needs but also as an approach for exposing NODD and stressing the rights of PWD to equitable access.

Line 388: Marcus: *I understand that for certain situations I need to ask for an accommodation and like I said, if you don't ask they don't know... they won't know what to do. You know? So, being able to talk to my doctor about what I need ...*

LV: *Yeah, you're not just your diagnosis?*

Marcus: *Right, about what I need, so he understands what needs to be done and then he can take that experience and sort of, if he's got another patient with disability, it might be*

different but at least he has a better understanding of how to handle, how to handle himself in that situation. You know?

Line 165: Tomás: *My primary doctor was on vacation and I was there for an annual physical examination. Um, and he was examining my neck and head and then he looked at me and said “So, I assume everything below the waist is good?” ... don’t assume that, please don’t assume that, get me on the table and do a proper examination. So, it’s like what are these guys thinking?*

Many of the participants described advocating for provider respect as an approach to rejecting the discrimination stigma they experience in healthcare. The participants learned this was vital to their own health and wellness but also part of a broader resistance to accepting established patterns of inequitable healthcare provision. Eve’s strong identity as an advocate for the disability community was spurred by personal indignities she has experienced.

Line 377: Eve: *I knew that this had to happen I said, NO! This can’t be! When I found out about the bathrooms, that none of them were accessible. And then, oh my god, I was like no way! Come on! It’s unbelievable, I couldn’t believe it this has to stop! It’s bullshit.*

Line 513: Eve: *I speak up for my rights, especially when I know I am being wronged, violated, intimidated or disrespected. I am going to speak up, I will do something about it and I am not going to endure any kind of humiliation or discrimination.*

Eve described in this passage how her confidence in advocacy was supported by her knowledge of her civil rights. She used knowledge of her civil right as a tool to support efforts to expose indignities and injustice by providers. For Eve, one of her needs was being treated with respect – the respect she believed was lost because of provider bias and disability stigma. She also

understood that without laws to support her claims for equitable care she would receive neither respect or care.

2. Super-ordinate theme two: Understanding rights to care

Experiences in healthcare have taught the participants to understand that their recognized healthcare needs may conflict with provider's perspectives. This was a major factor in having agency in self-advocacy and confidence to make accommodation or access requests for each of these PWD. Having an understanding of rights to care and how to incorporate this knowledge into advocacy efforts was another important factor for the majority of the participants. Physical access and access to medical services for PWD is legally required in the United States (United States Department of Health and Human Services, 2010). Tomás was convinced that within healthcare systems this knowledge exists. Tomás: *"Somewhere within the administrative body they know what their legal requirements are under the ADA"* (Line 504) yet failed to implement this legal requirement. Participants interpreted this failure to comply as indifference.

Line 33: Lala: *Instead of making accommodations they're like 'well look, you have to try to get on here' and they don't make any type of accommodations and I felt, like, embarrassed and everything and then I became upset and I'm like, look, you need to make some type of accommodation ... they just don't want to help at all.*

According to Eve, the disability community has some of the responsibility to make providers and healthcare systems care.

Line 70: Eve: *You'd think that they would be thinking about the people that can't stand and think ahead like that but they're not.*

LV: *Why?*

Eve: *Maybe because they just don't care? And maybe because we're not voicing our needs as much? Because we don't speak up and say anything when it is important. But there are very little of us that are experienced and we're not saying anything. So, they get away with it.*

Lala recognized that provider power and authority can smother a person's confidence to speak up against the injustices.

Line 235: Lala: *I hear a lot of people saying, you hear people talking about becoming intimidated you know and everything, and I'm like here, you have a right to this. Many people don't know their rights and stuff like that.*

While many of the participants felt providers' failure to care and lack of understanding made civil rights invaluable for PWD in advocating for their needs. Marcus, however, described a strong allegiance with his providers who attend to the civil rights of PWD.

Line 419: LV: *Do you think that the ADA influences providers in how they work with you?* Marcus: *How they work with me? I would say yeah... I think, I think most definitely, I think the people that I see, have a real understanding of the ADA. So you know, because, they're a part, even though they are a part of like, they are doctors, they are... they, interact with the disability community. So, they know, okay, they understand the ADA and even fought for the ADA.* LV: *So, most of your providers, do you believe that they are fellow advocates?* Marcus: *I would say so. Yep.*

Line 433: Marcus: *So, I'm grateful that some of my doctors, they are a part of the disability community. They are not disabled per se but they work within the disability community and they have an understanding of sort of the, understanding our needs in terms of accommodations.*

Marcus' experience with providers is a stark contrast to Tomás' sense that stigma of disability emanates from his provider.

Line 501: Tomás: *Okay, so [in the provider's mind] the person is disabled and they can't speak for themselves, he's not educated, he's etc., and you'll try to dictate terms and try to be autocratic and not respect what they have to say, thinking I don't know any better.*

Participants in this study defy these stereotypes as most had a firm grasp on the knowledge and language of their civil rights to access as well as the specification recommendations for equipment standards from the U.S. Access Board. This knowledge was powerful but participants described using caution in how they use them. Lynn described how she uses the language of the ADA versus claims of legal rights to access, to help her work with providers without putting them on the defensive.

Line 493: Lynn: *It seems to me, maybe it's different for others but the ADA, citing the ADA is not too effective. Now... I will use the language of the ADA, to sound intelligent, right. To be assertive, it helps me to be assertive to know the language of the ADA.*

LV: Is there a specific part of the language you find especially powerful? Lynn: Well the general right to accommodation, sometimes I'll bring that up gently. Cuz that's what works for me right now. Like, well ... 'You do know that the law does require that we be provided equal service, I mean that's just fairly common knowledge.'

Tomás echoed these statements and raised concerns that forceful claims of entitlement to accommodation can backfire.

Line 705: Tomás: *Right, self-advocacy is NOT [emphasis], is not necessarily, you know, 'the ADA says this', 'the Rehab Act says this', 'you have to do this, because I know what my legal rights are' - that's not self-advocacy. That's trying to forcefully, you know*

educate someone who might otherwise have been receptive to you, but the approach makes a difference. So, um, but self-advocacy when done right it works, it helps you get the things addressed and you feel better as a result of it.

These advocates recognized the importance of knowing how, where, and when civil rights information should be used in self-advocacy. They also discussed how this knowledge should be shared with individuals newly disabled. Eve stressed the importance of a disability mentor in the process of assuming agency in self-advocacy. She believed members of the disability community should be the leaders in disseminating the knowledge on rights to access and accommodation.

Line 224: LV: *Do you think it's important for PWD ...maybe even early in their acquired disability to ...do you think having a mentor who is an advocate is a critical thing for becoming a self-advocate?* Eve: *Yeah, cuz if you don't know anything about advocacy who better to learn from than a person who has been there and done that?*

Growing up with a disability, Marcus had little exposure to disability rights and advocacy strategies. He discovered disability mentors at his local CIL and attributed his capacity for knowing how to speak for himself as stemming from the exposure he's had from this community.

Line 402: Marcus: *So, when you come out of there, when you come out of [CIL] you understand ok, as a PWD you have a right to an accommodation, you have the right to speak to your healthcare provider about an accommodation. You have those rights and once you understand that you can go into an office and you can just, you know exactly what to do and you know exactly what to say.*

Tomás considered the timing of introducing the ADA and other civil rights to those with newly acquired disability. He reflected that this knowledge is critical to self-advocacy but also part of the process of embracing a disability identity.

Line 714: LV: *Do you think that ... that when people are newly injured you know at (hospital), that um, patients aren't ready to hear that stuff? [disability rights/ADA] That you know if you want to try to expose them to their rights so that they have some level of knowledge to self-advocate that they don't want to hear about their disability rights because they're, they don't think they are disabled yet, they're not there yet. Do you think that there's a period that is inappropriate or too soon I mean? Can you comment on that issue?* Tomás: *You know, there's some merit to that. For the longest period of time, I mean it took me years to get my arms around the fact that I'm a person with disability um, so and, but, but I think it is important when somebody is injured early on, when they are still at the [hospital], trying to rehab from a spinal cord injury that they know that there are bodies of laws out there that protect them and when used, or complied with, is going to make their life better on a daily basis. Expose them to the law early, by letting them know look, you know when you're ready for this there's some things out there that can really help you.*

A few of the participants described educating providers on their failure to accommodate as the sole reason for making their request. They choose to advocate for accommodation to make a point of the injustices they endure because of provider failure to offer accessible medical equipment.

Line 416: Lynn: *All I can think of is the need to be weighed. I request it, although I know I'm not going to get it, I just want it to be on the record. 'Here's another request for an accessible weight scale' and I hope it adds up somewhere.*

Tomás echoed advocacy's role in achieving meaningful system change.

Line 242: Tomás: *If nobody is insisting on their rights and if we continue to enable them by doing or ignoring it or bringing somebody else to do what they are supposed to, do then they're not compelled to comply and if they're not compelled to comply then why comply? If nobody's complaining.*

In spite of physical and emotional demands of self-advocacy, participants' commitment to the disability community as a whole motivated them to continue the fight.

Line 438: Lynn: *You are weighing other considerations as to whether you can speak up at that time and what the consequences are....and it goes back to why we have to do this.*

3. **Super-ordinate theme three: Context informs self-advocacy strategies**

This super-ordinate theme emerged from five of the six participant interviews and commands discussion because of the powerful yet subtle meaning behind the interpretations of how contextual factors influence their self-advocacy and their approaches. Participants described the considerations and methods used in managing some of the contextual factors identified as influencing decisions to advocate. Within this super-ordinate theme there are two sub-themes: respectability politics and the influence(s) of significant others.

a. **Sub-theme one: Respectability politics**

Professional and social dominance of providers over people with disability called for the participants to be critically “attentive to how it is perceived” (Kennedy, 2015). The disability community has critiqued the medical community for the oppression and discrimination

they continue to endure. Four of these participants describe being keenly aware of provider perceptions on a one-to-one scale and sensitive to the negative stereotypes that providers associate with PWD in their healthcare visits. Participants' interpretation from past encounters taught them the importance of incorporating strategies to preempt the negative stereotypes as part of their effort to access care. Lynn used subtle ways and Eve more overt, to counteract disability stigmas, and heightened collaboration and team work within the healthcare visit. For example, Lynn understood that her demure personality might be mistaken for passivity and submissiveness in provider visits. She was conscious that these behaviors are linked to disability as well as to feminine stigma and sensed provider authority might be reinforced if she 'allows' her shyness to surface. Instead she prepared for healthcare visits in order to project confidence and control, a role she resented having to play.

Line 640: LVP: *I get a sense from the conversation that you have learned over the years to be a self-advocate, to be in control, I love that concept that you have learned...my interpretation... you have learned to be in control as a tool that you use.* Lynn: *It's a survival tool...I can't, I cannot be passive or show that I'm uncertain, even if I am. It's a performance, is what it is. Even if you don't feel like performing it's a performance and I wouldn't have learned that if I didn't have to learn that.*

Her preparedness includes notes she used to ensure she addresses her concerns but possibly as props to demonstrate her authority.

Line 107: Lynn: *The doctor was very rushed. I had my notes so I knew what I needed to cover that day so...but he was in such a hurry he took the notes from me...like, "let me see what you have" and I said, "Ah ... no, those notes are for me [chuckled to herself].*

Eve was sensitive to other disability stigmas that providers may have toward her and is careful to avoid any image that might link this stigma to her during provider visits.

Line 465: LV: *Is there a higher standard for PWD to look, um, put together?*

Eve: *Oh yeah, presentable. To look decent. Cuz, if you don't they're going to think you are just some homeless guy downtown. Looking for a quick fix.*

Eve was conscious that her physical appearance can support disability stigmas she believes exist. She also avoided behaviors that could be interpreted as being belligerent or the 'angry cripple' or 'angry feminist' and thereby dismissed.

Line 235: Eve: *Because anybody can be a loud mouth and walk around and yell out things with a stick but who's going to hear you? Is it going to accomplish anything? I think um, there's a way there's a way to um, there's a way to get things done...the right way, the appropriate way.*

LV: *What way is that?*

Eve: *Well, for example, like what I did. Instead of barging into the office and yelling or coming out of that clinic and yelling and cursing and barging into his office and making a big deal out of it. I don't think it would have worked in my favor to behave that way. As well as doing it the appropriate way like writing a letter to get his attention. Not only get his attention but to let him see that I am a person I am not just a nobody, but I'm an educated woman and I felt at the time I was disrespected and I was overlooked as a woman with some knowledge and strengths.*

Eve approached her advocacy and complaints of wrong doing in a respectful yet forceful and productive manner. Her activism efforts and the outcomes of these type of efforts have taught her strategies that lead to permanent changes in policy and accessibility. Eve: *Yeah, I felt good, I felt*

proud of myself ... yeah, I felt powerful. Because I made changes, I know they made changes in that clinic. Line 180. Her decisions to strategically approach her self-advocacy in a respectful manner is used to achieve access but also to achieve her other needs – respect and dignity.

b. **Sub-theme two: Influence of significant others**

Tomás and Lala described a deep understanding that significant others can influence provider behaviors and increase the chances of accessible and equitable care. However, they purposively choose to remove or exclude significant others in contexts of healthcare decisions-making to ensure that provider respect their authority in their care decisions. Tomás described the challenges he assumes by attending provider visits without his family, but also his hopes of what it will accomplish.

Line: 290: Tomás: *I don't want to be dragging my family there simply to help me out for that convenience so ... it's not fair to them, it's not fair to me, and ultimately, ultimately if all I do is, is lean on my family and others and don't have the doctors and the nursing staff do what they can do and should be doing then it's going to make it more difficult for me the next time, um, -- and --- it's going to make it difficult for someone that comes behind me that doesn't have the voice or the strength to speak for themselves.*

Tomás understood provider visits will be completely different with his family present. While things may be easier in the moment Tomás risked his authority in that encounter and future visits. Lala describes her perceptions that providers were more attentive when others are present, although she questioned the sincerity of their attentions.

Line 370: Lala: *I see a big difference though when I have someone with me, like say I have a friend with me. You know that amount of respect that they think that they will give*

me. Cuz they're going to give me my respect but they try to give me [shows a tiny sign with fingers and thumb].

While participants valued the support, they were cautious that it not distract from their authority for their care.

Line 371: Lala: *Like I said when my brother was there and my friend...they were like do you need me to speak, and I'm like no no, here you go to the cafeteria, look, I'll handle this. And then they actually try to over talk me to them. And my brother is like 'look, look she's right here' ... Right, I'm glad you know brother, you tell them...good brother.*

Marcus described that becoming his own agent in self-advocacy required that he go to visits without a significant other.

Line 341: Marcus: *It was a long process but I can speak for myself when I'm in a doctor's office I can actually speak for myself you know? LV: How did you learn that?*
 Marcus: *Just being able... going by myself you know, because most of the time when I was going to the doctor appointment my mom was there with me or somebody else was with me.*

In contrast, Gary recognized after years of self-advocacy attempts, support from an ally might enforce his authority.

Line 513: Gary: *I went back this last time and said, "this is how it is – I'm ten years post injury ... and I had, Amy [therapist] was with me they gave me the wheelchair set up that I wanted – Finally!*

Gary understood by having a former therapist join him – not to speak for him but simply be present – would affirm the seriousness of his request. Gary's strategy of manipulating the

contextual factors of his self-advocacy efforts ended with achieving his personal health goal by including a significant other.

These participants understood the effects that a significant other can have on self-advocacy. In the process of gaining agency in self-advocacy, understanding the factors that can impact that agency – either in removing it or reinforcing it – is a skill that these participants have learned over multiple experiences of advocating for access to healthcare. Choosing to self-advocate is complex and requires understanding what you need; benefits from developing an understanding of rights to care; and, understanding and possibly using context specific strategies. These participants describe learning these through exposure to the disability community, mentors, and in their own lived experiences of self-advocating for accommodation in healthcare.

C. **Choosing not to self-advocate**

Equally important to making the decisions to self-advocate were participants' conscious decisions not to self-advocate. What became obvious from participants' interpretations was the importance of understanding their agency to choose not to self-advocate. Deliberation of self-advocacy choices aligns with a more self-determined disability community embrace of self-advocacy versus a medical model prescription for demonstrating self-advocacy skill. The factors informing decisions to not request an accommodation were diverse across the participants including: avoiding care to protect self, understanding the social model helps, and a lack of strategy or knowledge. However, two super-ordinate themes emerged from participant interviews that influence decisions not to request accommodations or self-advocate: advocacy fatigue and a self-perceived burden to providers when making requests.

1. **Super-ordinate theme one: Advocacy fatigue**

Griffin-Basas (2015) calls the need to continually request accommodations *advocacy fatigue* and suggests this state “diminishes emotional and physical health” due to “ongoing exposure to stress and discrimination” (p. 1). Although only three of the participants described this state as directly impacting their decision not to self-advocate or request accommodation, these decisions are powerful and extend understanding self-advocacy decisions. Interestingly, these three participants had the longest histories of disability activism and worked within the disability community on issues of healthcare access.

Tomás acknowledged the irony he, and other participants saw with the need for advocating in healthcare settings.

Line 205: Tomás: *When I first got injured and getting out of the (hospital) and then going to different doctor's offices and clinics, eye care clinics, and dental clinics, I, I thought I'd be at home, that I'd be welcome and that you know, that - this is the one segment of the population that would get [emphasis] me! And that is certainly far from the truth.*

Lynn was matter of fact in her understanding of her decisions not to advocate.

Line 318: Lynn: *I'm not going to keep asking the same clinic for an accessible exam table when I know they don't have it. So, then I just don't ask, I don't. One example is I did not, I haven't had a gyn exam for probably 15 years. Because, just the issue of the exam table.*

She understood the drain advocating has on her and used this knowledge to selectively focus her efforts realizing the potential cost to her health.

Line 264: Lynn: *This whole thing is very draining on my energy. And I have limited amounts of energy period as it is without going to the doctor. Even when it's not too*

stressful but I have to be in charge, I have to go in and dictate what everybody should be doing it draws a lot on my reserves.

She expressed concern for those areas of her health she elects not to advocate for reflecting on recent friends' experiences with health scares.

Line 364: Lynn: *So, I convinced myself, I know the risk factors, I don't have those risk factors, but ultimately you do need to make sure things are... everything is going ok... with hormone changes and you never know. And so, I avoided demanding it for a long time.*

The words Lynn used to describe her decision to not advocate – ‘*avoided demanding*’ - exposed the effort she sees that would be necessary to receive this care, which creates an overwhelming sense of fatigue. Eve used a similar description of advocacy fatigue, resigning to the context that excludes accessible equipment and prevents her from receiving necessary care.

Line 301: LV: *Why do you think providers say they can't provide you with an accommodation?* Eve: *I think she just ... I don't know.* LV: *Do you think she felt bad?* Eve: *I don't think so, I just think that she just, cuz I asked her, I told her, I can't get on that table without assistance. Is there anybody to help? 'No, it's just me', and I don't think she really cared. She didn't care and at that time I guess I didn't really care either. I'm not going to force her to ... I can't make her help me.*

Eve's expression of fatigue came in a healthcare setting without equipment or trained staff that she's confronted in the past. Participants described the emotional impact of fighting an inaccessible system.

Line 419: LVP: *How does this make you feel, does it impact you emotionally?*

Lynn: *It's discouraging, again it's a reminder that I'm abnormal and that the accommodation is seen as something special. Not as a right. And it can be frustrating.*

Line 265: Tomás: *It's frustrating ... knowing that I have to go into a situation where I know I have to advocate for myself the minute I get through the door uh, creates a level of stress that I think should not be there. It creates a level of anxiety that I think shouldn't be there.*

The overarching cause of the advocacy fatigue appeared to be the never-ending demand to advocate across clinical experiences.

Line 209: Lynn: *It's frustrating because I've had that experience too many times so that there is an additional level of discouragement, like 'here we go...this again!'*

The need to continually enforce their rights to accommodation exhaust even these strong self-advocates and instead they choose to conserve their efforts for a time when they believe it more critical.

Line 317: Lynn: *So, I haven't been able to get on an exam table for I say ten years, but I think it's much longer than that. I don't insist on it. If I go in with an upper respiratory issue, it would be good to be able to get onto the exam table and just have some other things examined because I'm there but I'm not going to insist on it if that's not my main goal...something that doesn't require it. So, it's the urgency of need. And then it's the likelihood of getting it.*

These participants made judgements based on an assessment of their health concern, the probability of accommodation, and their own emotional and physical capacity to confront the discrimination in the moment to request accommodations or not. The ongoing need for this

determination impacted the quality of the care and produced stressors and emotional responses that likely impact their health as well.

2. **Super-ordinate theme two: Self-perceived burden**

Five participants of this study interpreted experiences when accessible equipment or accommodations are not readily available as creating extra effort and work for themselves as well as for the staff. They recognized that if providers lack understanding, training or resources on how to implement the accommodations, the demand on both parties multiply. Perceptions of being a burden have traditionally explored the relationships between long-term care givers or family members and persons in palliative care (McPherson, Wilson, Lobchuk, & Brajtman, 2007). The five individuals in this study who made sense of their accommodation requests as being a burden, direct these perceptions to healthcare providers including technicians, nurses, and office staff. These participants described feelings of guilt, responsibility, and concerns for repercussions in care when “asking too much” of providers. For example, Marcus rationalized away his need for accommodation.

Line 189: Marcus: *From time to time I do sort of... you know ... sometimes I don't ask you know, sometimes it's you know ok, in my mind this is simple, I don't need none of this and I don't ask.*

Some participants perceived their own inability to adapt to their provider's way of approaching them as cause for not advocating.

Line 308: Gary: *I feel like again, it's hard for me because I don't want to be a problem, I don't want to be an issue in any situation, and I know that I would just be asking for a simple thing but you're really inconveniencing them, is how I look at it.*

Marcus conceded his need for accommodation based on his assessed reality of the healthcare clinic.

Line 65: LV: *So, when you see your primary care doctor you're always seen in the chair?* Marcus: *Yes.* LV: *Do you ever feel like that is inadequate?* Marcus: *Not really, because, being on, getting on an exam table is pretty rough for me.* LV: *Well you would need then an accommodation?* Marcus: *Right, but I think they way, the way that the room is set up it's kind of difficult to do something like that you know?*

Participants indicated that these perceptions stem from systematic and normalized processes that mark their differentness (Phelan et al., 2014). Differentness created because routine access to healthcare equipment makes it significantly more difficult for providers to offer appropriate care in an equitable manner to PWD.

Line 192: Marcus: *It's hard to ask because you have this fear that you might get rejected or like you say you might...you feel like you're being treated differently.*

The failure to have readily available accessible equipment also creates scenarios where safety risks for staff were considered but the result was that their concerns as a patient were neglected.

Line 313: Eve: *I have felt like a burden like ok like I'm a challenge, 'How are we going to get her on the table, how are we?' ... which you know it's, I guess a legitimate thing for them to be concerned.*

Lynn empathized with the providers as she analyzed the context and what a request would mean, convincing herself not to advocate for her own interests.

Line 332: Lynn: *They are so uncomfortable, they aren't trained to do it. These are nurses, their bodies are being put under strain period. And so, their stress I can feel from*

them not knowing what to do and being afraid for their own safety. You know, I feel that and that helps me, in somehow and way, not just the exam table but – I know they say they could get me on it but – ohh...[shrugs] there's that too.

The participants demonstrated a learned understanding of what their presence might mean to the workers within a healthcare context that evolved from an ability to read perceptions of staff as a strategy to inform their self-advocacy decision.

Line 54: Eve: *I feel like I'm a burden to them. You know like this is just I'm putting them out. Like it's like, oh god, I'm more work for them. I look at them and see them look at us like oh man, now we have to really work and help these people. We have to lift them and ya, you know?*

Participants described different methods for accommodating providers – versus being accommodated – to minimize staff efforts, reducing the demands created by a lack of equipment and reducing their sense of being a burden. Lynn's efforts were in the form of reaching out to providers to educate them if they are receptive.

Line 476: Lynn: *I use methods that work for me. Offering to help, telling them what to do if I know what to do seems to be very effective especially with people who are unsure of what to do. You know I try to be understanding - and some would disagree with that. You know because this is a right and some would insist and be more demanding but for me I put myself, I try to put myself in their shoes, in other words what if I was completely unfamiliar what to do with a certain person, you know a person with whom I have no familiarity with, and I'm bound to stick my foot in my mouth and you know so I try to put myself in those shoes. That works for me. Understanding, I don't think a patient should be required to be understanding of their providers but it works for me.*

Tomás described the lengths he would go to positively impact his provider visits by lessening the perceived burden he produces.

Line 281: Tomás: *I tried for the longest time to schedule my doctor's appointments in the summer time. Because when I go in the winter, when I leave my house I'm bundled up, to be warm. When I leave a doctor's office, there's no telling what condition I'm going to be in...to minimize the things that staff has to do with me, I try to get my appointments all in the summer cuz I know I'm not going to need help getting dress, undressed, etc.*

Further, he detailed a winter visit when his decision to not request accommodation resulted in a detrimental outcome for his health.

Line 350: Tomás: *So, I opted to get examined in my chair while I had every single layer of clothes on and I knew better that I should have asked them to take it off and relied then upon them to get me dressed. But again, it was a concern, that they wouldn't do it correctly, I, and sometimes when staff comes in to help you out, it's in a rush, it's, it's, they're not listening to what you say you know... I had to lift up my coat, and he went under but not under the sweater, he just listened to my chest and my back that way and that, that's just a minor issue but again it's something, I deliberately decided not to ask because, I don't know what condition I'm going to be in when I leave. LV: Do you think that decision not to take things off landed you in the hospital? [with pneumonia] Tomás: It could have it definitely could have. Definitely could have, yep.*

Tomás has the knowledge of his right to request and is skilled in using the language to enforce his right to appropriate care, however, he chose not to request an accommodation based on concerns for how his care might be negatively impacted if he's perceived as being extra work or burden.

Line 313: Tomás: *Um, but look you know, I don't want to [emphasis] upset my doctors.*

Because if I think my care is substandard now, what happens if I complain and so I can't complain, I have to educate.

Tomás, like Lynn, has strong efficacy for using education as an approach for requesting an accommodation although at times their capacity for this method is reduced, influencing choices to not advocate. These experiences and those of the other participants – of self-perceived burden to providers – are interpreted as directly influencing decisions not to advocate for accommodations. The absence of readily accessible equipment places the onus on the person to overcome perceptions of responsibility for having to ask providers to do more, and at times the participants forego their own health needs to avoid this sense of burden. Decisions that can have a lasting impact on people's health and well-being.

D. **Lasting Impact**

This organizing category emerged from the larger research question, “*Do PWD attribute needs to recurrently request accommodations due to access barriers in healthcare as impacting their current or potential health capability?*” Interview questions relating to this research question asked participants to describe their perceptions of the physical, mental and emotional health impact of needing to self-advocate for accommodations – on the disability community as well as specific to their own health. As in the other categories individually unique themes and sub-themes surfaced in participants' interpretation of the health impact of experiences of advocacy decisions. For example, because of his unique focus at targeting healthcare institutional disability policy through civil rights cases, the theme of ‘seeing change happen’ emerged in Tomás' interview represented by an epitomizing quote “*you know it's starting to change but we...there's still a lot of work to be done.*” With Gary's developing understanding of the need to

self-advocate an emergent theme under the organizing category of ‘lasting impact’ became ‘developing disability & health identity’.

LV: Yeah, do you think that... like, this is important stuff because it does all build up and impact you to the point where it's like, um, feeling like... 'I don't want to say anything because I'm hoping that they'll just keep seeing me'...I don't know if that's what you feel when you see a doctor or something...you know?

Gary: Yeah, [subtle laugh] I don't know, it's wild when you are saying it out loud, I'm just like man... shi....., and it's sad, cuz I'm ten years, I was ten years out like three weeks ago, so... but I feel like, but, I would go, if I would go to another doctor, and it was something, like, I would still, even after ten years I would just do whatever would be the easiest thing for THEM. Right?

Despite this statement, Gary's sense of authority and agency for self-advocacy appeared to be evolving. His response to the interview dialogue and experience of reviewing his transcript appeared to spur his awareness of provider discrimination and presumptions of authority over his healthcare. In his clarifying interview, Gary had several new stories of recognizing injustices in healthcare - his own experiences and those related to him by peers.

Clarifying interview: Gary: My own doctor, my [emphasis] doctor told a friend of mine, a quad who uses a power chair who wants to try to use a manual, and the doctor says to him "I will not support you in your decision" ... can you ... can you believe that?

Gary reflected on his battle – drawn out over years - with this same provider in his request for a manual chair. His disbelief may be due to a dawn recognition that his was not an isolated experience but rather part of a system of discrimination and disempowerment of PWD by provider authority.

Although individual differences exist, two strong super-ordinate themes emerged from the category of ‘lasting impact’: impact on health; and empowerment through agency in self-advocacy.

1. **Super-ordinate theme one: Impact on health**

The descriptions of advocacy fatigue as a factor influencing participants’ decisions to not self-advocate was associated with an ever-present sense of emotional drain experienced when visiting providers. Lynn explained that with every provider visit the memories from past negative encounters invoked anticipatory anxiety and fear.

Line 173: Lynn: *So, there’s kind of a dread that I carry with me when I go to the doctor, um, about just attitudes.*

Lynn also described how discrimination she experienced negatively impacts her self-image.

Line 419: LV: *How does this make you feel, does it impact you emotionally?*

Lynn: *It’s discouraging, again it’s a reminder that I’m abnormal and that the accommodation is seen as something special. Not as a right.*

Gary echoed Lynn’s reflection on how healthcare experiences stay with a person long after the actual visit.

Line: 411: LV: *So emotionally it affects your emotional health?*

Gary: *Ya, no... ya, it definitely does. And I’ve been like, you know, like it’s, where it’s*

like, embarrassing and then you go home and it ruins your day. You know what I mean?

It’s like “That Sucked!” And then that feeling transitions to the people around you, sadly you know?

The impact of experiences of discrimination, created a build-up of stressors and micro-aggressions,²⁶ and micro-inequities²⁷ that participants interpreted to negatively impact their emotional health. Discrimination was both subtle and overt and had strong lasting impacts on emotional and mental health. Eve's description of the experience of public stripping conveys the sense of total degradation she experienced at the time, sensed to be still with her in her retelling of the story, as she moves her arms up, covering her turned away face.

Line 137: Eve: *He didn't introduce himself or anything he just stood by. He was paying more attention to the student, talking to him. Next thing you know he's putting these ...he's checking me down there ... he's spreading my legs and um, talking to the student. Ya ... I was so humiliated I was like this [head turned away and down and hands over her eyes] ... that was the biggest, that was one of the biggest things that has ever happened to me really. It was humiliating.*

This experience fuels her to advocate and confront this provider and this institution's abusive policies related to PWD. She used lessons learned from this experience to confront discrimination experienced with the lack of bathroom access at a local hospital.

Lala described the emotional and physical turmoil caused when healthcare access is denied.

Line 327: Lala: *They refused to give me a treatment and they said go home 'well look just go home and will give you a call' and next thing you know I had to go to the ER and my*

²⁶ Sue et al. (2007) in *Micro-aggressions in everyday life: race, gender, and sexual orientation*, describes micro-aggressions as "brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional that communicate hostile, derogatory, or negative slights and insults to a marginalized group" (p. 3).

²⁷ Brennan (2016, p. 184) describes that persistent inequalities in the workplace stem from biases operating below the threshold of deliberate consciousness, are unrecognized and unintended, but systematically place marginalized groups at a disadvantage.

levels was so low that I had to be admitted and he actually became upset. He was like 'why did you go to the ER?' Yes! This was this doctor, he actually became upset because I went to the ER...I had to be admitted to the hospital that same exact day. And that was a couple of hours later. And I just don't understand.

Past rejections led to concern among participants that future requests would be similarly denied.

The lasting impact of the fear, anxiety, embarrassment, and humiliation added stress to these participants' lives. How this stress impacted their overall health is difficult to quantify, however, Tomás was unequivocal about the long-term impact on him and other PWD.

Line 650: LV: *Do you think these experiences have a long-term impact on your health? All of this?* Tomás: *Without question, without question it does ... it's going to have a long-term impact on my health, not so much on my emotional well-being, but it actually, just the physical well-being.*

Lynn was similarly convinced her physical health had been impacted by her reaction to a lack of accommodations, and her decision to delay care rather than confront the inaccessible and discriminatory healthcare system.

Line 532: LV: *Many PWD request accommodations because they have to just to be able to get basic care so how do you think this impacts a person's physical, mental and emotional overall health?* Lynn: *So, let's take the physical: I'm going to postpone and I have postponed-my treatments have been delayed at times, because I have postponed the visit. Because I know it's not accessible – so in my own mind I down play the symptoms I'm having. So physically when you delay the diagnoses you delay the treatment...sometimes it's more complicated than it would have been so I think that's all physically related.*

Marcus has the most positive assessment of the health impact of self-advocacy - based on his perception that his providers view him as an equal member of his healthcare team. As a result, he felt they were and are knowledgeable of his needs and rights to accommodation.

Line 543: LV: *How do you think the need to ask for accommodation in a healthcare setting impacts your overall health?*

Marcus: *Hmmm....I think that it effects my overall health, I think it effects it very well. I think that I'm in a position where I know if I need an accommodation I can ask. If I don't necessarily need it then that's fine as well. But I also think that healthcare providers if they already know your situation if they already know that you MIGHT [emphasis] need an accommodation for a certain thing that makes it a lot more easier.*

It is striking that he felt accommodated in spite of the fact that his providers have no accessible equipment. For him a strong collaborative relationship and the ability to problem solve to achieve his health concerns or goals if an accommodation was necessary trumped inaccessibility.

Participants described their perceptions of how the need to request accommodation or a lack of accommodations might impact the health of PWD – including their own. The participants' responses to this direct question in the interviews offers insight into their interpretations of the impact on their emotional, mental and physical well-being. However, revisiting the transcripts on factors that influence decisions not to self-advocate provides a deeper understanding of participant experiences, interpreting a lasting impact they may not have previously identified. Themes from that section - perceiving yourself as a burden in healthcare, descriptions of fatigue to the point of denying care of self, fear of rejection by providers - are not experiences that produce positive health impacts. The participants describe situations that put them at risk of medical complications as a result of not advocating. As seen in Tomás'

experience of developing pneumonia, more research is needed to discriminate how these experiences ultimately impact the long-term health of PWD.

2. **Super-ordinate theme two: Empowerment through agency in self-advocacy**

The participants described repeated instances of discrimination – some so much a part of the normalized practices that providers appeared unable or unwilling to see what the participants experience. Participants reported times when providers defend inappropriate or inadequate care as caused by issues beyond their control. The participants reflected how normalized processes and inept practices maintain provider authority over the health and healthcare of the PWD. Participants identified different paths to this insight but all came to a point when they recognized knowing what they need, their rights to requests, and strategies for requesting, as steps toward being more empowered.

Line 510: Lynn: *And, you know, the language of accommodations – reasonable accommodations just seems to, it makes me feel more empowered because it is reminding me that I have a right - so using the language of the ADA or any terminology is helpful to me.*

Knowledge of the ADA goes beyond simply knowing she has the right to request an accommodation. She is ‘reminded’ or prompted to use the language of the ADA to support her agency and accommodation requests when if she deemed it necessary. While empowerment in advocacy was a shared participant experience, five of the six interpreted using their knowledge of their rights to care or the language of the ADA as empowering. Gary was the exception, and his confidence in self-advocacy remains fragile but increasing.

Clarifying interview: Gary: *Every time they would go in and convince me, well, try to convince me this was all of the other stuff that I needed. And I knew that I didn’t want any*

of that, and I just – I mean they would try to make me feel insecure, like I didn't understand.

The lack of confidence within the broader disability community was also alluded to by participants.

Line 235: Lala: *I hear a lot of people saying, you hear people talking about becoming intimidated you know and everything, and I'm like here, you have a right to this. Many people don't know their rights and stuff like that.*

Knowledge of laws and accessibility guidelines was identified as a source of power. For example, Lynn's grasp on her rights included the United States Access Board's recommendations for medical diagnostic equipment standards²⁸ which facilitated her ability to formulate requests for physical accommodation.

Line 518: Lynn: *To even say, 'oh, that's insufficient turning radius' is very different from saying 'oh, I know if I can get my chair to turn around in there' LV: Right. Lynn: It's very different, it's going from uncertainty and a little bit of vagueness to being very clear. And I think that helps. Because it's not a matter of personal preference as now it's something that is fairly common knowledge.*

Lynn reflected on how her knowledge of these specifications changed her ability to achieve access to healthcare. She believed this information provided her the authority and power to circumvent discriminatory behaviors or actions from providers.

Line 645: LV: *Was there a time before you learned that - where you had negative outcomes? Lynn: Yes, I think I had quite a few. And I think attitudinally I think is how it*

²⁸ For the U.S. Access Boards Standards on Medical Diagnostic Equipment go to <https://www.access-board.gov/guidelines-and-standards/health-care/about-this-rulemaking>.

impacted me the most. Because I wasn't able to show that I had some power in the situation – that's really when negative attitudes come out more, right?

The importance of having the knowledge and believing in their own capacity as self-advocates was a vital personal factor that participants see as changing the scenario of a healthcare visit.

Lala recognized her empowerment and how different her experiences are now from her past.

Line 405: Lala: *I'm able you know to speak up for myself, I'm able you know, what if I was in, you know? There are many things, many situations that have happened that would have been much worse. And everything. It's just being an advocate for myself, it means, it means a lot.*

Participants described using their knowledge to support their authority which they translate as directly impacting the quality of their care and provider behavior. Tomás credited educating providers on his rights to accommodation to improving healthcare experiences.

Line 253: Tomás: *I've had a number of good experiences with my doctor's but only after I've educated them, on what the legal requirements are and who I am and um, and that, to listen to me. You know after we've been able to communicate that then I, you know, then doctor's offices they welcome me with open arms and I don't feel um, I don't feel rushed, I am listened to, and I'm given prompt care and ...it's worked out.*

Self-advocacy backed by knowledge of rights offered participants opportunities for recursive learning of strategies in advocacy. Eve built on her knowledge and sense of power to pursue formal advocacy that led to systems change.

Line 356: Eve: *I have a whole list of the stuff that they are going to do. Making rooms, certain rooms above the size or percentage required by the ADA. Rooms that are accessible, beds and then um, the parking lot, just a lot, several things that they are going*

to do. But um yeah, because of what we endured. They are going to make some changes. But it took a lawsuit to do that because they um, totally just ignored the ADA for 25 years.

The participants discussed how having a solid knowledge on their rights empowered them to educate providers on concerns beyond immediate accommodation. Eve's description of 're-educating' a provider on the culturally competent disability language emphasized her confidence in demanding provider respect when working with the disability community.

Clarifying interview: Eve: ... *when he came into the room, and I, I told him - in a mild manner [softens her speech] - in the disability community, we do not use the term 'wheelchair bound' we prefer "disabled" or "wheelchair user" and yeah, he just had this look on his face like 'oh' he was so embarrassed and I...it's just a form of re-educating him, that we don't use those terms.*

Marcus is learning advocacy strategies and growing his sense of empowerment through activism efforts with mentors and peers in his disability community. He recognized one of the benefits of having access to a dynamic Center of Independent Living included learning how to advocate for disability community rights - providing opportunities for his confidence to grow.

Line 467: Marcus: *I feel like here, you know, we fight for our rights, you know, we are at actions we are at different places, you know, fighting for our rights. I don't know if in other places that there's that level of work.*

Tomás believed that knowing the language of the law and how to use it when advocating is in itself empowering for PWD.

Line 637: Tomás: *I think knowing what the law is and knowing how to communicate what the law is in a way that is going to be received well without being antagonistic and without being threatening I think really helps a PWD get a sense of empowerment.*

This statement is likely true but it falls short of explaining the full impact these laws have on individual advocacy efforts. Understanding the laws apply to their needs - as a member of an oppressed minority community - produced a possibility for participants to increase disability identity development.

Line 706: Lynn: *This has helped me to form a disability identity. To recognize that you're a different group of person. And I think that is empowering. Because that takes it off of the individual. When you realize that you're part of a community having these experiences – that this is an identity perhaps imposed at some point. But then it's left open for you to choose that identity or not. That can be very empowering. Otherwise...it's just medical. "I'm stuck in the medical model" ... it's just happening to me. Right, but when you see it from a bigger picture that's happening to a group of people then we're going into the social model. It's very interesting.*

The realization that it's 'not just happening to you' shifts the context of an unaccommodating healthcare visit considerably for these participants. Understanding the oppressive forces at work provided participants with knowledge just as critical as the knowledge of the laws that support their requests for accommodation. Lynn's analysis of the "bigger picture" helped her understand that insults are not directed at her individually but as an individual belonging to a marginalized group. She described this knowledge as a source of strength to survive the experiences.

Line 690: Lynn: *To be able to start to understand it to be able to accept it. I don't want to accept it if I don't understand what's going on. For me, that's been a very healthy*

experience and again, only because I have [emphasis] to do that. So that's why I think I'm a stronger person, as long as I can survive the immediate impact in the long run I'm a stronger person.

This sense of shared experiences of discrimination and oppression was recognized across all of the participants. The agency to self-advocate was informed by this understanding.

Line 407: Gary: ...*you are just like "mannnnn, this could be wayyyy easier if, like this was set up some other way you know!" And if somebody would just say something... "If SOMEBODY would just speak up and let them know" [sarcastically mocking himself] this would be, could be really nice.*

Interpreting that the status quo represents a form of oppression in healthcare that attempts to deny them of agency over their health and their body is empowering. The participants' understanding of this bigger picture, the social constructions of their exclusion from primary and preventative healthcare is what provides them with the agency to make a fully informed decision to self-advocate. For the participants, successful advocacy experiences in confronting NODD, created a lasting sense of empowerment for future agency in decisions to request an accommodation. For example, Marcus' agency to self-advocate empowers him to have confidence to achieve his ultimate healthcare goal.

Line 530: Marcus: ... *and emotionally, I feel I actually do feel empowered [by advocating], cuz I'm like, this is something that I'm doing to make sure that I live a long life, you know?*

All of the participants of this study detail experiences of recognizing the need for self-advocacy, factors that influence decisions on advocating, and the lasting impact of the need to self-advocate for accommodations in healthcare. From these broader conceptual categories nine

superordinate themes emerged across participants. These nine themes provide insight into the experiences of self-advocates with mobility disabilities when confronted with a lack of accommodation in healthcare. These themes offer an overarching view of the contextual and personal factors that influence decisions in self-advocacy. The act of self-advocating is part of a larger process of agency in self-advocacy, a process that includes disability identity development, and establishes and validates a sense of empowerment based on this identity.

VII. DISCUSSION

A. Overview

The aim of this study was to *explore the meaning that barriers to healthcare have for people with mobility impairments as well as the personal and contextual factors that influence decisions to self-advocate for accommodation*. Interpretative Phenomenological Analysis (IPA) was used to gain an in-depth understanding of how PWD make sense of their experiences within an inaccessible and often discriminatory healthcare system. The specific research questions:

- How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?
- What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?
- Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?

Analysis of individual cases and cross cutting themes identified nine super-ordinate themes. While individual approaches to self-advocacy varied, participants recognized a normalization of disability discrimination and disability stigma which in turn influenced provider understanding of disability necessitating the need to develop of agency in self-advocacy. Decisions to self-advocate were complex and participants described weighing a variety of contextual and personal factors when deciding to advocate or not. This process had a lasting impact on people that include a shared embodied experience of disability as well as a sense of empowerment based on their collective and individual identities as disabled people. The findings from each category will be considered in answering the research questions with critical reflection of how this study's findings are informed by past research on healthcare access barriers for PWD

and use of critical theories and the social model of disability to analyze and highlight the essence of participants' experiences. Discussion on implications of the findings will focus on proposing methods to support individual consumer advocacy efforts as well as the need to address the normalization of disability discrimination within healthcare at systems levels. Finally, recommendations will be made for areas of future research.

B. **Research question one: How do people with physical disability make sense and give meaning to experiences of barriers to healthcare?**

Informed by the rights based self-advocacy research of Malhotra and Rowe (2014) and Engel and Munger (2003), this study's interview questions asked participants to share their experiences, positive or negative, of addressing barriers to healthcare. Participants went beyond describing the barriers to include their understandings of what it meant to be excluded from primary and preventative healthcare.

Participants described a process of coming to recognize and even expect discriminatory treatment within healthcare based on their disability status. Within the process of making sense of these experiences, participants embodied their disability identity in developing agency for self-advocacy. Findings in *Rights to Inclusion* (Engle & Munger, 2003) and *Exploring disability identity and disability rights through narratives: Finding a voice of their own* (Malhotra & Rowe, 2014) report a similar recursive relationship between recognizing exclusion, understanding rights to inclusion, and development of disability identity.

The majority of participants described their recognition of disability discrimination as a fundamental *a priori* step to becoming aware of the necessity for self-advocacy. For example, Gary described reflecting on how bodily difference, rather than health and well-being, became the focal point for healthcare encounters as raising his awareness of the need to self-advocate. He

described how many individual provider experiences left him with feeling bad physically and emotionally. Overtime, he recognized a consistent pattern of discrimination and that the problem was not with him or his body but with issues of access within the healthcare system.

Routine experiences of one-on-one discrimination dominated descriptions of experiences in healthcare encounters. Many of these experiences are supported by research on lack of access to preventive care (Chevarley et al., 2006; Diab & Johnston, 2004), provider offices (Iezzoni et al., 2002) and equipment (Winters & Story, 2006). However, the participants' reflections on the causal factors of these barriers shed light onto the meanings they give to the experiences. The majority of participants made sense that the barriers to healthcare stem from: 1) lack of provider knowledge about disability; and 2) the normalization of disability discrimination. Providers' lack of knowledge, ignorance, and/or stigmas about disability is supported with literature exploring the attitudinal impact on access for PWD (McColl et al., 2008; Sanchez et al., 2000).

1. **Normalization of disability discrimination**

Participants also recognized a trickle-down impact of institutional or structural policies and choices that cause the culture of a clinic to normalize acts of disability discrimination into everyday routine provider practices and behaviors, or what this study calls NODD. These findings are supported by research describing the influence of disability stigma as a social environmental barrier to meaningful participation for disabled people (Daruwalla & Darcy, 2005; Garcia et al., 2015). Participants describe recognizing NODD, and how it led to their marginalized and stigmatized status within healthcare environments.

There is a vast body of literature which began in the early civil rights era on the concept of institutional racism (Carmichael & Hamilton, 1967, 2001; Knowles & Prewitt, 1972). Defined by Carmichael and Hamilton (1967) as a "failure for institutions to provide appropriate and

professional services to people because of their color, culture, or ethnicity” (Anthias, 1999, p. 2.1). The concepts of institutional or structural discrimination further broaden the concept to describe a process that “manifests itself as rules, policies, and procedures of private or public entities in positions of power that can consciously and purposefully restrict rights and opportunities” (Corrigan, Markowitz, & Watson, 2004, p. 1). Oliver (1990) extended this concept to PWD and described institutional discrimination as “established structures of disadvantage toward PWD, supported by those in power that require anti-discrimination legislation in order to change behaviors” of discrimination (p. 83).

Kreiger (2014) emphasized that structures and processes of discrimination in healthcare adversely influence decisions of healthcare providers and is a result of a “societal phenomenon that creates and preserves privilege for dominant groups at the expense of subordinated groups” (p. 687). Participants recognized that inaccessible clinics did not occur by chance but rather are the result of conscious or unconscious failures to comply with the ADA and Rehabilitation Act. These failures in turn create an environment where provider behaviors - experienced as day to day acts of discrimination - are so normalized that providers and others may not notice – however participants did.

Study participants identified provider behaviors at times as a form implicit or unconscious bias or micro-aggressions. However, these may not be conceptually accurate or comprehensive explanations of the cumulative impact of provider behaviors that participants interpret as NODD in primary and preventative healthcare. A better overarching conceptual foundation for NODD may lay in exploring research on the existence and impact of micro-inequities faced by marginalized and minority groups (Rowe, 1990; Sandler, 1986). Micro-inequities are “small, unjust inequalities often pointed to as part of the larger story about larger

scale inequalities ... and while individual instances may seem trivial, their cumulative effects can account for differences in outcome” (Brennan, 2016, p. 184). Research exploring employment micro-inequities emphasize they are easily overlooked by both those at the delivering and receiving end of the act. It is their insidious nature that allows them to build and it is the resultant cumulative impact that leads to harm (Brennan, 2016). While the snubs, body-language, and rolled eyes are overt expressions that shape the individual experiences of micro-inequities (Rowe, 1990), the failure to provide accommodation or training in use of accommodating equipment are more institutionalized practices that reinforce these inequities at a structural or system’s level. It is not the single act of a provider that leads to the long-term health disparities of PWD but the cumulative effect of the inequities over time and context. NODD may in fact be the cumulative effect of micro-inequities across the entirety of healthcare contexts in concerns of the disability community.

While qualitative and phenomenological research do not provide a mechanism to test causal relationships, study participants described how provider behaviors influenced their decisions to advocate or not. Baldrige and Veiga (2001) found that “an organization’s accommodation culture regarding the extent to which an organization supports and values the integration of PWD will influence accommodation request likelihood” (p. 93). Critical analysis of participants’ interpretations suggests healthcare organizations inactions in implementing policies and practices to support access to healthcare help maintain the status quo of the social structures that exclude disabled people (Kreiger, 2014). A critical legal theory and social model lens suggests that implementation of the ADA within healthcare systems would demand ideological changes that many people are not prepared to make (Asch, 2001; Hahn, 1988, 2005). The status quo reinforces micro-inequities in practice patterns that normalize disability

discrimination and provider's lack of disability competence. It also upheld providers' authority over people with disabilities, thereby maintaining the hegemony of medicalization and disablement of PWD.

Using a critical disability studies perspective, participants recognized how disability impacts their health and informs their need for self-advocacy. The participants understood the need to attend to their body and to their health in ways were different from non-disabled people. PWD rely on healthcare providers for specialized skills and knowledge but by doing so they risk disablement. "Disabled bodies challenge normative ideas of able bodies" (Goodley, 2017, p. 85) including conceptualizations of health. The challenge for participants was allowing the medical model to attend to their healthcare without allowing the oppression of medicalization to filter in. Processes of micro-inequities and established normalized patterns of discrimination can dominate the context beyond the obvious fact that the physical environment is inaccessible. From a critical disability perspective, it's when people recognized NODD that the disabled body was made to matter (Goodley, 2017) and the full cumulative force of the micro-inequities surface and discrimination can be felt.

NODD shaped the lived experience as participants move through their healthcare encounters. NODD was both an important concept in its own right and it is entwined with providers' lack of understanding about disability.

2. **Providers' lack of understanding**

Study participants described subtle and overt acts of discrimination as part of routine healthcare practices. They recognized that providers are unable to see these actions as acts that discriminate. Lala and Eve described providers as simply not caring as one reason for a

failure to receive care. More often participants believed providers did care but had little to no understanding on how to provide disability competent care.

Literature supports participants' claims of providers' lack of knowledge on health and disability (Pharr & Chino, 2013; Scheer et al., 2003). Dillaway and Lysack (2014, 2015) have done extensive research on women with disabilities' healthcare access barriers and report across all of their studies "the primary social barrier women discuss is providers' lack of education and training" (2015, n.p.). Participants had sophisticated insights into how limited provider knowledge limited their capacity to offer appropriate care, and placed people with disability in harm's way.

While providers' limited knowledge was a key determinant for all participants in recognizing access required self-advocacy, most participants also perceived broader societal or administrative level causes as understanding why this type of barrier exists. Other research on provider and healthcare administrators' lack of knowledge on appropriate accommodations and care (Pharr, 2014; Stillman, Frost, Smalley, Bertocci, & Williams, 2014; Tervo et al., 2002) support the claims of participants that systemic discrimination perpetuates the lack of accommodation and training on disability as well as biased behaviors of providers.

'Rejecting rejection' was a sub-theme that emerged from the larger superordinate theme of 'providers' lack of understanding disability'. Other research on attitudes toward disabled people identify how feelings and behaviors reject inclusion of PWD, despite pretenses of acceptance (Daruwalla, 1999; Daruwalla & Darcy, 2005; Friedman, 2016). Research exists that identifies and describes how healthcare providers' attitudes and behaviors are impacted negatively by varying characteristics of a PWD (Thomson, 2017; Wright, 1988; Yucker, 1988).

Participants' agency in self-advocacy was fueled by their recognition of the need for self-advocacy and that provider negative stereotyping, bias, and prejudices are supported by the social construction surrounding their disability. This recognition revealed a path for developing disability identity similar to Bartky's (1990) process of changing consciousness on the road to developing feminist identity. Exposure to mentors – helped expose everyday acts as normalized discrimination and a form of oppression. Only by recognizing disparate care as discrimination, were the participants consciously able to reject the rejection through self-advocacy.

The social model of disability relocates the cause of limited participation and disability from within the person to socially created barriers of disablement. Using a social model lens to further explain these two super-ordinate themes suggest interventions might turn the gaze (Snyder & Mitchell, 2001) *from* the 'patient' *onto* the provider and healthcare system to analyze the disabling practices that exist within a healthcare context for people with disabilities.

The conceptualization of able-ism (Campbell, 2001, 2008) is similarly socially constructed and notions of compulsory able-ness (Campbell, 2008; Kafer, 2003; McRuer, 2010) may help explain why participants tolerated healthcare services without appropriate accommodations. The need for accommodation and experiences of failed accommodation, highlighted both their body's otherness and at times caused participants and providers to see their bodies as "the problem." Both send powerful messages of what 'bodies matter' (Butler, 2011) within the healthcare context. Inaccessible design of diagnostic and everyday medical equipment within healthcare is informed by the constructed norms of able-bodiedness (Campbell, 2009). Descriptions of participants tolerating poor provider alternatives or electing to not self-advocate for accommodation and instead endure the pain, discomfort and possible injury in efforts to use

standardized equipment may stem from their own conscious or unconscious understandings to conform to compulsory able-bodied (McRuer, 2010) requirements within healthcare systems.

Theories of compulsory ableness can also be used to help explain the normative approaches of care received by participants. Examples can be seen in Gary's experience with his urologist and experiences of inappropriate handling techniques described by all participants. In all of these examples providers' approaches to care were informed by presumptions of ablebodiedness. The social construction of able-ism may also inform providers' failures to recognize that disability and health can co-exist. Only when healthcare systems and independent private practice providers recognize this reality can full and equal participation exist.

Despite the existence of civil rights laws that promise access, healthcare continues to exclude PWD and necessitates they self-advocate for accommodation. The findings from this study suggest that negative provider behaviors and disparate practice patterns, lack of provider knowledge of disability and negative disability stereotypes, and the perpetuation of inaccessible diagnostic medical equipment may reflect external representations of a pervasive process of normalized disability discrimination in healthcare.

C. **Research question two: What factors influence decisions to self-advocate for an accommodation to care when confronted with a barrier?**

When asked about experiences of self-advocacy, participants offered interpretations of when they advocated or not. Decisions to advocate or not were based on those contextual factors and personal factor variables. Participants were informed by previous experiences in healthcare and advocacy and engaged in deliberative processes that included in the moment assessments of the likelihood of success, emotional toll of fighting the system, and urgency of healthcare needs. The responses to research questions shaped two organizing conceptual categories in analysis:

factors that influence decisions to self-advocate, and factors that inform choosing not to self-advocate.

1. **Factors that influence decisions to self-advocate**

Three super-ordinate themes arose from interpretations of experiences when participants elected to advocate: ‘knowing what you need’, ‘understanding rights to care’, and, ‘context informs self-advocacy strategies.’ Each of these themes described a process of learning.

Participants relied on self-advocacy strategies learned through healthcare and other advocacy experiences. They described learning from mentors and through their own experiences of trial and error. The iterative processes participants describe of developing agency in self-advocacy is supported in the literature of social learning theory (Bandura, 1989).

Agency is the capacity to exert control, but Berger (2008) expanded this definition to include “the possibility of transforming the social relations of personal experience” (p. 311). By participants developing agency in self-advocacy, participants sought to redistribute power imbalances that privileged providers.

a. **Knowing what you need**

By attending to their body (Nazli, 2012; Shakespeare, 2012) each participant described understanding what they need to manage their health. Each participant defined themselves as being in good health, similar to other reports in the literature that disabled people claim health despite disability (Nazli, 2012; Shakespeare, 2012). Learning to manage the different healthcare needs that stem from disability also included learning how to educate providers on these differences. Participants described many instances of educating providers that basic health concerns have little to do with their impairment however, their impairment may require different approaches to basic care. Further, these approaches should be provided in ways

that maintain dignity and respect. Unfortunately, participants' stories provide many examples of degradation and humiliation.

Embodied understanding of health is an individualized phenomenon. Yet, in accessing healthcare, disability becomes a shared phenomenon across all participants of this study. Tension within the social model positions the “problem of disability” in social constructed barriers, yet healthcare requires attending to the individual with individualized health needs. The reality of healthcare is that people do need medical model perspectives for diagnostic, treatment, and preventive health outcomes. Indeed, asserted by Shakespeare (2012) “rejecting anything to do with medicine obscures the vital priority of achieving access to good quality healthcare” (p. 131). Understanding that PWD live within a thinner margin of health (Beatty et al., 2003) would suggest that working to receive equity in healthcare should be a priority for the disability community. However, embracing the positive aspects of healthcare delivery is often overshadowed by the history of medicalization, oppression, and the social construction of disability experiences. Siebers (2017) posits healthcare’s potential for unifying members of the disability community “not based on impairment similarity but on social experiences that includes a shared encounter with oppression, discrimination, and medicalization and a shared knowledge of survival strategies, healthcare policy, and environmental conditions” (p. 119).

Each participant understood what their bodies need for health and how social constructions of *disability* make it hard to get needs addressed appropriately. For example, Lynn’s intersecting disabilities require her to confront provider discrimination much differently than Marcus, but both seek out medical care to “*live long and healthy lives.*” Eve and have very different health related concerns but both position provider respect as critical to managing their disability.

Knowing what their body needed from a medical perspective, was a form of embodied authority and the primary force in participants' decisions to advocate for their rights to an accommodation. However, each participant described a level of consciousness that engaging in the healthcare system subjected them to the medicalization of their experience and created an opportunity that medical/professional authority would consume their embodied authority. This is similar to the conceptual foundation offered by Hughes and Patterson (1997) in describing the relationship between impairment and disability: "The impaired body is a 'lived body'. Disabled people experience impairment as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction" (p. 334). For the participants in this study this interpenetration is experienced in understanding that their healthcare needs require confronting processes of disablement and as such, readies them to the potential need to advocate.

Most participants described working against provider authority and a targeted focus of educating providers. Marcus is an exception. Although he is cognizant of the many socially constructed physical and process barriers to access, he reports positive relationships with his providers through the majority of his healthcare experiences. Although recent experiences have made him more conscious of barriers and their impact, he is confident that his social model informed and disability competent providers will work collaboratively with him as co-experts in his care. His experiences indicating perhaps that more balanced healthcare receipt is possible.

The most seasoned healthcare advocates saw advocacy as way not only to get appropriate care but also as an opportunity to educate providers for the good of the broader disability community. Indeed, while advocacy was typically motivated by individual health needs, all of the participants, even those not confident in their advocacy ability, recognized the need to

advocate in healthcare encounters in order to expose larger social injustices. These participants recognized that “disability in itself is not the sole marker for experiencing social injustices” (Kottorp et al., 2016, p. 382) and felt an obligation to others in the disability community, others who did not have the knowledge or ability to self-advocate. While all participants recognized the importance of exposing unjust practices, only four of this study’s participants, actually described acting upon it. Research on social participation barriers and supports suggest disabled people believe performing collective advocacy contributes to perceptions of greater social participation (Magasi et al., 2009). Other research suggests that with social participation PWD gain a stronger understanding beyond rights based knowledge for what they are individually entitled to (Young & Quibell, 2000). This suggests a reciprocal relationship exists between collective advocacy experiences and development of individual agency in self-advocacy. Participation in collective community advocacy may fuel the learning processes that participants described as being critical to developing their strategies and styles for personal self-advocacy.

b. **Understanding entitled – rights to care**

Findings from this study showed that working knowledge of the civil rights was essential to self-advocacy efforts. Five of the six participants described understanding the language of the ADA or recommendations for equipment standards as a strategic self-advocacy tool. Knowledge alone was insufficient to support self-advocacy, similar to findings from Engel and Munger (2003) participants needed to build skills and confidence to be ‘activated’. The activation process is a recursive relationship between understanding and using disability rights in advocacy and disability identity development. Although Engel and Munger (2003) found that even activated individuals struggled to assert rights in employment scenarios.

In contrast, the findings from this study show that knowledge of rights and recognition of their personal application appears to have directly supported reinforcing positive disability identity.

Participants described that rights based knowledge provided “*the language*” for advocacy. Of the five participants who interpret the importance of the ADA as the basis for a request for accommodation, three had at some point formally mobilized their rights, taking steps to legally enforce claims of disability discrimination in healthcare. Each of these five described preferences for using the ADA to frame advocacy requests but were reluctant to use phrases such as “*the ADA says*” preferring to state “*an accessible table would be one that lowers down*” as approaches they interpret as more acceptable to providers. Fear of retaliation or alienating providers prompted a more restrained use of the law versus formal enforcement (Harpur, 2014). Participants similarly interpret that brandishing the ADA upfront in accessing care ineffective, potentially risking backlash (Tomás, Eve) or rejection (Lynn, Gary) from providers.

These interpretations echo Engel and Munger’s (2003) identification of PWDs hesitancy to invoke the law in their everyday lives. Despite the reluctance to cite the ADA participants appreciated that it establishes their right to accommodation, and described incorporating it as part of their varied strategic approaches in self-advocating.

c. **Context informs self-advocacy strategies**

The strategies participants used in advocacy were informed by personal and contextual factors. Each participant described strategies they’ve learned overtime and rely upon to allow for having a level of control within a context. Participants incorporated strategies in self-advocacy that mesh with their personal preferences and personalities. Lynn’s quiet demeanor led her to use strategies that establish order and optimize her authority, while Gary’s lack of confidence led him to bring an ally to his provider visit.

Participants also described a contextual appreciation of providers' perceptions of disabled people and sought to counteract negative stereotyping by consciously managing their appearance and behaviors. Specific strategies included: note taking, sounding intelligent and calm versus "*barging into the office yelling and making a big deal of it*" (Eve). These findings are consistent with research from other marginalized groups who recognize how behaviors that deviate from social norms of polite, white, middle class, risk reinforcing negative stereotypes (Inzlicht, McKay, & Aronson, 2006). Participants also recognized the impact of significant others' in healthcare encounters can help shift the balance of power.

One critical contextual factor informing participants' self-advocacy was their perceived level of personal authority or control. Participants used this information to make advocacy decisions. They recognized the importance of establishing relationships that supported personal authority and earn provider respect. Establishing personal authority and educating providers on their disability related needs, basic health needs, cultural competence, equipment standards, and accommodation types and use, were strategies used by participants. Other research has previously found PWD use provider education as a strategy in overcoming access barriers (Kroll et al., 2006).

Requesting accommodations in healthcare by study participants was distinctly different from requests in employment research (Baldrige & Viega, 2001; Engel & Munger, 2003; Harpur, 2014), tourism/recreation literature (Darcy, 2010), and transportation and education studies (Malhotra & Rowe, 2014). For example, Baldrige and Viega (2001) found that accommodations in employment contexts were understood as requests for assistance and used "help-seeking theories to inform their analysis" (p. 88). In this study, participants were less motivated by asking for help or assistance than they were for social justice and rights based

claims for equity in treatment, dignity, and respect from providers in order to receive appropriate and necessary healthcare services.

Malhotra and Rowe (2014) found that in the context of transportation, education, and employment that when participants deemed access essential, resistance to oppression through acts of self-advocacy emerged. Disability scholar Tom Shakespeare states, “without meeting the human right to health, it is hard for someone to enjoy their other rights” (2012, p. 130) thereby reinforcing the notion that self-advocacy in the healthcare context takes on a particular urgency and importance. The essential need of accessing healthcare and the oppressive meanings participants give to the barriers to care are the contextual and critical factors that inform their decisions in using a rights’ based perspective of self-advocacy.

2. **Factors that influence decisions not to self-advocate**

Participants were just as intentional in their decisions to not self-advocate as to advocate. Two superordinate themes in this organizing category were personal factors that caused participants not to choose: advocacy fatigue and self-perceived burden to providers. Experiences and feelings of fatigue or emotional exhaustion were described by four participants in making ‘in the moment’ decisions not to advocate for accommodation. Participants describe that normalization of disability was so pervasive that “battling” the system became an intrinsic part of seeking health and medical care. Participants, Lynn, Eve, Tomás, and Lala²⁹, who describe advocacy as a ‘fight’ for access and equity experienced the phenomenon of advocacy fatigue.

²⁹ Although Lala describes advocacy fatigue and emotional exhaustion, she describes not having these feelings impact her decisions in advocacy.

a. **Advocacy fatigue**

Griffin-Basas (2015) defines “advocacy fatigue as the increased strain on emotional, physical, material, social, and wellness resources that comes from continued exposure to system inequities and inequalities” (p. 39). She theorized that the experiences of compassion fatigue, burnout, and stress recognized in teachers, healthcare workers, lawyers and others working on education rights based advocacy efforts are also experienced by families and students. She identified the lasting impact caused by individual advocacy efforts when coupled with a corresponding commitment to collective community activism. Lynn, Eve, Tomás and Lala each have committed themselves to extended community advocacy efforts. These four participants described advocacy’s emotional toll as ‘*exhausting*’, ‘*frustrating*’, ‘*stressful*’, ‘*draining*’ and believed that these experiences negatively impact their physical and emotional health.

Griffin-Basas (2015) described the arc of advocacy experiences extending between individual informal confrontation to formal legal efforts and the stamina required from individuals in enforcing their rights. This study’s participants have different experiences from within this arc of advocacy. Gary is just beginning to develop strategies in individual advocacy and Marcus is new to his work in disability community activism while Lynn, Lala, Tomás, and Eve, those with expressed feelings of advocacy fatigue, have each had sustained exposure to formal advocacy experiences. Despite frequent descriptions of this type of experience from study participants there is little to no literature describing the phenomenon of advocacy fatigue among the disability community in confronting the barriers to healthcare so well documented. Advocacy

fatigue likely contributes to what Gill (2004) described as “disability burn-out”³⁰ that disabled people experience with “years of exposure to disability prejudice and devaluation” (p. 180).

b. **Self-perceived burden to providers**

The other super-ordinate theme that emerged as influencing participants’ decisions to not self-advocate was a perception of being a burden to providers. Self-perceived burden research almost exclusively investigates perceived burden to caregivers of individuals with long-term progressive chronic conditions or persons in palliative care or end of life (McPherson et al., 2007). Five of the six participants interpreted being a burden to providers as reasons not to self-advocate. Lala was unique in her defiance to this label and asserted that she never felt she was a burden. Indeed, she interpreted providers’ attempts to make her feel guilty as a way of manipulating her into compliance. “*They try to make me feel like I am bothering them*”. Lala’s heightened sensitivity to perceiving these as acts of manipulation and disability discrimination may be in part due to her frequent encounters with unknown providers requiring diligence on her part not to acquiesce in her requests.

Baldrige and Swift (2011) found that disabled employees were less likely to request accommodations if they were younger and with less severe disability. Two study participants were in the later early adulthood (thirties) and the others were all in middle age (fifties). The two younger participants (Marcus and Gary) describe accommodating providers more often than requesting accommodations. However, these individuals were also more recently exposed to the disability community, knowledge of their rights to request, and strategies for self-advocacy, and had previously had strong parental involvement in their healthcare management. Future research

³⁰ Gill (2004) describes, “the psychological reality of disability burn-out is that it tends to discolor one’s entire outlook. Not only does life appear devoid of value but the individual’s sense of self may be affected as well” (p. 181).

should examine how age influences self-advocacy decision-making, especially in the post-ADA generation.

Concerns about increased stigma, perceived fairness, what others will think, all factor into people's decisions regarding perceiving appropriateness of the accommodation requests (Baldrige & Veiga, 2001) and perceived burden reduces the likelihood of requests. Engel and Munger (2003) found personal factors such as family, class, race, and gender, versus knowledge on rights, as having an impact on decisions in advocating for accommodation or not in employment, while supportive networks, increased resources, and personality characteristics such as resilience and determination support advocacy efforts. These traits may also moderate the impact of advocacy fatigue and perceptions of burden.

Each of the super-ordinate themes that emerged from participants interpretations of why they elect not to self-advocate are examples of the impact of providers failure to understand disability as a social construction versus a medical reality. Providers repeatedly fail to recognize disabled people have general primary and preventive health needs that require the approach to treatment be tailored (Pothier & Devlin, 2006). With this failure, accommodations are absent and participants assume the responsibility for the inability to conform their bodies to the 'natural order of things' (McRuer, 2010). For participants in this study, the repeated need to conform or to draw upon resources to defy the demands were interpreted as exhausting, stressful, with resultant detrimental effects on their overall health.

D. **Research question three: Do PWD attribute needs to recurrently self-advocate for access to healthcare as impacting their current or potential health capability?**

The findings that emerged from participants' experiences in barriers to healthcare went beyond describing the barriers that exist to healthcare access and use (Drum, 2014; Hwang et al.,

2009; Iezzoni et al., 2010; Kroll et al., 2006). These findings provide insight into participant understandings of the pervasive and perpetual lack of accommodations across healthcare experiences. As a disabled person, they each recognized achieving meaningful access to appropriate healthcare required decisions to self-advocate for accommodations in some if not all healthcare encounters. Each participant described multiple experiences of inappropriate care and failures to receive care due to socially constructed barriers within healthcare facilities.

1. **Embodiment of disability and impact on health**

All participants describe repeated experiences of providers' lack of disability knowledge and worse, presumptions of authority over the body similar to findings across healthcare access literature (Dillaway & Lysack, 2015; Morrison, George, & Mosqueda, 2008; Rust, Pattillo, Matthews, & Dubois, 2007). Findings from the reports of all participants also correspond to other literature describing how experiences of stigma and discrimination reduce their likelihood of seeking out or delaying visits to necessary care (Moscoso-Porras & Alvarado, 2016). The impact of perceived discrimination and stigmatization was interpreted by participants to have a much broader effect on their health as participants reported physical and emotional stress, perceptions of provider micro-aggressions, loss of dignity and respect, and, fatigue and perceptions of being a burden as a direct result of encounters with providers. The negative impact of discrimination is consistent with research with other stigmatized groups (Inzlicht et al., 2006; Krieger, 2014).

Participants' accounts of the impact of negative experiences in accommodation requests can be understood by examining literature on the impact of micro-aggressions or from literature exploring the physical/biological impact of discrimination (Inzlicht et al., 2006; Pascoe & Smart Richman, 2009; Schmitt, Branscombe, Postmes, & Garcia, 2016; Schmidt & Nosek, 2010; Sue et

al., 2007). This literature directly supports claims that health is negatively impacted by perceptions of discrimination. Other research describes how contextual factors, similar to those perceived by study participants such as a lack of control over their care, feelings of rejection, perceived prejudice, can contribute to stress and poorer health (National Research Council, 2014; Pescosolido, Martin, Lang, Olafsdottier, 2008). This research has yet to be extended to PWD but findings from this study support at least a perceived connection that warrants further study.

Gary offered a glimpse into the health effects of provider discrimination. Gary's pride in his decision to self-advocate for his needs was evident in his claim that, *"Ever since I've taken control of my body ... I feel better"*. He recognized that as he gained control or authority over his body, he experienced a greater sense of well-being. Throughout his interview he talked about ascribing to provider rules and following provider prescriptions, having his authority replaced by provider control, and losing efficacy for his own healthcare. He described struggling between listening to his body and knowing what it needed versus listening to provider authority. In the process of this struggle, he began developing his agency in self-advocacy, and embodying disability. His interpretations of self-doubt in self-advocating described an ongoing and emotionally painful process however, he recognized feeling better by resisting his provider's medicalization of him. He described his own physical and mental health as improving, but only after seeing the impact of the prevailing beliefs of providers - that disability and health are incompatible – lessons he described learning through trial and error, and from mentors and allies that exposed him to strategies in resisting this form of oppression.

2. **Impact on empowerment**

Hughes and Patterson (1997) described the embodied disablement experienced by individuals with disability when medical authority marginalizes and medicalizes them.

Experiences of medicalization by providers were understood by participants as the cause for self-advocacy and a critical step in the process to developing their own strategies of self-advocacy as strategies of resistance as bodies that matter (Loja et al., 2013) in health and healthcare promotion. As participants took authority over their bodies they increase their agency in self-advocacy by integrating understanding of the laws that support their right to accommodations, empowering them as a disabled individual and recognizing membership of a collective community of disability.

Research aligning identity with group membership supports individual self-esteem and self-efficacy in resisting the negative consequences of discrimination (Inzlicht et al., 2006; Major, Quinton, & Schmader, 2003). However, disability scholars have warned of supporting efforts to embrace individualized self-advocacy as a necessary skill set for a person with disability and assert true disability advocacy crosses to the entirety of the disability collective (Oliver, 1996a; Shakespeare, 1996). Findings from this study, indicate that participants' experiences in successful advocacy aligning and reinforced their identities of being part of the disability community as they were advocating not just for themselves but as representatives of the broader community. Thus, their advocacy efforts align the understanding that disability self-advocacy is part of a larger process that extends to and includes the collective community – including those that may participate “only by their presence” (Dowse, 2001, p. 135).

Participants' understanding of their different care needs because of their impairment - their embodied differences - lead them to empowered agency in self-advocating for their right and a collective right to accommodation. This finding contradicts Watson's (2002) assertion that rejecting disablement is “constructing a narrative identity that allows for a separation of body image and self-identity” (p. 524) but instead embracing the collective differences of those

disabled. This study's findings more closely align with Engel and Munger's (2003) that the relationship between disability rights and disability identity holds the key to understanding how specific provisions of the laws "become active in the lives of their intended beneficiaries" (p. 142). They conclude that if rights holders cannot recognize unjust and disparate treatment "they may come to accept as natural and appropriate what might otherwise be considered exclusion or discrimination" (Enger & Munger, 2003, p. 144). Participants not only recognized discrimination embedded in healthcare but they had the power supported by legal rights and embodied authority to get their needs met and in some cases, change the system for the larger community. With learned approaches and increased knowledge participants' rejection of medicalization and social construction of barriers to healthcare empowered their disability identity development and promoted agency to self-advocate.

VIII. SUMMARY OF STUDY

A. Summary of Findings

This study sought to explore the meaning that barriers to healthcare have for people with mobility impairments as well as the personal and contextual factors that influence decisions to self-advocate for accommodation. The findings of this study identify two superordinate themes that were shared across all six participants: ‘knowing what you need’ and ‘the lasting impact of empowerment.’ These two themes have a reciprocal relationship as the development of empowerment was through understanding their healthcare needs would not be met unless they advocate. Participants self-advocated but understood they have the power (at times) to affect barriers to healthcare access that can result in necessary changes to the social creations that exclude difference and discriminate against PWD. The normalized practices of disability discrimination in healthcare are pervasive and persistent, can be explicit and overt but at times implicit and hard to notice. Recognizing NODD and knowledge of disparate treatment strengthened disability identity but personal and contextual factors influenced participant’s agency in decisions to self-advocate. This finding is consistent with Seibers’ (2008) claim that disability identity is “socially created through the discriminatory practices that effect the reality of exclusion” and the growing understanding of their right to healthcare services and the right to receive the “benefits of receipt of these services, enjoyed by non-disabled persons” (p. 189) are necessary for self-advocacy and empowerment.

Participants described the processes they move through to recognizing membership within the disability community and the shared experience of embodying disability as a means to support their agency in claims to accommodation. Agency in self-advocacy can develop through exploration of the strategies that work best for them. There is no one “right way” to self-

advocate. The individuality of their impairment disappears as they recognize the similarities they share with the collective (Siebers, 2017). The shared experience includes an understanding that their healthcare will likely be impacted by their bodily difference. The participants of this study interpret experiences in applying this knowledge as empowering them to be prepared, similar to evidence from other research, to “challenge ableism by adopting disability as a positive identity” (Loja et al., 2012, p. 198).

In his clarifying interview, Tomás captured the essence of the study findings, “[As a disabled person attempting to access basic healthcare] *you will have to combat prevailing beliefs of disability held by providers and understand you can and are living the life we were told – either directly or indirectly in the form of social myths of disability – that we cannot.*” By rejecting social myths of disability, the medical model ideologies, and expectations of health and disability, the participants developed both a strong sense of agency and an empowered disability identity quite similar to the critical consciousness Freire (1973) suggested as necessary for people who are marginalized and discriminated against to overcome the processes of oppression.

The findings of this study demonstrate how this critical consciousness influenced the participants’ ability to perceive micro-inequities and more broadly NODD. By recognizing disparities in care, participants were able to mobilize their agency in self-advocacy within healthcare. The meanings of experiences recursively informed participant understandings. As this study only explored the experiences of self-identified advocates with physical disability further research is needed to explore how PWD with limited awareness of the influences of negative stereotypes and stigmas of disability influence their healthcare and advocacy experiences. Similar to other studies of disability self-advocates, this studies participants’

perspectives lend support to the important role of self-advocacy has in the development a positive disability identity (Caldwell, 2011).

B. **Implications**

Interpretive Phenomenological Analysis (IPA) was used to explore the meanings PWD construct about their experiences of barriers to healthcare and self-advocacy using critical disability theories and the social model of disability to understand participants' decisions of when and how to request healthcare accommodation. This approach in conjunction with the strong theoretical foundations allowed me to identify and analyze individual and collective meanings, linking these back to the study research questions. The individual stories exposed unique accounts and experiences in advocating for accommodations but looking across cases a shared process in developing agency in self-advocacy, embodiment of disability, and a sense of individual and collective empowerment occurred in recognizing the normalization of disability discrimination within healthcare. A common and powerful theme from participants was recognizing the disparity in the care they received compared to care they would receive if not disabled. This larger understanding was coupled by repeated exposure to provider behaviors perceived as normalized processes of disability discrimination or prejudice and micro-inequities against them. Knowledge of their individual health needs, an understanding of rights to care, and efficacy in strategies specific to the context were the shared factors that informed their agency to advocate or not. These factors all combined to create a lasting impact of embodiment of disability and health, and a sense of empowerment. The implications of these findings can be used to: 1) inform and support community advocacy efforts in accessing care; 2) offer greater insight to needed changes within healthcare systems to make it more inclusive of PWD; and 3)

provide further evidence of the need for stronger enforcement of the ADA across all of healthcare.

1. **Informing and supporting community advocacy efforts**

- a. **Recognizing and naming disparate care & discrimination**

Exploring the meanings of barriers and how people decide to self-advocate for healthcare access and accommodations has exposed factors previously rarely described in the literature. The findings illuminate the normalization of disability discrimination (NODD) - perceptions of discrimination experienced as the status quo - that go virtually unnoticed in the day to day practices of healthcare organizations by administrators and providers. Although individual providers at times were overtly discriminatory, participants believed that societal and administrative influences support perpetuating micro-inequities that are the scaffolding for a culture of prejudicial behavior against PWD. They experience these as more insidious and in many ways more harmful than explicit acts. This finding has multiple implications for informing the disability community on efforts in healthcare advocacy.

Similar to the exposure of acts of sexual harassment against women increasingly reported in the media, sharing of experiences and identifying successful strategies for eliminating healthcare discrimination could be a powerful tool for the individual and the collective community. The ‘Naming, Blaming, and Claiming’ model used in research by Harpur (2014) exposing to the wider disability community experiences of discrimination within work and employment, could also be used to expose acts of discrimination within healthcare. Research on implicit bias demonstrates that non-disabled individuals are unable to pick up on unconscious or even conscious prejudicial behaviors when they occur (Friedman, 2016). Researchers working to understand acts of micro-inequities emphasize they are often wrongdoings by people who think

they are doing the right thing (Brennan, 2016). Exposing behaviors for what they are - as inequitable care and discrimination can act to educate and sensitize providers on how behaviors are perceived by members of the disability community.

However, naming the act as an inequity or as discrimination requires a conceptual understanding of the social construction of the barriers to care versus locating the blame on the self. This shifts the lens from accepting practices of oppression as normal to recognizing the acts as attempts to maintain the established structures of dominance. It also requires individuals possess a basic understanding of what the healthcare facilities legal requirements of access are. The process of identifying and naming discrimination facilitates what participants identified as an initial step toward developing agency in self-advocacy. This also provides a transformational shift of understanding described by Bartky (1990) for feminists and Twine (2010) for racially mixed families of color that helps people develop their disability identity and disability health literacy.

This dissertation's findings identify how this process might be facilitated among the disability community based on experiences of participants. Healthcare access models describing *barriers to care* might shift the language to 'naming' barriers as *physical, attitudinal, informational acts of discrimination*. For example, inaccessible physical access to exam tables, MRI machines, dental exam chairs, scales, and more were experienced as discrimination against people with bodies that fail to conform to normative standards. Negative attitudes and stereotyping were perceived as discrimination with harmful emotional and physical impact. Body language, shifts in tones of voice, and rolling of eyes are examples of provider acts of micro-inequities. Discrimination was the meaning participants gave to times when providers failed to understand how to offer basic healthcare to differently functioning bodies. Naming these as

inequitable care provision and discrimination helped participants develop empowered approaches to self-advocating that might be used by the larger community. Disability community efforts in research, community actions, and mentoring workshops might reconsider naming barriers to care as discrimination to more accurately describe the experience as acts of exclusion in healthcare. By doing so, healthcare access may emerge as a critical priority standing alongside other disability community concerns such as discrimination in housing, transportation and employment.

b. **Equipment standards and knowledgeable providers**

Community members also can develop increased understanding of addressing the physical discrimination through use of the U.S. Access Boards recommendations for medical equipment standards as a practical tool for understanding individual needs, and simultaneously educating providers to what meaningful access truly is. Exploring specifics that apply to their own physical access needs such as the height of an accessible exam table (17 inches minimum and 25 inches maximum – or paired to be at or near the height of the person’s mobility device) to use this language in advocacy and provider education. While the Access Board’s recommendations as presented are overly complicated, the disability community could work to simplify the recommendations for dissemination purposes, increasing individual and community disability health literacy.

In efforts to address informational discrimination, participants recognized the benefits of seeking out knowledgeable providers who had both an understanding of the social constructions that disable plus experience in working with individuals with impairments demanding different approaches to providing care. The participants in this study each recognized that they needed an upfront discussion with providers on their healthcare needs. PWD must recognize that not all

providers are equally capable of providing disability competent care. People should be supported in changing providers when advocacy fails to yield desired outcomes.

Using this study's findings to apply these considerations for the disability community does not disregard the responsibility of healthcare institutions and providers to eliminate the normalization of disability discrimination that dominates the experience of the participants in this study and likely other disabled people. It does however imply a more active stance, suggested by participants from this study, from members of the disability community to have their voice be heard and engage the support of allies when necessary. Disability scholar Carol Gill provides very practical suggestions on how PWD can be "armed against the destructive, sometimes lethal, power of stigma" (2016, p. 1000) that include: exposure to the social model of disability, disability rights, and arming PWD with strategies to recognize and deal with stigma. Suggestions that are supported by the experiences of these self-advocates.

2. **Use of disability mentors**

Five of the six participants describe the impact of exposure to the collective disability community or to disability mentors as educating and influencing their self-advocacy. Tomás was the only participant who did not specifically identify learning from mentors, however his legal education and training may have substituted for providing a formal mechanism for self-advocacy education. The findings provide a window into the critical value of learning from others in addition to personal trial and error. Study participants describe being exposed to Centers for Independent Living, organizations such as ADAPT, and disability community social groups as providing mentorships that directly influenced their understanding of the social model of disability and oppression of people with disabilities.

Recognizing that negative attitudes and stereotyping of PWD by providers is in fact cultivated by social and cultural beliefs of disability played a powerful role in developing agency in self-advocacy for study participants. The participants described how the shared recognition of the experiences spurred them to develop strategies for self-advocacy that aligned with personality characteristics. These findings highlight the importance of exposing people with disability to disability mentors to offer opportunities to help build on their collective knowledge and to increase efficacy of advocacy efforts to ultimately increase healthcare quality.

These findings also provide a framework for shifting approaches in allied health interventions within rehabilitation. Occupational therapists are committed to recognizing occupational injustices and enable clients with disabilities to participate in the occupation of health, including health promotion and health maintenance (Tucker, Vanderloo, Irwin, Mandich, & Bossers, 2014). Rarely are interventions directed at facilitating health with disability. Efforts in rehabilitation to reduce disability versus optimizing health may be a missed opportunity for occupational therapy's potential benefits to the people we serve. Rehabilitation professions such as occupational therapists are in a position of power to acknowledge and include disability mentors as experts in managing health with disability and as a resource for working with individuals newly disabled. Working in partnership, disability community members and providers such as occupational therapy can work to develop interventions directed at recognizing individual healthcare needs, and exposure barriers to care – including those subtle barriers perpetuated by NODD, and introduce strategies that align with personal preferences for times when self-advocacy is necessary.

3. **Recognize the impact of prolonged activism efforts**

Each participant had a sense of responsibility to advocate against discrimination for the collective disability community when accessing healthcare. Decisions to self-advocate were influenced by beliefs that individual advocacy efforts might act as a catalyst for change – if not at the system level at least on the behaviors or practice patterns of the individual provider. This in turn reinforced participants’ disability identity and sense of empowerment and a sense of working for the greater good of their community. However, these findings also expose some of the detrimental impacts of extended advocacy including advocacy fatigue. This information can be used by the disability community to increase an emphasis on concerns for care of self, especially for those individuals with extended periods of involvement in disability activism efforts. Community disability activism is invaluable however, community organizations should also be mindful of the risk of fatigue or burnout and implement programs to support its members.

4. **Recognize the reciprocal relationship between agency and empowerment**

The findings of this study suggest the importance of recognizing individual impairment as a vital part of embodied experiences of disability, especially in concerns of health and healthcare access. These self-advocates describe understanding their normal processes of caring for their basic health needs are not part of routine practice approaches within the United States healthcare system. This created a link in understanding exclusion from standard care was a shared disability experience and substantially influenced their agency in self-advocating for accommodations as it: 1) increased an understanding of the implications of care receipt; 2) helped them identify ignorance of providers to healthcare needs; and 3) exposed to them their rights to an accommodation as members of the disability community. As a result, and through activating their right to receive what they need for their health, participants describe similarly

being empowered as the expert in managing their healthcare and as a disabled person. This finding can be used to extend the conversation on the meanings of impairment to the phenomenon of disability as well as further exploring acts of discrimination - especially by our healthcare system - toward health with disability.

5. **Offer greater insight to needed changes within healthcare systems**

One of the primary reasons for carrying out this research was that in spite of a relative large body of knowledge of barriers to access for PWD there is limited understanding of how people deal with and interpret these experiences. The findings fill a gap in understanding the impact of healthcare organization's continued failure to incorporate accessible medical diagnostic equipment into standards of practice. Using the 'Naming, Blaming, and Claiming' model (Harpur, 2014) study participants recognized the behaviors and negative stereotyping, inequities in care and normalized practices of disability discrimination of providers link directly back to the culture of the organization and its embedded beliefs about disability and health. Participants 'blame' the failure of organizational authorities to implement accessible equipment as manifestations of the value they place on PWD. As Tomás attested to, these organizations know the ADA (42 U.S.C. § § 12101-12213) prohibits discrimination on the basis of disability (Title II and Title III) and that Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. § 792 *et seq.*) prohibits exclusion to the benefits of or discrimination against participating in the receipt of services, programs or activity but they chose not to act. Without a formal approach for enforcing the laws the status quo of discrimination against PWD will persist.

Participants also identified a lack of disability competence among healthcare providers working with PWD. Even in instances where an accommodating piece of equipment could be dusted off, providers did not know how to use it. Research shows that knowledge dissemination

and translation on practice standards can improve (Perleth, Jakubowski, & Busse, 2001) a healthcare organization's approaches to clinical and policy practices (Kitson & Straus, 2010). Incorporating disability competencies has been recommended by many accessibility focused researchers (Kirschner & Curry, 2009; Lagu et al., 2014) as well as disability scholars (Gill, 1987; Shakespeare et al., 2009) yet translation to meaningful education is rare. To fully capitalize on the experiential and embodied knowledge within the disability community education on cultural disability competence requires members of the disability community lead development, implementation and oversight of these trainings. The participants of this study were shocked by the pervasiveness of bias of providers toward PWD. The fact that of all contexts – healthcare for PWD would be one of the least accessible experiences is incongruous with the tenets of benevolence and non-maleficence. Routine education as part of yearly competencies in addition to inclusion in educational curriculum could potentially reduce the kind of negative healthcare experiences described by study participants.

To create a cultural change within healthcare systems requires a collective responsibility and commitment to behavior change that does not occur easily. This would include a commitment within entry-level medical education of providers focusing on health *with* disability as well as ongoing competency trainings of all healthcare staff. It would also recognize the need for diligence in monitoring inequitable care delivery as these would be recognized as links that contribute to disparities in healthcare outcomes. Naming and blaming discrimination is one approach however recognizing and reinforcing examples of equity in care – from institutional examples to individual ones can also highlight how to “do things right”.

6. **The need for stronger enforcement of the ADA across all of healthcare**

At present, there are no national-level data on the accessibility of healthcare facilities and services (Singer et al., 2017). Still, 25 years after the ADA full and equal access and appropriate provision of healthcare does not occur for the majority of people with disabilities who use wheelchairs because of the continued presence of constructed barriers (Stillman, Bertocci, Smalley, & Williams, 2017). The disability community and disability advocates have provided recommendations for greater enforcement of accommodations in healthcare that are reasonable and achievable (Panko-Reis et al., 2004; Singer et al., 2017; Stillman et al., 2017). The ADA establishes the right of PWD to receive accommodations to achieve full and equal access and the Access Board's recommendations (2017) eliminate the ambiguity to what meaningful access is. Although substantial efforts were taken in developing these standards, they remain unenforceable as the Access Board has "no statutory authority [as] it requires a federal agency, in this case the Department of Justice through a separate ruling to adopt the standards as mandatory" (U.S. Access Board, 2017, p. 2). At this time, the medical diagnostic equipment standards remain in limbo, in part due to current political threats to repeal the Affordable Care Act and additionally a moratorium has been issued by the Attorney General of the United States to the DOJ stopping the adoption of any new regulations.

In an Executive Summary submitted with the dissemination of the standards, the Access Board suggests the impact of these standards when adopted by an enforcing agencies would be that "individuals with mobility...disabilities will benefit from access to and use of diagnostic equipment...and as a consequence be able to receive health care comparable to that received by their non-disabled counterparts" (U.S. Access Board, 2017, p. 1).

Seventeen years ago, a legal scholar, Crossley questioned the impact of the ADA on the healthcare of PWD and concluded it had not failed but had so far been inadequate in reducing disparities related to health of PWD through improved access (Crossley, 2000). Based on the findings from this study a radical reframing of discrimination with the healthcare system may be required to spur system change. Given that NODD not only limited healthcare access but also led to the provision of inappropriate and inadequate care, shifting the conversation from civil rights based language to neglect and “malpractice” may be the radical shift needed to force change. Although admittedly few participants were ready to make that leap.

Study participants each describe multiple experiences of failure to receive meaningful access through reasonable accommodations. Title II and Section 504 have made it much easier for both PWD and provider services to understand what meaningful access implies. If a person using a wheelchair isn’t accommodated by a ramp or a door allowing access to the building it is clear to both parties that meaningful access into a clinic have been denied and discrimination has occurred. With the establishment of the U.S. Access Board’s medical diagnostic equipment recommendations, meaningful access to services that would otherwise be made available to a person without a disability - requiring a table to lower, etc. - becomes more tangibly recognizable. The Board’s recommendations are the standards that establish meaningful access. Study participants describe the benefits of using the knowledge of the ADA and the language as a foundation for developing agency in self-advocacy. These finding suggest the value for the disability community to widely disseminate and promote the basic language of the standards for disabled people when accessing care, as the findings also show it is unlikely that healthcare organizations will pro-actively implement these changes. Pro-active changes that might be addressed through relatively minor shifts in care delivery practices, and easily supported by all

stakeholders can include increasing provider education, targeting and addressing acts that are perceived as micro-inequities, and disability cultural competency trainings. Addressing these recommendations through facilitating collaboration between multiple stakeholders to prioritize efforts would be an important focus of future research and service.

C. **Study Limitations**

While every attempt was made to bracket my own bias, my clinical and academic background presented a limitation to this study. This limitation is based on a history where the social relationship between a clinically informed researcher and the researched is grounded in the researcher as expert (Oliver, 1992). By choosing Interpretative Phenomenological Analysis as the approach to this research and using the participatory methods, careful reflection was given to contextual variables - including power relations – that bias this study (Linton, 1998). Relevance to the disability community was enhanced through using research questions developed in conjunction with members from the disability community. Research and interview questions were informed by activist from the disability community and their input was informed by their sensitivity to the concerns of the larger disability community.

Other limitations include, single researcher and researcher bias during data analysis, and the decision to lessen the homogeneity of the participants by including both males and females, and PWD who identify as self-advocates. Sample size does limit the findings to the participants in this group and informed only by self-advocates and people with physical disability, and therefore not transferable to the larger population of PWD. However, the differences within the group that include gender, race, age, and physical disability type offer some evidence that these shared experiences may be similarly reported from others with physical disability.

Although IPA recommends exploring research for shared homogeneous participants and eliminating differences such as gender, age, culture, race, I reflected on and determined the common phenomenon of experience, the shared experience of physical disability, to be the unifying condition. Another characteristic that limits the reach of the findings is the common geographic location. Each person currently lives in a large urban setting with potential access to multiple providers. How these experiences might be different for PWD in an area with little to no choice might drastically shift the phenomenon as it is experienced and interpreted. Gary's experiences provide a glimpse into how a disabled person might have significantly different interpretations of experiences in self-advocacy if living in a more rural setting.

Given that this study intentionally focused on the experiences of people who identified as self-advocates, it is not known how members of the disability community without the similar levels of knowledge, efficacy, or capability for self-advocacy in healthcare might interpret experiences of lack of accommodations. It is therefore unknown if the conceptual findings described by participants, specifically NODD are identified by the larger disability community. Future research might further explore how this concept is experienced and mobilized by other PWD.

All but one of the participants was a person I had met previously and four of them I knew through different academic and research experiences. While this may be a limitation in influencing how the participant responded to questions, it provided an opportunity for deeper analysis from the ideographic standpoint. My understanding of the person from past experiences allowed me, at times, to delve into deeper meanings they gave when interpreting their experiences.

It was a challenge during coding to ignore or put aside emergent themes from previous case analysis to begin the next case fresh – free of bias. However, every attempt was made to attend to methods such as those recommended by Callary, Rathwell, and Young (2015) to critically reflect on the creation of specific codes as they emerged inductively or deductively from an earlier established theme. I used this approach throughout this study referring back to my reflective hermeneutic diary and audit trail and following meetings with my advisor as I reviewed evolving theme development.

Analysis was also largely informed by a single researcher. I believe my interpretations to be true to the meaning and intent of the interpretations by participants of their experience but recognize other perspectives may expose differences I could not see. Steps taken to reduce this limitation included returning to the participants for the clarifying interview, use of the data analysis team, and discussions with my advisor. A valuable tool in the advising process included having my advisor read individual cases followed by discussion of the identified emergent themes. The guidance of her expert qualitative researcher's eye helped me to better organize and conceptualize links between themes and validate emerging superordinate themes.

D. Future Research

Using IPA as an approach for exploring the lived experience of PWD as they interpret the meaning of barriers to healthcare - and their need to self-advocate to access - is a significant strength of this research study. Directions for future research include exploring the experiences of members for the disability community who do not identify as self-advocates as understanding their interpretations would be of critical importance in advancing understanding of concepts that emerged from this study. Research might also explore the processes of developing the tacit knowledge of disability health literacy evident in each participant and how agency in self-

advocacy might be facilitated, including those who have no access to disability mentors. One fruitful area to explore may include exploring the processes of evolving agency in self-advocacy that appeared to be facilitated in some participants by exploring their own interpretations and meanings of healthcare experiences.

Exploring the relationship that exists between collective advocacy experiences, perceptions of social participation, and development of agency in self-advocacy could also be invaluable to inform stakeholders invested in promoting the disability communities' healthcare self-advocacy efforts. Translating findings to meaningfully strengthen disability advocacy efforts and optimize access to primary and preventive healthcare in an important next step to achieving the goals of this research.

The different experiences of advocating as a person with sensory, cognitive, and behavioral accommodation needs would extend the knowledge of shared and different interpretations across the disability community. As described earlier, exploring the experiences from other lived worlds including rural and culturally different contexts would extend the understanding of advocacy in healthcare. Finally, another potential future research area might examine the perspectives of providers on the concepts that emerged on NODD including exploring the relationships between an institutions level of dedicated commitment to healthcare accommodations and disability cultural competency and implicit and explicit bias against PWD.

IX. CONCLUSION

The ADA and its implementing regulations require equal and independent access for people with disabilities for all covered facilities (not just pools). Allowing covered entities to store lifts and only take them out on request places unnecessary additional burdens on people with disabilities. People with disabilities have long faced the challenges of dealing with portable accessibility features – e.g., staff are unavailable or too busy to help locate and set up the equipment, the equipment is missing, the equipment isn't maintained, or staff do not know how to safely set up the equipment. In addition, the ADA Standards specify that a lift must be located at the proper water depth and with the necessary space around it to maneuver a wheelchair. Moving a portable lift around raises the likelihood that the lift will be improperly located, making it difficult or dangerous to use. (ADA.gov, 2012, p. 1)

In 2010, the Department of Justice adopted the 2010 Standards for Accessible Design that include accessibility standards for swimming pools for entities covered by Title III of the ADA (1991). Today hotels, parks, and city pools have clearly visible accommodations for people with physical disability allowing for meaningful participation in the activity of swimming. Seven years after this ruling, PWD still are not afforded the same opportunity of meaningful access to basic healthcare. During analysis, I was struck by statements and experiences of participants that describe experiences of normalized discrimination within healthcare. As I explored the meanings within the transcripts I returned to resources from disability studies, dialogue with committee members, and conversations with members of the disability community on this lived phenomenon. It resonated with disability community members as an experience they recognized.

Socially imposed restrictions to effective management of health goes beyond not only undermining these participants psycho-emotional well-being, it also really impacted their health. Exclusion of people with disabilities from healthcare is a matter of fact and the practical solutions are twofold: disabled people and their allies must expose discrimination for what it is, and healthcare organizations must take responsibility that failing to support accessible environments perpetuates micro-inequities in care delivery and prejudicial behaviors and

attitudes of providers. Bartky (1990) offers that “psychological, political, and economic modes of oppression serve to maintain a vast system of privilege of race, sex, and class” (p. 32).

Similarly, the medicalization of disability maintains the systems that privilege health. Why else would swimming pools be accessible and medical diagnostic equipment not?

Each participant interpreted the meaning of their healthcare experience from the embodied position of disability. What variables made the experience stand out as significant and how it informs their thinking and choice depends on intersecting personal factors from past experiences in healthcare and healthcare relationships and self-advocacy. How they make sense of barriers to care as discrimination is a first step to empowered agency in healthcare.

Recognizing the oppressive processes that continue to view the disabled body as the property of the provider is critical to understanding these same processes will not view that same body as healthy.

APPENDICES

APPENDIX A

IRB Stamped Approved Recruitment Letter

THE
UNIVERSITY OF
ILLINOIS
AT
CHICAGO



Dear (potential participant name),

You are invited to participate in a research study exploring your experiences with healthcare access barriers and your decisions to request an accommodation. People with disabilities experience many barriers when trying to receive healthcare because providers' offices and equipment aren't accessible. An accommodation request is often required of the PWD to receive necessary care. Many things influence why a person may decide to advocate for an accommodation or not. Understanding these experiences can provide valuable information on the complex ways that healthcare access barriers impact the health of PWD.

If you are older than 18 years, identify as a person with physical disabilities and a user of a wheelchair for home and community mobility you may be eligible to participate in this study. Eligibility also requires that you have had a healthcare visit in the last 2 years and at some point in your past have requested an accommodation in a healthcare visit based on your knowledge of the Americans with Disabilities Act.

If you decide to join this study you will be asked to participate with me in a series of two one-on-one interviews. The interviews will take place at a location of your choice and last for 1.5 to 2 hours. The interview will be recorded and then transcribed by me. Your decision to participate is totally voluntary. If at any point you decide you do not want to or can't participate I will respect this decision and there will be no consequences to you in any way based on this decision.

If you would like to find out more or to see if you might be eligible to participate please contact me at lvampu2@uic.edu OR call me at 773-860-0201. Thank you so much for your time and interest in this study.

Sincerely,

Laura VanPuymbrouck

Laura VanPuymbrouck
University of Illinois at Chicago
lvampu2@uic.edu
773-860-0201

APPENDIX B

IRB Stamped Approved Telephone Screen

Rights to accommodation in healthcare Phone Screening Survey for potential study participants



Thank you very much for taking time with me today. People with disabilities experience many barriers when they try to receive healthcare because providers' offices and equipment aren't accessible to them. When this happens a PWD can ask the provider to make access easier by requesting an accommodation like an exam table that lowers to make transfers easier. Many things might influence a person's decision to make this request or not. The purpose of this study is to understand the experiences of deciding to request an accommodation in a healthcare setting. I am asking people to participate in one interview that will last between 1.5 – 2 hours and then one additional - but shorter interview - to follow up on the first one. **If you are interested in participating and to find out if you are eligible, I will have to ask you some basic personal questions like your name, age, address, etc. Do you think you might be interested in participating in this research?**

NO ____ Stop the survey and thank the participant for taking time to talk.

Yes ____ Inform the participant that they are now being asked for their verbal consent to answer some basic questions. Inform them that their answers will be recorded on paper and safely locked and stored if they are eligible to participate and decide they would like to participate in this study.

Do you provide your verbal consent for me to ask these questions and document them on paper? NO ____ thank them for their time. YES ____ Continue on to survey questions.

To make sure that you are eligible for the study I need to ask you a few questions. Is now a good time?

1. How old are you? ____
(If the person is not over 18 years of age they are ineligible due to parameters of the inclusion criteria of study)

2. Do you consider yourself to be a person with a disability?

____ Yes. If yes proceed to question 3.

____ No. If no STOP SCREENING and say "thank you for your interest in this study unfortunately we are looking for people with disabilities and this makes you not eligible."

3. Do you identify as a person with a physical disability that uses a wheelchair in home and community for mobility?

____ Yes. If yes proceed to question 4.

APPENDIX B (continued)

_____ No. If no STOP SCREENING and say “thank you for your interest in this study unfortunately we are looking for people with disabilities who primarily use a W/C for all mobility and this makes you not eligible.”

4. Do you identify as a person that has a basic knowledge of your rights to an accommodation supported by the Americans with Disabilities Act?

_____ Yes. If yes proceed to question 4a.

_____ No. If no STOP SCREENING and say “thank you for your interest in this study unfortunately we are looking for people with disabilities with knowledge of rights to accommodation under the ADA and this makes you not eligible.”

4a. Have you ever had to request a physical accommodation in a healthcare setting?

_____ Yes. If yes proceed to question 5.

_____ No. If no STOP SCREENING and say “thank you for your interest in this study unfortunately we are looking for people with disabilities with at least an experience of requesting an accommodation once in the past and this makes you not eligible.”

5. Have you had one healthcare visit in the last 24 months that where you would have needed a physical accommodation?

_____ Yes. If yes proceed to question 6.

_____ No. If no STOP SCREENING and say “thank you for your interest in this study unfortunately we are looking for people with disabilities with at least one healthcare visit in the last 24 months where you would have needed a physical accommodation and this makes you not eligible.”

6. Do you consider yourself to have a mental, intellectual or developmental disability?

_____ Yes, if yes STOP SCREENING and say “Thank you for your interest in this study unfortunately this is an exclusion criteria for our study”

_____ No

7. Do you currently have a surrogate – or someone you rely on to make your healthcare decisions?

_____ Yes, if yes STOP SCREENING and say “Thank you for your interest in this study unfortunately this is an exclusion criteria for our study”

APPENDIX B (continued)

_____ No

“Thank you for your interest in this study, now that I know you are eligible to participate I will need to collect some information from you in order to move forward and receive official written consent from you. I will be mailing you a copy of the written consent form as well as the interview questions that I will be asking you when we meet. Once you receive this please review and call me if you have any questions before making your trip to our meeting. For this meeting we can decide on a place that is easy and comfortable for you to get to. Please expect about 1.5 – 2 hours to for this initial interview.”

Name: _____

Mailing Address: _____

Phone number: _____

Date, location and time available for written consent and initial interview:

Date: _____

Location: _____

Time: _____

APPENDIX C

IRB Stamped Approved Consent Form



**University of Illinois at Chicago
Research Information and Consent for Participation in Social Behavioral
Research**

**Rights to accommodation in healthcare: Self-advocacy experiences of People
with Disabilities**

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title: Laura VanPuymbrouck, OTR/L, Doctoral Candidate Disability Studies
Department and Institution: Disability and Human Development, University of Illinois at Chicago
Address and Contact Information: 1640 W. Roosevelt Road, Chicago, Illinois
 Lvanpu2@uic.edu or 773-860-0201
Faculty Sponsor: Dr. Susan Magasi, PhD Dissertation Advisor
Address and Contact Information: 1919 W. Taylor Chicago, IL.
 Smagas1@uic.edu or 312-996-4603

Why am I being asked?

You are being asked to be a subject in a research study exploring the experiences people with disability have with healthcare access barriers and decisions to request an accommodation - or not - when one is needed. You have been asked to participate in the research because you self-identify as a person with physical disabilities who uses a wheelchair for home and community mobility; identify as a self-advocate in a past healthcare experience; and you identify that you are knowledgeable in rights to accommodations in healthcare.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. Your decision whether or not to participate will also not affect services provided at UIC. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

APPENDIX C (continued)

Approximately 6 subjects may be involved in this research at the University of Illinois at Chicago or a location mutually agreed upon between the researcher and yourself that is comfortable, safe and accessible.

What is the purpose of this research?

Over 56 million people with disabilities experience barriers to participating in every aspect of life - including accessing basic health services. Understanding PWD's advocacy experiences can support efforts to change the healthcare system to make it more inclusive of PWD and also support advocacy efforts for individuals and the disability community. The purpose of this qualitative research study is to **understanding the meaning and impact that barriers to healthcare have for people with physical disabilities. We also want to understand how past experiences influence decisions to request an accommodation.**

What procedures are involved?

This research will be performed at the University of Illinois at Chicago or a location mutually agreed upon between the researcher and the participant that is comfortable, safe and accessible.

You will need to come to the mutually agreed upon study site (between the researcher and participant) two times over the next 6-8 months.

Each of those visits will take about 1.5 to 2 hours although the second visit will be shorter (1 to 1.5 hours).

If you agree to be in this research you would be asked to do the following things:

- Following this informed written consent you will participate in an individual informal interview that follows the Interview Question Schedule that you received in the information packet. With your consent the interview will be audio-recorded.
- This interview will focus on asking you about your experiences of healthcare access barriers.
- The researcher will analyze the first interview.
- In approximately 2 months, you will be asked to participate in a second interview further clarifying some of the issues that were identified during the analysis. This will provide you with an opportunity for feedback and reflection of the accuracy of the researcher's interpretations. The second interview may take place in person, by phone or Skype according to your availability and preference. This second interview will also be audio-recorded following your permission.
- It is important that you understand that at any point in these interviews or study you are free to leave the research/interview for any reason with no negative outcomes on your relationship with the researcher or UIC.

APPENDIX C (continued)

What are the potential risks and discomforts?

- To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.
- The interviews of this study will ask you to think about and describe experiences that will then be interpreted by the researcher. This may create emotional responses when reflecting on the meanings of an experience during the interview process as well as in the second clarifying interview. The second clarifying interview may create distress if investigator interpretations are inaccurate. However, accuracy in interpretation may also have strong emotions as they may validate your own interpretations of an experience – positive or negative.
- There is a small risk of breach of privacy (others may find out that they are participating in the research) and/or confidentiality (others may find out identifiable information collected or disclosed during the research).

Are there benefits to taking part in the research?

You may not directly benefit from participation in the research. It is hoped that the findings may contribute to a greater understanding of the factors that influence people with disabilities.

What other options are there?

You have the option to not participate in this study. You may choose to stop participating at any point in this study. If you pull out of the study for any reason before completion of the Phase one interviews none of the data collected will be used and all data collected up to that point destroyed immediately. If you must pull out of the study following the Phase-two individual interview the data will be used in analysis and all data collected will be de-identified as described.

What about privacy and confidentiality?

The people who will know that you are a research subject are members of the research team. Otherwise information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare (for example, if you are injured and need emergency care or when the UIC Office for the Protection of Research Subjects monitors the research or consent process) or if required by law.

A possible risk of the research is that your participation in the research, or information about you, might become known to individuals outside of the research. While a breach in confidentiality is a possibility, to prevent a breach of confidentiality your name will be replaced with a unique study ID number. Study ID numbers will be used on all study documents. A master list linking study ID numbers to your information will also be stored separately from all study evaluations and in a locked file cabinet that only the principal investigator can access.

When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity.

APPENDIX C (continued)

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

What if I am a UIC student?

You may choose not to participate or to stop your participation in this research at any time. This will not affect your class standing or grades at UIC. The investigator may also end your participation in the research. If this happens, your class standing or grades will not be affected. You will not be offered or receive any special consideration if you participate in this research.

What if I am a UIC employee?

Your participation in this research is in no way a part of your university duties, and your refusal to participate will not in any way affect your employment with the university, or the benefits, privileges, or opportunities associated with your employment at UIC. You will not be offered or receive any special consideration if you participate in this research.

Remember:

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

Signature of Subject

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form.

Signature

Date

Printed Name

Signature of Person Obtaining Consent

Date (must be same as subject's)

Printed Name of Person Obtaining Consent

APPENDIX D

Participant Interview Schedule Original Version 1

Interview Question Schedule

1) Exploring the experiences of past healthcare visits

- a) Can you describe for me an experience you've had when you requested an accommodation during a healthcare visit?
 - i) Prompts: This might have been during an annual check up, dentist or eye doctor visits, healthcare screenings or maintenance like a mammogram or even needing to be weighed.
- b) How did the interaction with your healthcare provider(s) or the office staff make you feel about making your accommodation request?
 - i) Prompt: How did the provider or office staff support/or not support your request?
- c) Can you describe to me a time when your provider took the initiative to accommodate you?
 - i) Prompt: What things does your provider do to accommodate you without having to be asked?
- d) Can you describe a time when you asked for an accommodation but didn't have one provided?
 - i) Prompt: How has your provider failed to accommodate you?

2) Advocacy issues and decisions to request or not request an accommodation

- a) If you know you need an accommodation and know that you have to ask for one what different things influence your decision to ask for one or not?
- b) Can you describe to me how your knowledge of rights (such as the ADA) to an accommodation plays a role in your decision to request one?
 - i) In what ways do you use your knowledge of your rights during healthcare encounters?

3) Meanings of a lack of accommodations

- a) Can you describe to me the impact that advocating for your right to an accommodation has on you?
- b) Do you feel the ADA influence providers in how they work with you?

APPENDIX D (continued)

Participant Interview Schedule Final Version

Interview Question Schedule

Thank you for agreeing to participate in this interview. I want to remind you that this interview is totally voluntary and you can stop it at any time. You are also free not to answer a question or questions. I will be audio-recording this interview and then using this as data in my research project exploring the experiences of self-advocacy in healthcare access. I also wanted to remind you that this interview is scheduled for about an hour and a half to two hours. So if you need to take a break for any reason please don't hesitate. What you say in this interview will remain totally confidential however, I wanted to remind you that this interview will be recorded but will be de-identified during the transcription process. I am now turning the audio-recorder on. TURN ON RECORDER.

1) Exploring the experiences of past healthcare visits

- a) Describe for me an experience you've had in the past when you needed an accommodation during a healthcare visit?
 - i) Prompts: This might have been during an annual check up, dentist or eye doctor visits, healthcare screenings or maintenance like a mammogram or even needing to be weighed.
 - ii) A lot of people feel stressed when going to a healthcare visit. In what ways do you think PWD have additional or other stressors? What factors have you experienced that reduce these stressors?
- b) During the visit you described earlier or in other times what factors influence whether or not you decide to request an accommodation?
 - i) Prompt: What are some of your important reasons for making the decision to request an accommodation?
- c) How do providers or office staff responses to your request influence your decision?
 - i) How does it feel when your provider(s) says they cannot provide an accommodation?
 - ii) How do you feel when you come to a decision not to request an accommodation when you believe you need one?

APPENDIX D (continued)

2) Advocacy issues and decisions to request or not request an accommodation

- a) How do your past experiences influence what or how you advocate for yourself when interacting with providers or the staff?
 - i) If you know you need an accommodation and know that you have to ask for one what past experiences influence your decision to ask for one or not?
- b) Can you describe to me how your knowledge of rights (such as the ADA) plays a role in your decision to request an accommodation?
 - i) In what ways do you use your knowledge of your rights during healthcare encounters?
- c) Do you feel the ADA influences providers in how they work with you?

Prompt: Can you give me an example of how providers understand or fail to understand their responsibility with the ADA?

3) Meanings of a lack of accommodations

- a) We talked today about the experiences you've had about needing and requesting a healthcare accommodation. Many PWD need to request accommodations frequently to get care. How do you think this impacts a person's overall physical, mental or emotional health?
- b) How do you think the need to ask for accommodations in healthcare settings impacts your overall health?

4) Is there anything I didn't ask you that I should have?

APPENDIX E

Participant Second Clarifying Interview Schedule

Second Clarifying Interview Question Schedule

Thank you for agreeing to participate in this second clarifying interview. I want to remind you that this interview is totally voluntary and you can stop it at any time. You are also free not to answer a question or questions. I will be audio-recording this interview and then using this as data in my research project exploring the experiences of self-advocacy in healthcare access. This interview is a follow-up to our initial interview. The purpose of this interview is to provide an opportunity for your feedback, clarification and reflection of the accuracy in the emergent interpretations that I have made. I also wanted to remind you that this interview is scheduled for about an hour to an hour and a half. So if you need to take a break for any reason please don't hesitate. What you say in this interview will remain totally confidential however, I wanted to remind you that this interview will be recorded but will be de-identified during the transcription process. I am now turning the audio-recorder on. TURN ON RECORDER.

1) Emergent Themes from questions to participant exploring the experiences of past healthcare visits

a) At this time I have identified (# to be determined) themes in the answers to the interview questions concerning your experiences of past healthcare visits. These are:

1. _____
 2. _____
- (More if appropriate)

Can you tell me what your thoughts are on these themes individually or as a whole?

i) Prompts: Please tell me how my interpretations are accurate or inaccurate to the meanings you were describing.

2) Emergent Themes from questions to participant exploring advocacy issues and decisions to request or not request an accommodation

a) At this time I have identified (# to be determined) themes in the answers to the interview questions concerning advocacy issues and decisions to request or not request an accommodation. These are:

1. _____
 2. _____
- (More if appropriate)

Can you tell me what your thoughts are on these themes individually or as a whole?

i) Prompts: Please tell me how my interpretations are accurate or inaccurate to the meanings you were describing.

APPENDIX E (continued)

3) Emergent themes from questions to participant exploring the meanings of a lack of accommodations.

a) At this time I have identified (# to be determined) themes in the answers to the interview questions concerning the meanings of a lack of accommodations. These are:

1. _____

2. _____

(More if appropriate)

Can you tell me what your thoughts are on these themes individually or as a whole?

i) Prompts: Please tell me how my interpretations are accurate or inaccurate to the meanings you were describing.

IF INDICATED

4) There were a few other themes that have emerged based on our conversation concerning (X*).

a) At this time I have identified (# to be determined) themes in the answers to the interview questions concerning the meanings of a lack of accommodations. These are:

1. _____

2. _____

(More if appropriate)

Can you tell me what your thoughts are on these themes individually or as a whole?

i) Prompts: Please tell me how my interpretations are accurate or inaccurate to the meanings you were describing.

(*This is to provide an opportunity to discuss themes that emerged in spontaneous discussion with the participant as a result of the semi-structured approach used in the initial interview. This semi-structured approach allows for divergence from the questions if a participant elects to discuss other topics or concerns).

APPENDIX F

Participant clarifications – example

RAHC CLARIFYING INTERVIEW
#3

QUOTE	CODE	INTERPRETATION & ?	FEEDBACK
I was like ok...so there ya go, there's the difference. I guess the accommodation is getting two people but I thought it was going to be that the table would be accessible...lower you know? But that was a misunderstanding on my part I guess.	Failure to accommodate Providers solutions inadequate	<i>Failure to provide needed accommodation – providers solution less than adequate</i> <i>Failed expectations that a special room would actually be special</i> <i>*She interprets her misunderstanding to what her knowledge is of an accommodation.??</i>	She wanted to clarify that it was more than this. That even the second person was inadequate because she still needed to educate both of them on how to transfer her. They had no disability knowledge at all. So it was really a poor alternative.
The PAs um were starting to undress me and the doctor was in the room with a medical student. And I was um like “hey, wait a minute what’s going on here?” And they were like you know, we need to take your clothes off because he’s going to be doing some exams down there or something like that. I was getting upset because they were just undressing me right in front of everybody and in front of him and in front of the student. Without asking me or nothing!	Abuse by providers, Feeling violated, context impact on SA	Minimized her protests Patient privacy doesn’t pertain to her...she’s not worthy???? Inability to SA because provider overpowered her – have authority over her. Emotionally traumatized.	She wanted to emphasize how totally humiliating and abusive this situation and experience was for her. She was traumatized with her arm over her face but speaking out against what they were doing. She did speak out but was ignored.

APPENDIX G

Example of theme evolution

Master List and subthemes

Provider not knowing disability

- Necessitates being in charge
- Battle for authority
- Need to educate
- Battling stigma of disability
- Excluded from regular care
- Intentional ambiguity – sensing indifference
- Provider response to request risky

Learning from experience

- Becoming stronger
 - Learning what works
- Learning to ID Able-ism
- Understanding SA is context specific

Approaches & reasons to SA

- Disability identity development
- Entitled to care – rights based
- Easy way to accommodate
- Healthcare survival tool
 - Types of SA – right ways and wrong ways

Impact of ADA –

- Knowledge of language and specs
- Learning about the ADA

Negotiating for Care-

- Impact of educating providers
- Knowing what you need
- Need to be understood – listened to
- Causing more harm than good
- Loss of authority
- Lasting impact on health

Exposure to SM

APPENDIX G (continued)

Example of theme evolution – early theme analysis

- Empathize with providers
- Helps understand why

Decisions not to SA

- Context and needs matter
- Risky
- Advocacy fatigue
- Not recognizing practices as discrimination

Lasting impact

- Loss of authority
- Understands discrimination impact
- Emotional toll

How Stigma and Discrimination influence care

- Demands PWD to do more
 - Demands PWD educate providers
- Informs decisions to SA – context matters (merged “submitting to NODD to this” could have gone also to “reasons not to SA”)
- Status quo
 - Invisibility of disability

Three potential but important themes subthemes:

There is a difference between group and individual advocacy – it is easier to do it as a group and this might be a way to ‘learn’ SA (if you and group are on same page).

2. Being identified as a SA expert or professional can lend to assumptions you are able to SA individually

3. Time is a contributing context that influences SA decision: There is almost always a background concern for time or not enough time; staff typically don’t understand or are ignorant to time as a factor for PWD
(Time equals energy)
Crip Time – Carrie S.

APPENDIX G (continued)

More evolved theme and Sub-theme analysis

Master themes and subthemes

RECOGNIZING WHY

- PROVIDERS DON'T KNOW about disability
 - Necessitates being in charge
 - Battle for authority
 - RECOGNIZING THEY DON'T KNOW [Need to educate]
- NODD - Battling stigma of disability
 - NODD - Excluded from regular care
 - NODD - Intentional ambiguity – sensing indifference

DECISIONS IN SA

Approaches & reasons to SA

- Knowing what you need
- Entitled to care
- Healthcare survival tool
- Ways of self-advocating

Choosing not to SA

- Context and needs impact decisions
- Advocacy fatigue
- The social model helps understand why

Lasting impact – on health / empowered

- Learning from experiences ways to cope
- Becoming stronger
- The toll it takes - health
- Developing a disability identity

APPENDIX H

Institutional Review Board Approval

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

November 3, 2016

Laura Van Puymbrouck, MS
Disability and Human Development
1919 W Taylor St, Rm. 309
Occupational Therapy, M/C 811
Chicago, IL 60612
Phone: (773) 860-0201 / Fax: (312) 413-0256

RE: **Protocol # 2016-0891**
“Rights to Accommodation in Healthcare: Self-advocacy Experiences of People with Disabilities”

Dear Ms. Van Puymbrouck:

Please note that stamped and approved .pdfs of all recruitment and consent documents will be forwarded as an attachment to a separate email. OPRS/IRB no longer issues paper letters and stamped/approved documents, so it will be necessary to retain the emailed documents for your files for auditing purposes.

Kindly note, that consent documents do not count as data and signed consent documents should be retained at UIC for a minimum of 5-7 years, or however long the funder or any affiliated association (e.g. APA) requires retention.

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on November 3, 2016. You may now begin your research

Please note the following information about your approved research protocol:

<u>Protocol Approval Period:</u>	November 3, 2016 - November 3, 2017
<u>Approved Subject Enrollment #:</u>	6
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Sites:</u>	UIC
<u>Sponsor:</u>	None
<u>PAF#:</u>	Not applicable
<u>Research Protocol(s):</u>	-

Phone: 312-996-1711 <http://www.uic.edu/depts/ovcr/oprs/> FAX: 312-413-2929

APPENDIX H (continued)

Page 2 of 3

- a) Rights to Accommodations in healthcare; Version 2; 10/16/2016

Recruitment Material(s):

- a) Telephone Script; Version 1; 08/28/2016
- b) Welcome Letter; Version 1; 08/28/2016
- c) Recruitment Letter; Version 2; 10/16/2016

Informed Consent(s):

- a) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for recruitment purposes only; minimal risk; verbal consent to screening/eligibility questions will be obtained; written consent/ will be obtained at enrollment.
- b) Consent (no date); Version 2

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

- (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.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
09/02/2016	Initial Review	Expedited	09/23/2016	Modifications Required
10/20/2016	Response To Modifications	Expedited	11/03/2016	Approved

Please remember to:

→ Use your **research protocol number** (2016-0891) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website at,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-0816.

APPENDIX H (continued)

Page 3 of 3

Sincerely,

Alison Santiago, MSW, MJ
Assistant Director, IRB # 2
Office for the Protection of Research Subjects

Enclosure(s) will be sent in a separate email:

1. Informed Consent Document(s):

a) Consent (no date); Version 2

2. Recruiting Material(s):

a) Telephone Script; Version 1; 08/28/2016

b) Welcome Letter; Version 1; 08/28/2016

c) Recruitment Letter; Version 2; 10/16/2016

cc: Tamar Heller, Disability and Human Development, M/C 626
Susan R. Magasi (Faculty Advisor), Disability and Human Development, M/C 811

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Zola, I. K. (1972). Medicine as an institution of social control. *The sociological review*, 20(4), 487-504.

VITA

Name:

Laura VanPuymbrouck

EDUCATION

University of Illinois, Chicago, Illinois, Ph.D. Candidate in Disability Studies, fall 2012 to present. Dissertation title: *Rights to accommodation in healthcare: Self-advocacy experiences of people with disabilities*

University of Illinois, Chicago, Illinois, 1983-1985. Bachelor of Science, Occupational Therapy. Graduated with honors.

University of Idaho, Moscow, Idaho, 1981-1983. Bachelor of Science, Psychology, with Honors. *North Idaho College*, Idaho, 1979-1983. Associated of Science, with honors.

Licensure Information/Registration Number:

Occupational Therapist/ 056.001415

Certifications:

National Board for Certification in Occupational Therapy # AA554725

RESEARCH

Dr. Susan Magasi Research Lab
University of Illinois at Chicago
February 2013 to present

- **Project Coordinator and Co-Investigator** for an American Occupational Therapy Foundation Intervention Research Grant – “*Negotiating the Healthcare System as a Person with Disability: An OT-Peer led intervention*” – a CBPR based one year study
- **Project Coordinator** for a 5-year (beginning 2014) community-engaged federally funded NIDRR grant (H133B140012) to develop a peer health navigator intervention for Medicaid enrollees with disabilities to improve access to community health care services.

Funded/Grant Activity

Spencer Foundation – “The Impact of Occupational Therapy Graduate Education on Conscious and Unconscious Disability Attitudes”

Spencer Reference # 201700112

Award amount -- \$48,980

Co-Principal Investigator

January 2017 – 2022

Other Research Activity

Principal Investigator – “*Occupational therapists as Disability Allies*” a community engaged research project using qualitative methods to collect and analyze the opinions and views of practicing occupational therapists on the philosophic and pragmatic issues and processes that function as either as barriers or supports for inclusion of issues and concerns from the disability community for attending to the social production(s) of disability during clinical intervention. Institutional board approval #2015-1016 for human subject research: 2015-2018.

Principal Investigator – “*Rights to access in healthcare: self-advocacy experiences of people with disabilities*”: An Interpretive Phenomenological Approach to understand the meaning and impact of experiences of barriers to healthcare for people with physical disabilities as they influence decisions to request an accommodation. This is the dissertation research done as partial fulfillment for the PhD in Disability Studies and Human Development. Institutional board approval #2016-0891 for human subject research: 2016-2017.

TEACHING

University of Illinois-Chicago

- *Guest lecturer-PT600 Introduction to Physical Therapy*. Fall 2016. Introduction to Disability Models and Disability Frameworks presentation to first year Physical Therapy Doctoral students.
- *Guest lecturer-OT 500 Theories of Occupational Therapy*. Fall 2016. Introduction to Disability Studies and the Social Model of Disability to Master and Clinical Doctorate Occupational Therapy students.
- *Guest lecturer-OT 512 Human Structure and Function*. Spring 2015-2016. Responsible for multiple individual class lecture/discussions/labs for this first year Master Occupational Therapy class requirement. Provided input to course instructor on appropriate methods of evaluation to determine level of knowledge translation of lecture material.
- *Co-Developer of Disability Studies DHD202: Disability, Health, and Society*, first available Spring Semester, 2014. One of three core courses required for fulfillment of the undergraduate minor in Disability Studies. Instrumentally involved in objective and concept development, syllabus content and course design. Repeat *guest lecturer* to facilitate course implementation and achieve first year course and departmental goals for undergraduate minor (2014-15).
- *Guest Lecturer/multiple topics – Introduction to Rehabilitation Sciences AH210*: required undergraduate course for BS in Rehab Sciences degree. 2015-2017.
- *Adjunct Clinical Teaching Associate* in the Department of Occupational Therapy. Fall Semester, 2011, College of Applied Health Sciences. *OT 406; Therapeutic Use of Self*. Assisting Instructor to Dr. Renee Taylor, responsible primarily for laboratory facilitation in classroom experiences and evaluation of student projects.

Rush University Medical Center, Chicago

Adjunct Faculty to the Department of Occupational Therapy, July 2009 to present, College of Health Sciences.

- *Occupational Therapy Interventions II, OCC512: 2011 to 2016.* A 5-credit course for second year OT Master Students concerned with application of theories and conceptual models for restoration of occupational performance based on biomechanical and rehabilitative principles. Planning and implementation processes for OT are introduced and developed through concurrent interface with the pre-clinical experience.
- *Occupational Therapy Interventions III, OCC512: 2016.* Responsible for lab experiences and evaluation of student clinical assessment and application of knowledge from lab to clinical treatment.
- *Interventions in Occupational Therapy I, OCC512: 2011 - 2014:* Responsible for Physical Dysfunction lab instruction, education and evaluation of orthotic knowledge, clinical treatment interventions, grading of classroom projects, student treatment plans and examinations.
- *Introduction to Neuroscience for Occupational Therapy: 2010.* A 9-week, classroom lecture based introductory course encompassing education of anatomy, physiology, clinical presentation and interventions for first year Master Student Occupational Therapists. Primary responsibilities included lectures, assignment of projects, grading projects, development and grading of take home exams and mid-term/final exams.
- *Introduction to Orthotics and Upper Extremity splinting: 2011.* Responsible for instruction in static and dynamic splinting; theoretical and clinical application of orthotic management and assessment of skill/grading of Master Level OT students in orthotic fabrication.
- *Guest lecturer - Occupational Therapy Perspectives in Health and Wellness: 2015, 2016.* Introduction to the World Health Organization's International Classification of Function focusing on influences and impact for occupational therapy evaluation and intervention design and intersections with the OTPF.
- *Guest lecturer – Health Care Organizations OCC 543: 2016, 2017.* Implementing Health Literacy concepts and interventions into clinical practice.

Peer Reviewed Publications

VanPuymbrouck, L., Heffron, J., Sheth, A., The, K., Lee, D. (2017). Experiential Learning: Critical analysis of standardized patient and disability simulations. *Journal of Occupational Therapy Education*.

Heffron, J., Lee, D., **VanPuymbrouck, L.,** Sheth, A., Beck, J. (In Press). "The bigger picture": Occupational therapy practitioners' perspectives on disability studies.

American Journal of Occupational Therapy.

Freidman, C. & **VanPuymbrouck, L.** (In Press). Community based services for people with brain injury: A national analysis. *Rehabilitation Research, Policy and Education.*

Friedman, C. & **VanPuymbrouck, L.** (In Press). Occupational therapy in Medicaid Home and Community Based Services Waivers. *American Journal of Occupational Therapy*, 72(2).

VanPuymbrouck, L. (2014). Promoting client goal ownership in a clinical setting. *The Open Journal of Occupational Therapy*, Vol. 2(2).

Other Articles

VanPuymbrouck, L. (2017). *Supported decision-making in the United States: A whitepaper by CQL | The Council on Quality and Leadership.* Towson, MD: CQL | The Council on Quality and Leadership.

Mahaffey, L. & **VanPuymbrouck, L.** (2016). Development of an AOTA Special Interest Section forum on disability studies. *The Communique: Illinois Occupational Therapy Association*, 3(July/August/September).

VanPuymbrouck, L. (Nov/Dec 92). Functional Assessment: The Occupational Therapy evaluation of component skills. *Focus On Geriatric Care and Rehabilitation*, Vol. 6(6).

VanPuymbrouck, L. (Jan. 93). Functional Assessment: The occupational therapy evaluation of ADL's. *Focus on Geriatric Care and Rehabilitation*, Vol. 6(7).

Book Chapters

Morley, J., Patel, A., **VanPuymbrouck, L.**, & Schwartz, C. (2015). Occupational therapy interventions related to cardiovascular & cardiopulmonary disease. In: Barney & Perkinson, (Eds). *Occupational therapy with aging adults: Promoting quality of life through collaborative practice*, Elsevier Publishers.

Taylor, R.R. & **VanPuymbrouck, L.** (Oct 2012). Therapeutic use of self: Applying the Intentional Relationship Model in group therapy. In: O'Brien, J. (Ed.) *Occupational Analysis and Group Process*, 1st Edition

Published Abstracts of Peer Reviewed Presentations

Reis, J. P., Martin, M., Wilson, T., **VanPuymbrouck, L.**, Beaumont, J., & Magasi, S. (2015). Screen-ABLE: A mixed-methods study on breast and cervical cancer screening disparities among women with disabilities. *American Journal of Occupational Therapy*, 69(Suppl. 1)

Peer Reviewed Scientific and Professional Presentations (those not previously cited above under abstracts)

Sheth, A. & **VanPuymbrouck, L.** *“Sometimes we don’t even know who to write to or where to go”*: Exploring effective knowledge translation of research on the integration of disability studies into occupational therapy practice. From Tradition to Innovation: 6th Annual Occupational Therapy Summit of Scholars 2017, Boston, MA. June, 2017.

Friedman, C. & **VanPuymbrouck, L.** *Analysis of occupational therapy services in Medicaid Home and Community Based Service*. AUCD 2016 Conference, Washington, D.C., Dec. 2016.

VanPuymbrouck, L. & Lee, D. *Reflexivity in occupational therapy: Incorporating disability studies*. Southwest Conference of Disability Studies, Albuquerque, NM, Oct. 2016.

Magasi, S., **VanPuymbrouck, L.**, Lamp, S. & Wolski, J. *Negotiating the healthcare system as person with a disability – development and implementation of a peer-provider led intervention*. Southwest Conference of Disability Studies, Albuquerque, NM, Oct. 2016.

Heffron, J., Jordan, A., Kish, J., Lee, D., Mahaffey, L., **VanPuymbrouck, L.**, Cooper, J., Fonner, N., Heyburn, B., Thomas, J. *Shifting the power dynamic: collaborating with the disability community to promote a more client-centered practice*. The American Occupational Therapy Association National Conference, Chicago, IL. April, 2016.

Heffron, J., Jordan, A., Kish, J., Mahaffey, L., **VanPuymbrouck, L.** *(Re)Introducing disability studies to occupational therapy practitioners: perspectives from a professional focus group*. Sponsored event of the Human Rights and Social Justice Committee - Society for Applied Anthropology Annual Meeting, Vancouver, Canada, March, 2016.

VanPuymbrouck, L., Mahaffey, L., Jordan, A., Heffron, J. *OTs as disability allies*. Illinois Occupational Therapy Conference, St. Charles, IL., November, 2015.

Magasi, S. & **VanPuymbrouck, L.** *Knowledge Translation Collaboratives: A unique curriculum model to build occupational therapists’ capacity for knowledge translation*. AOTA/OTCAS Education Summit, Denver, CO. Oct. 2015

Magasi, S. & **VanPuymbrouck, L.** *Screen-ABLE: A mixed methods study examining disparities in Breast and Cervical cancer screening among women with disabilities*. American Occupational Therapy Association National Conference, Nashville, TN. 2015.

Magasi, S. & **VanPuymbrouck, L.** *They should stop calling it healthcare....because they don’t care: A qualitative study examining the healthcare experiences of people with disabilities – Implications for occupational therapy*. World Federation of Occupational Therapy Congress. Yokohama, Japan, 2014.

Roush, S., Sharby, N., Magasi, S. & **VanPuymbrouck, L.** *Helping health care professionals become disability allies*. Society for Disability Studies. Minneapolis, MN, 2014.

Magasi, S., Panko-Reis, J., Martin, M., Wilson, T., Thompson, A. & **VanPuymbrouck, L.** *Screen-able; a mixed-methods study examining disparities in breast and cervical cancer among women with disabilities in Illinois*. UIC Women’s Health Research Day, Poster winner for staff and faculty category. April, 2014: Chicago, Illinois.

VanPuymbrouck, L. *Client managed care versus client-centered care*, American Occupational Therapy Association Conference. April, 2014: Baltimore, Maryland.

VanPuymbrouck, L. *Acquiring skill In The Intentional Relationship Model through video self-analysis.* Illinois Occupational Therapy Association Conference. Nov. 2013: Peoria, Illinois.

Magasi, S., Panko-Reis, J., Martin, M., Wilson, T., Thompson, A. & **VanPuymbrouck, L.** *People with disabilities speak out on healthcare disparities.* Northwestern University Feinberg School of Medicine-Center for Community Health Poster Session. May 15, 2013, Chicago, Illinois.

VanPuymbrouck, L. *The process of learning to write for publication.* Illinois Occupational Therapy Associate Conference. Nov. 2012: Lisle, Illinois.

VanPuymbrouck, L. *Client managed care versus client-centered care.* Illinois Occupational Therapy Association Conference. November 2011: Galena, Illinois.

VanPuymbrouck, L., Myers, B., Rosen, H. *Is Proprioceptive Neuromuscular Facilitation part of the occupational therapy domain?* American Occupational Therapy Association Conference. May 1, 2010: Orlando, Florida.

VanPuymbrouck, L. *Sensory regulation for the neurologic client.* American Occupational Therapy Association Conference. May 1995; Denver, CO.

VanPuymbrouck, L. Scientific Roundtable: *evaluating sensory input strategies with the neurologic patient.* Illinois Occupational Therapy Assoc. Nov. 1994.

VanPuymbrouck, L. *Occupational therapy intervention in a Sub-Acute Brain Trauma Program.* American Occupational Therapy Association. June 1993; Seattle, WA.

VanPuymbrouck, L. *Occupational therapy intervention in a Sub-Acute Brain Trauma Unit.* Illinois Occupational Therapy Association, Nov. 1992.

VanPuymbrouck, L. *Treatment of time management skills with the head injured patient.* National Head Injury Foundation 8th Annual National Symposium, Dec.1989; Chicago, Illinois.

Invited Presentations

Lee, D., Sheth, A., VanPuymbrouck, L. (2017, February). Findings from an exploratory pilot study: catalysts and barriers to incorporating Social Model and social justice perspectives into practice. *Scholarship of Practice Lecture Series, University of Illinois at Chicago, Department of Occupational Therapy, College of Applied Health Sciences.*

Primary Instructor for Occupational and Physical Therapist: *Introduction to PNF*, co-sponsored by Swan Rehabilitation and John C. Lincoln Hospital, Phoenix, Arizona. Four-day course for the neurologic and orthopedic patient. September 2013 & 2016.

University of Illinois Chicago; Occupational Therapy Department, Research Methods. *Occupational Therapy Research Roles.* Professional Representative on a panel discussing OT and research for evidence based practice. 2011 - 2015.

Rush University, Chicago; Department of Occupational Therapy. Occupational Therapy Supervisor Fieldwork Panel. Professional Representative on a panel for second year Masters students' discussing fieldwork supervision. July 2012.

Guest Instructor for Ergotherapy staff at The Spinal Cord Research Center in Nottwil, Switzerland. Five day advanced course; *PNF Treatment in the care of Spinal Cord Injury*. September 2011.

2010 Annual Naprapathic Convention. Proprioceptive Neuromuscular Facilitation: *Patterns and Facilitation Techniques for Restoration of Normal Movement*. Chicago, Illinois, Oct. 16, 2010.

Primary Course Instructor and Developer, in conjunction with The IPNFA, Myers, B., and Rosen, H. Advanced practice series of three, one-week PNF courses for Dutch and German Occupational Therapists. Independently responsible for instruction of week-long course. These courses occur at *The Hogeschool, Maastrich, Holland; The Neurologic Clinic of Bad Aibling, Germany; The Spinal Cord Research Center in Nottwil, Switzerland*; as well as throughout Holland and Germany 2-3 times annually beginning in 1992 to present.

Primary Course Instructor/Developer of multiple 1-2 day long, *Introductory and Advanced PNF*, courses for OT's and PT's. Lecture circuit includes; Chicago, San Diego, Dallas, Houston, Atlanta, Portland, St. Louis; 1991 to present.

VanPuymbrouck, L. *Therapeutic Interventions in Neuro-rehabilitation*, Rehabilitation Institute of Chicago; Oct. 2009.

VanPuymbrouck, L., Myers, B., Rosen, H. *PNF Application to Patients with Hand Injuries and Related Shoulder Problems*, Lakeland Hand Clinic, St. Joseph, MI.; June 2001.

VanPuymbrouck, L., Kelly, D. (CCC-SLP). *PNF for the Neurological Client: Focus on Oral Facial/Swallowing Impairments*, 1997, Chicago; 1999, Tulsa, Oklahoma.

VanPuymbrouck, L., Olson, T. (PT). SUMMA Health Care System PNF 1: An Integrated Therapeutic Exercise Approach for Patients with Neurological and Orthopaedic Conditions, Week long course, April 1997; Akron, Ohio.

VanPuymbrouck, L., Myers, B. Two-Day Conference-WorkShop, *Application of Proprioceptive Neuromuscular Facilitation*. Louisiana Occupational Therapy Association State Conference. May 1997; New Orleans, LA.

VanPuymbrouck, L., *NDT and PNF: Functional Application to Adults with Neuromotor Involvement*. The Rehabilitation Institute of Chicago, Sept. 1992.

Other Scholarly Products

VanPuymbrouck, L. (2017, March, 14). Enabling occupation through client goal ownership. [Webinar]. In *Canadian Association of Occupational Therapists, Lunch and Learn Lecture Series*. Retrieved from

http://www.caot.ca/site/page_404?url=http://www.caot.ca/caot_lunch_learn_listings.asp

VanPuymbrouck, L., & Eckerle, L. (2015). Promoting client goal ownership in a clinical setting for OT, PT and SLP. [Webinar]. In *MedBridge Breakouts* Retrieved from: <https://www.medbridgeeducation.com/breakouts/11-promoting-client-goal-ownership-in-a-clinical-setting>.

Audience ongoing and unlimited

Continuing Education Workshops Organized

Chicago Disability Studies Conference Intersectionality & Disability, April 15, 2016. Presented by the Disability Studies Student Council (Officer)

Chicago Disability Studies Conference. Power, disability, justice and coalitions, March 13, 2015.

Presented by the Disability Studies Student Council (Officer)

Membership in Scientific/Professional Organizations

UIC Disability Studies Student Council, Secretary 2015 and 2016

Editorial review board member *Open Journal of Occupational Therapy* 2017

Founding and current board member of Disability Studies+Occupational Therapy Network 2015 to present

American Occupational Therapy Association (peer reviewer for AJOT 2016)

World Federation of Occupational Therapy

Illinois Occupational Therapy Association (member of conference proposal review committee, 2014-2016)

- Committee board member Emerging Leaders Program 2016 to present

American Public Health Association (conference proposal review committee, 2016)

Society of Disability Studies

International Proprioceptive Neuromuscular Facilitation Association – membership approval based on recognized expertise in the approach – ongoing

Student Sub-committee board member to the UIC Chancellor's Committee on the Status of Persons with Disabilities, 2015, 2016, 2017

Consultative and Advisory Positions Held

CQL - The Council on Quality and Leadership. Clinical and research consultant on targeted issues addressing quality of life and quality of service delivery for people with disabilities, people with mental illness and older adults. October 2016 to present.

Elsevier Publishing Inc. Clinical Expert for the Mosby Occupational Therapy Skills Collection. Responsibilities include authoring and updating clinical skills references, performing peer reviews of clinical skills, and addressing clinical queries for the occupational therapy content of the online resources project. June 2016 to present.

Service

Equip for Equality's Voting Access Chicago Project – training and day of monitoring/rectifying of voter access to polls in Chicago's 2016 Presidential election

FIT4LIFE: Wheelchair Basketball Tournament and Health & Fitness Expo, University of Illinois, Chicago. Volunteer sports and conditioning expert. April 2013.

Certified Chicago Public School Volunteer Coach for Cross Country and Track, Boys and Girls with yearly top finishing individuals and teams at CPS city competitions. 1999-2011

President of The Friends of Lincoln, Fund raising organization for Lincoln Elementary School, CPS, 1998-2008

Founder/organizer of "BLTN" Woman's Soccer Organization; promoting fun and fitness with soccer for all ages - 2001 to present

Fund-raiser for Big City Mountaineers, a teenage/youth organization focused on providing urban youth with opportunities to experience challenging outdoor environment

Honors and Awards

Summer Intensive on Community Engaged Scholarship – selected through a competitive nomination process to attend the National Collaborative for the Study of University Engagement at Michigan State University, June 2016. This program accepts a small cohort of early career researchers to participate in a dynamic workshop on community-engaged scholarship with master senior scholars focusing on developing engaged scholarship knowledge and skills.

University of Illinois-Chicago, Occupational Therapy department nominated representative to the 2013 Vivette R. Rifkin Memorial Seminar luncheon and Seminar: Dr. Alan Jette, "Preventing Disability in America"

Henry B. Betts Innovation Award Finalist: *Client Managed care versus Client-centered care*. The Rehabilitation Institute of Chicago, September 2010

Continuing Education Attended (select)

Community-Based Participatory Research Workshop: Balancing issues of power, methodological rigor, and the voices of diverse stakeholders. University of Illinois - at Chicago, Department of Occupational Therapy and the Department of Disability and Human Development. April, 2016.

Measuring Rehabilitation Outcomes in Older Adults, Workshop for integrating outcome measurement into clinical practice. The Rehabilitation Institute of Chicago, July 2014. WFOT Congress, Yokohama, Japan. June 2014.

Society for Disability Studies Annual Conference. Minn. MN. June 2014.

Second International Institute on the Model of Human Occupation A Tribute to Dr. Gary Kielhofner and a Celebration of the 30th Anniversary of the Model of Human Occupation. The University of Illinois at Chicago, January 7-8, 2011.