

**Re-imagining Disability:
Performance Art and the Artists' Perspectives**

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DISSERTATION

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DEDICATION

For Cheryl—who changed everything. And to Greg, who believed, and made it all possible.

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SUMMARY

A study to investigate the relationship between disability experience and artistic representation was conducted using qualitative methods. Interviews with 2 disabled women performance artists, and analysis of one solo autobiographical work from each, yielded rich data. The data offered information on five categories: interrogating cultural designations and assumptions; re-articulating disability experience into art; self-representation and identity; creating disability culture; and the visibly disabled body in performance. In addition, other themes emerged, including performance approaches and strategies that utilize the artists' particular disability perspectives.

Three interviews were conducted with each artist, and thematic analysis of performance texts—scripts, videos, and live performance viewings of *Blurred Vision*—was completed. Artists were given opportunities to interact with analyzed data—thematic review of the artist's performance text and previous interview data—to provide feedback, clarification, and additional themes. This process generated interplay between artist and work, experience and artistic depiction, and researcher, participant, and data.

Findings revealed performance strategies that incorporated disability-centric and politically aware perspectives by the artists. Wade's "radical vulnerability" strategy shakes up her audiences and exposes ableist practices at the root of disability experiences and resists them, while she complicates reality for disabled lives. Lomnicki uses universal aspects from her experience to "build bridges" between disability and able-bodiedness. She comfortably connects with audiences, while cleverly re-creating common disability narratives and tropes. Both transform meanings of disability. The strategies and perspectives revealed provide powerful

models for alternative disability representations that could narrow the “representational gap” between dominant depictions of disability and disabled people’s lived “realities.”

I. INTRODUCTION

Re-imagining Disability: Performance Art and the Artists' Perspectives is a manifestation of my personal journey toward transformation and empowerment that began in 1996. At the time, I had recently become legally blind, and was already a person with deformities, chronic pain, and mobility impairment. My attempts to secure employment were met with my first experiences of discrimination. At the time, I felt this was more personal than systemic, since my previous experience with employment had been equitable and respectful. Yet, once I attended the 1996 Paralympic Congress/conference in Atlanta, my perceptions changed.

The conference featured my introduction to a variety of disabled artists: dance troupes with dancers in wheelchairs, disabled actors, comedians, writers, poets, and cartoonists. I soon became more familiar with the impact of the disability rights movement, which had spawned the development of the disability arts and culture movement that the conference was highlighting. I became acquainted with “disability culture,” “disability pride,” and learned to recognize “disability cool” (Longmore, 2003b). Everything, including the conversations I had with other attendees and presenters, turned my world upside down. Different messages and new ideas amended my self-definition, and initiated a journey of re-interpreting my personal history. The story about disability I had internalized from a young age no longer accurately applied. The ways I viewed myself and other disabled people were necessarily altered.

During this journey, I came across Cheryl Marie Wade. First, her words intrigued me. Reading the lines from “I am Not One of the” (Wade, *Sassy Girl*, unpublished manuscript) left me wanting more. Next, I located a photo of her online, and from her picture, and that she was called “the Queen Mother of Gnarly” (Walker, 2005), I knew instantly she was a “sister” in disability: she and I had the same impairment type. Encountering Wade online accelerated my

journey. Reading her poetry challenged my self-perceptions, and I could not be the only one. I decided that I wanted to change lives on a larger scale. Already working as a vocational rehabilitation counselor, helping to fit disabled people into employment sites that never envisioned such workers, I decided to pursue disability studies. I wanted to change the world.

This research is how I chose to transform the ways internalized and culturally inscribed definitions and stories of disability are created. I seek to change disability perceptions and assumptions on a cultural level, transforming the mechanisms that perpetuate them. After finding Wade's poetry, I found her videos, *Here* (1990) and *Body Talk* (2001), and excerpts from *Sassy Girl* in *Vital Signs: Crip Culture Talks Back* (in Mitchell & Snyder, 1996), which deeply challenged my assumptions. Wade and artists such as Mike Ervin, Lynn Manning, Susan Nussbaum, David Roche, and Tekki Lomnicki triggered self-reflection and re-evaluation of cultural meanings and ideas with their work. What I saw was that these artists derived their works from personal experiences and strong self-definitions that disavowed the dominant culture's designations of disabled people. I wanted to understand how they came to re-frame and re-interpret their personal stories and transform them into empowered performances.

This project uncovers how the autobiographical works of two women artists with disabilities are powerful, transformative disability representations. The key to revealing these performances' effectiveness is to investigate the ways each artist expresses personal experience artistically. Cheryl Wade and Tekki Lomnicki contribute insights and cultural awareness to expose their creative processes, performance strategies, and artistic perspectives. Their performance art works achieve transformative, empowering, and deeply engaging cultural events that celebrate difference, disability, and human variability.

II. LITERATURE REVIEW

A. Introduction

This chapter examines selected literature from disability studies, feminist studies, performance studies and the work of scholars that combine disability studies with other disciplines. This review includes topics that are relevant to this project's focus: closing the representational gap between art and life as it pertains to disabled people and disability representations. Disability is everywhere in literature, film, television, and other media, but its ubiquity frequently precludes the participation, inclusion, or equality of disabled people in the world. Mainstream cultural constructions of what it means to be disabled pervade what English and feminist disability studies scholar Rosemarie Garland-Thomson has called the "representational system" (2002) or the "ability system" (2005), resulting in detrimental effects on disabled people's lives. The "representational gap" (Garland-Thomson, 1997) privileges able-bodied figures in depictions and uses disabled figures as metaphors and other devices for the narrative. Conventional disabled characters are limited, undeveloped symbols without political agency, subjectivity, social value or realism. Disabled people, through social relations, oppression, and common misperceptions, experience the consequences of prevailing disability images along with the belief that ability, or the "ideology of ability" (Siebers, 2008) is the only acceptable means of being human. Therefore, the literature selected for this review helps frame social and cultural constructions of disability, reveals how these constructions have been challenged, and covers specific literature about solo autobiographical performance work, which I claim has the greatest promise for re-imagining disability both in art and life.

This chapter is divided into three sections. In the first section, prevailing concepts in disability studies introduce critiques of society and culture as limiting, silencing, and fracturing

to the freedom and psyches of disabled people. The second section, where I discuss the representational gap more fully, looks at the ways disabled people have resisted what has been broken by society and culture through disability identity and pride, and the ways they have reclaimed their power with disability culture. Finally, the last section looks at strategies for resisting dominant cultural notions of disability, including counter-narratives, performance art from other marginalized groups (women and people with queer identities), and specific performance literature and criticism about disabled artists.

B. **The Medical Model, Psycho-Emotional Dimensions, The Social Model, and Structures of Ableism**

1. **Introduction**

This section outlines fundamental aspects of disability oppression such as medical power, psycho-emotional dimensions, and structures of ableism within society. I focus on literature that is relevant to these issues and to the ways in which many disabled artists deal with such issues in their work. For example, the medical model has had a powerful influence on the lives of disabled people, and both artists in my study deal with the medical model in their autobiographical performances. The social model of disability is a response to the medical model, and has been effective in relocating the so-called problem of disability in society, removing it from individuals. The medical model has had much influence, however, on the meanings and understandings of disability that it leaves psychological and emotional scars in its wake. Individuals with disabilities can internalize negative meanings of self and body, and interpret their lives in negative ways, as a result of psycho-emotional dimensions of disability. Finally, the concept of ableism is explored and how these models and dimensions discussed

comprise the structures of ableism. Each artist works against the structures of ableism as part of her creative processes and political views.

2. **The medical model**

Medicalized views of disability have been at the root of oppressive, discriminatory, and isolating practices toward people with disabilities, according to historian and disability studies scholar Paul Longmore, from his 1995 essay “The Second Phase: From Disability Rights to Disability Culture” (as cited in Longmore, 2003b). Disabled people with impaired bodies have become subject to the normative values espoused by a “medical model” of disability, suggesting that a disabled person’s body is “broken” and should be “fixed” (Longmore, 2003b). In his essay, Longmore contends that the first phase of the disability rights movement—the fight for equal access, equal opportunity, inclusion and equal rights—based its political activism on a critique of the medical model. Working against the heavy medicalization of people with disabilities, activists fought the medical model’s tendency to isolate people with disabilities based on diagnoses (Gill, 1994; Longmore, 2003b). Defining people with disabilities within a medical framework keeps them subject to medical authority as patients, clients, and people who need care. It also keeps them separated: the individual patient is singular and tragic, while the medical professional holds the power to “cure” or “fix” the patient. This system often isolates disabled people into institutions—hospitals, nursing homes, and group-homes (Longmore, 2003b)—and controls their access to independent living services such as housing, transportation, home care, and employment assistance. Furthermore, the influence of the medical model spreads to social perceptions and interactions with disabled people, perpetuating the idea that disabled bodies must be managed and controlled inside and outside of institutions. Arguably,

the medical model has created a social environment where everyone has power over disabled bodies except for the disabled person.

3. **Psycho-emotional dimensions**

Power over disabled bodies can extend to the psychological workings of individuals. This is particularly important in this research project because of the medical model's impact on disabled children. Both artists in this study were diagnosed and treated for their disabling conditions as young children, and both deal with the psychological impact of the medical system in their autobiographical performance works. Both recount meetings with doctors, being hospitalized, and medical interventions that occurred at fragile times in their emotional development.

Many children and adults with disabilities have experienced what British disability studies scholar Deborah Marks calls "the objectifying gaze" (1999). During interactions with doctors and other medical professionals, many people with disabilities will experience this gaze, which has a "shaming" effect. Marks explains:

The experience of repeated medical interventions involves a critical gaze. This gaze can be experienced as shaming since it implicitly carries the message that the disabled person is not acceptable *as they are*. (1999, p.69, emphasis original)

Thus, the "objectifying gaze" causes the disabled person to feel unacceptable, like an object of the medical system, rather than an individual with agency and autonomy.

Psychologist and disability studies scholar Carol Gill (1997) argues that these feelings of shame have little or nothing to do with the individual's impairment(s). Rather, what causes such feelings is the "manner in which family members, professionals and other significant social figures frame the impact of disability for the individual" (1997, p. 43). Specifically, when families with disabled children pursue medical professionals for a cure, they deny the difference

of disability in favor of “normalization” (Gill, 1994, p. 14). As families seek medical interventions, the experience may leave a disruptive impact on the child. Gill explains that medical professionals commonly refer to affected (disabled) body parts as a “bad leg” or the “bad arm,” and encourage patients with disabilities to “see their ‘normal’ intellects as separate from their damaged bodies” (Gill, 1994, p. 14). Both the “objectifying gaze” (Marks, 1999) and negative framing of impairment can disrupt the psychological development of a personal sense of self, leading instead to a sense of shame.

When medical professionals frame an individual’s body in terms of “good” or “bad” physical attributes, and disabled individuals are told to “seek value in parts of his/her being that had not been impaired” (Gill, 1997, p. 43), the possibility for an integrated identity is lost. Marks (1999) describes a similar response by children exposed to the objectifying gaze, which lacks empathy in practice. The repetition of the gaze, the repeated lack of empathy, like negatively framing impairments (Gill, 1994) can lead to further shaming and fragmentation. Marks explains:

Because repetition of an unempathic look, for those disabled children who have been subject to repeated medical examinations, can lead to just such a sense of shame and the loss of, or failure to develop, a sense of entitlement. Medical practice forces an intrusive and powerful other onto the patient, and disintegrates the subject’s ‘organization... aims and intentions’. (1999, p. 70)

Thus, Marks argues that medical practice “forces” an intrusive gaze onto the disabled children, and “disintegrates” the subject, which leads to shame and “failure to develop a sense of entitlement.” In other words, the individual does not develop a sense that he or she is deserving, or entitled to, such things as rights, goals, freedoms, or a sense of belonging. The loss of entitlement, like being objectified through medical treatments, can lead to what Marks and Gill

call “shame.” The feelings of being an object and of shame may result in feeling entitled only to the attention of medical professionals.

Utilizing Foucault’s concept of the “docile body,” Marks argues that Foucault’s “fragmenting, classifying ‘gaze’” (1999, p. 71) works well alongside psychoanalytic descriptions of repeated medical experiences. Marks reasons that the “gaze” fragments identity through the practice of medical rounds. Rounds multiply the impact of the gaze, ensuring that a variety of doctors critically examine, and therefore objectify, each patient in a hospital ward. Furthermore, fragmentation occurs through increased specialization. Through specialists, patients are “no longer considered as a whole person,” (Marks, 1999, p. 74) but more like a series of body parts cared for by different medical specialists.

Marks’ use of the term “disintegrate,” above, to describe the process of identity separation and loss of entitlement is helpful because Gill also calls similar processes “disintegrated identity” (1997). “Disintegration” or the term I prefer, “fragmentation,” describe psychological processes that typically accompany repeated medical interventions, separating, or “splitting” (Gill, 1997) one’s fragile sense of self from her disabled body. Gill explains:

Any splitting of the self into acceptable and unacceptable parts would qualify as pathological in most systems of personality development. Yet as most children with disabilities grow up, they feel accepted and valued only conditionally— loved *in spite of* their disabilities, not *with* them, and required to fix or hide their disabled parts. (1994, p. 15, emphasis original)

This is important because it demonstrates the internal/psychological and family/sociological obstacles that many disabled individuals face when seeking a positive identity, self-esteem, or integration into the larger society.

Fragmentation processes and re-integrating the discarded parts of the self are included in each of the autobiographical works in this study. These works demonstrate, as Marks (1999)

argues, that even against such powerful social, psychological, and medical forces, disabled people learn ways to defend themselves and their psyches. Marks said:

For those disabled people who have undergone repeated medical ‘treatments’, particularly when they attempt to bring about ‘cure’, it becomes necessary to defend the self against an objectifying gaze. This may be done through withdrawal or exhibitionism. In both [cases,] the humiliation of being exposed is defended against by taking control over how much the Other sees. (1999, p.71)

Marks claims hope for disabled individuals who experience fragmentation in psychological development and identity. She posits that “withdrawal or exhibitionism” is a way to take back control from medical power by limiting what doctors or other professionals “see.” Gill acknowledges that, while many disabled persons “learn to view themselves through the prevailing medical model” (1994, p. 14), they can re-integrate their discarded parts and “come together” (1997, p. 43). With knowledge about the disability community, and by integrating parts of the self that are the same and different from other members of society, a disabled individual can develop a whole, disabled identity. This process of “coming together” seems to be a necessary part of developing “Disability Identity,” which will be discussed more fully in section “B” of this chapter.

4. **“Normal” and the need to “overcome”**

The concept of “normalcy,” according to English literature and disability studies scholar Lennard Davis, is constructed. “Normal,” which entered the English language in 1840 (2006), ushered in the idea of a normal range of bodies, minds, emotional responses, and other ways to measure human beings. Before this term came into usage, the concept of the “ideal” prevailed. An ideal body had been considered unattainable by human beings, and people believed ideals could not be found in *this* world-the realm of human beings. Thus, where ideal bodies are impossible, all bodies fall short.

Yet, “normal” became the predominant concept to denote what is average, or within acceptable limits of being human. As the discipline of statistics grew, —simultaneously with eugenics— statistical concepts like the bell curve, the average, and deviations from average also grew. The bell-shaped curve is a statistical and mathematical representation of a “normal” data distribution. Deviations from the normal distribution, which are based on the bell curve, signify extremes because of their distance from normal. Therefore, deviations from a typical population distribution, such as disabled people, are deviations from what is considered acceptable and normal.

Gill points out that most disabled people are born into nondisabled families and “surrounded by the nondisabled culture” (1994, p. 13). For parents of disabled children, the desire to seek medical strategies, or “normalization,” is strong. For some families, denial of disability and difference is common. These parents tell their disabled child that he or she is not disabled and not like other disabled kids. Both methods—denial or normalization—inadvertently damage the individual child’s quality of life because both leave the disabled person feeling unacceptable (Gill, 1994). Additionally, family and societal pressure to be or act “normal,” along with social and cultural disparagement of disability, can lead many individuals to internalize feeling unacceptable, to avoid other disabled people, and to deny themselves realistic expectations. This can lead to constant attempts to “prove their worth” (Gill, 1994, p. 15).

Pursuing “normality” or attempting to “prove worth” is also known as “overcoming.” While medical professionals or society may encourage disabled people to recognize the value in some of their unaffected body parts, the harsh reality of how they view their “bad” parts remains. Gill states: “The mandate accompanying this reality is that such persons must try as hard as they can to overcome their defective, invalid parts” (1997, p. 43). Overcoming, however, will never

redeem disabled people: they will still fall short of being “wholly acceptable” human beings who need to continually prove how “normal” they are (Longmore, 2003b). In the overcoming mandate, Gill sees two choices available to disabled people who idealize normality: he or she either chooses “the course of exhaustion” (1997, p. 43) by continuously working to achieve “normality,” or simply gives up, accepting his or her “invalidity.” Either way, the disabled person is never fully valued by society.

In the first phase of the disability rights movement, the medical model has had sufficient power to convince disabled people that they must strive for “some semblance of normality” (Longmore, 2003b, p. 221). Longmore argues that disabled people are instructed to “perpetually labor to ‘overcome’ their disabilities” (p. 221) in order to prove their value. He says of people with disabilities:

The evidence of their moral and emotional health, of their quasi-validity as persons and citizens, has been their exhibition of the desire to become like nondisabled people. This is, of course, by definition, the very thing people with disabilities cannot become. Thus, they have been required to pursue a "normality" that must forever elude them. They have been enticed into a futile quest by having dangled before them the ever-elusive carrot of social acceptance. (Longmore, 2003b, p. 221)

The desire to be “like nondisabled people” is required by the dominant society in order for disabled people to be included. Longmore says such a task is impossible, and “social acceptance” will forever elude disabled individuals. Thus, inclusion requires “overcoming disability”: an exhausting and futile obligation internalized by many disabled people.

Overcoming discourse focuses not only on the quest for social inclusion, but also on how individuals with disabilities manage to cope with obstacles on their own. According to disability studies scholar Simi Linton (2006), “overcoming” usually refers to a disabled individual who “seems competent and successful” as a result of personal initiative, “willpower,” and assimilating into society (p. 165).

Sociologist Caroline Gray utilizes a cultural sociological approach to explain three prevailing disability narratives: assimilation, or the “miraculous cure” in which disability is eliminated; hyphenation, which focuses on “overcoming” disability; and multicultural, which values disability as difference (2009). Assimilation “always rests on this desire to find ‘the cure’, as it appears to offer the only suitable societal response to supposedly deficient disabled bodies” (Gray, 2000, p. 324). Such cultural and social stories restore disabled individuals to their “natural” state of ability. Gray’s hyphenation/overcoming narrative is necessary for social inclusion, a similar outcome described by Longmore. However, Gray notes that hyphenation stories allow for social inclusion when disabled people “attempt to heroically overcome his or her disability by adopting a positive attitude” (2000, p. 325). Thus, the right attitude, along with the desire to be normal, is key. It means that a deficient disabled body could be overlooked, and therefore included into society, if it is conquered by an appropriate state of mind. Gray writes: “Being ‘just like everybody else’ means that the disabled individual must appear to reject pity and instead insist that others simply see him or her as leading an essentially normal life” (2000, p. 325).

Embedded within all three of Gray’s cultural sociological modes are what English and disability studies theorist Tobin Siebers calls the “ideology of ability” (2008, p. 102). Even Gray’s multicultural narrative upholds ability as normative because it attempts to move disability towards a “different kind of ability” (Gray, 2000, p. 326). For Gray, multicultural narratives have the most potential to change societal attitudes. Yet, all three maintain the invisibility and prevalence of “normal” and enforce able-bodiedness.

5. **The social model of disability**

Moving from an individual and medical model of disability, Michael Oliver described the term “social model” in the 1980s. Oliver was making a distinction between what he called “the individual model” of disability or “personal tragedy” and the social model of disability. The individual model includes the “medicalization of disability,” which encompasses functional limitations and psychological losses that are assumed to stem from the disabled individual (Oliver, 1990). Yet, the social model, which was developed by disabled people, removes the individual and subsequent medicalization from the term *disabled*, placing disability instead within social contexts. Functional limitations, medically significant concerns, or psychological limitations are now referred to as “impairment,” distinguishing the body’s concerns from how disability is understood. Disability does not disappear in the social model; it is put in its place. Oliver states: “the social model of disability... does not deny the problem of disability but locates it squarely within society” (1990, p. 3). Furthermore, the social model of disability rejects individual limitations or impairment as the cause of the “problem” of disability claiming that the cause is “society’s failure” to ensure services, accommodations, access, and needs of disabled people.

While the social model has redefined understandings of disability in Europe, the US has focused similarly on a “minority-group” or “minority model” of disability (Gill, 1994; Hahn, 1983; Longmore, 2003b). Both models remove disability from the individual’s body, referring to physical limits as “impairments.” Disability emerges in society in the minority model as it does in the social model—in barriers of architectural design, communication, visual dominance, and pace barriers. “Disability” is regarded as a socially constructed idea, and as a role where “prejudice is a far greater problem than any impairment” (Longmore, 2003b, p. 218). Thus, the

barriers in society and social constructions create and define disability within the social and minority models.

The social and minority models of disability reframe conversations about disability, redefining its terms and allowing disabled people to coalesce around shared experiences of oppression and discrimination. With this paradigm shift, disabled people can emphasize the commonality of their experiences, share information, and begin re-shaping policies and practices that oppress them (Gill, 1994). However, disabled people are still frequently excluded from social, cultural and civic discourses in ways that maintain social and cultural misperceptions toward disabled individuals. When impairment issues spill over into the social environment, or disability overwhelms and confounds able-bodied people, disabled people become more noticeable—a “problem” —and simultaneously more invisible. This paradoxical situation often goes unresolved, but is no less oppressive because it may leave the disabled individual without needed assistance. In such situations, disabled people must find a way to challenge the ingrained discourse of “disability,” since neither the social or minority models would assist an individual during such moments. Instead, the responsibility for resolution belongs to the individual disabled person.

Oliver never intended the social model to be an all-encompassing theory of disability. One of the things he wanted to convey was a power shift. The individual or medical model gave medical professionals power over disabled people, but the social model was “a prescription for sharing power” (Oliver, 1990). The social model may be limited, but the distinctions between bodily and social issues are helpful and empowering to many. The phrase “disabled people” rather than “people with disabilities,” more aptly describes and references the location of disability for people with impairments.

6. **The structures of ableism**

The medical model creates structures of ableism by defining and perpetuating “normality.” While an important aspect of having impairment is having quality health and medical care, the medical model also demonstrates power over disabled people by being the social institution that legitimizes who have “disability.” It bestows disability as valid for those who require services, and exposes disability as fraud by those who wish to take advantage of the system. In addition, the power of medical professionals and systems can have lasting, negative effects on the psychological development of people with disabilities. As a result of medical dominance, many parents of disabled children, according to Gill (1994), prefer to deny disability rather than accept it and act for social change. All of these issues wrap around disabled people and keep them marginalized from a society that refuses to accept them.

The structures and practices that enforce disabled people’s marginalization are what Australian disability studies scholar Fiona Kumari Campbell calls “ableism” (2009). She defines it as:

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. (Campbell, 2009, p. 5)

In addition, Campbell argues that, at the root of this network is the fact of ableism’s “formation of a naturalized understanding of being fully human,” which is articulated through “an enforced presumption that erases difference” (2009, p. 5). Thus, the “corporeal standard” within this network is an able body.

Similarly, Siebers argues that the “ideology of ability” (2008 p. 102) defines and enforces what it means to be human by representing ability as “normative,” and in so doing, mandates that all human beings demonstrate ability. Siebers writes:

The ideology of ability makes able-bodiedness compulsory, enforcing it as the baseline of almost every perception of human intention, action, and condition and tolerating exceptions only with difficulty. Ability appears unmarked and invisible because it is the norm, while disability, as an affront to ability, feels the full and persistent force of an ideological impulse to erase from view any exception of ability. (Siebers, 2008, pp. 102-103)

In other words, by enforcing “able-bodiedness” as required for being human (acceptable, valuable), the “ideology of ability” erases disability. This places enormous responsibility for disabled people to be normal and “just like everybody else” in order to ensure acceptance and visibility. Yet, Siebers argues that disability, as an “affront” to ability, will feel the “full force” of ability to ensure that any “exceptions” to it are “erased from view.” The ideology of ability threatens disability, making disabled people invisible and their social inclusion impossible.

The structures of ableism described by Campbell and Siebers most likely seem “normal” to most people because they have “able” bodies. In *Crip Theory* (2006), Robert McRuer exposes structures of ableism within complementary systems of compulsory able-bodiedness and heterosexuality, which are measured in opposition to disability and queerness. McRuer calls these configurations “fundamentally structured in ways that limit access” for disabled people (2006, p. 151).

Just as the origins of heterosexual/homosexual identity are now obscured for most people so that compulsory heterosexuality functions as a disciplinary formation seemingly emanating from everywhere and nowhere, so, too, are the origins of able-bodied/disabled identity obscured, allowing what Susan Wendell calls “the disciplines of normality” (1996, p. 87) to cohere in a system of compulsory able-bodiedness that similarly emanates from everywhere and nowhere. (McRuer, 2006, p. 8)

These institutionalized structures of heterosexuality and able-bodiedness are ubiquitous and invisible, and “perpetuate able-bodied hegemony, figuratively and literally constructing a world that always and everywhere privileges very narrow (and ever-narrowing) conceptions of ability” (McRuer, 2006, p. 151). These systems permit and enforce heterosexual and able-bodied

identities as “true” and natural, while those who deviate from those subject positions “fall away” (McRuer, 2006).

Structures of ableism are incessant, pervasive, and ongoing, even at this historical moment 24 years after the signing of the Americans with Disabilities Act (ADA). While the disability movement’s first phase was successful in passing this important civil rights legislation, Americans still have room for improvement in breaking down the remaining structures of ableism. Disabled people have physical access in many places in the United States, but still do not have the same taken-for-granted freedom of movement, choice, and opportunity that most Americans enjoy. For example, activities like driving a car, using public transportation, renting an apartment, buying a home, finding a job, living independently in the community of your choice, entering and participating in any public event, going to any restaurant and being able to read and order from any menu are taken for granted by people with ability. The first phase of the disability movement proved, however, that such activities are not available to *everyone*. Additionally, and perhaps paradoxically, as part of the “second phase” of the disability movement (Longmore, 2003b), disabled people must define themselves, determine their own paths, and unite as a community in order to uncover and detail the values, goals, and culture for present and future disability communities. By defining itself apart from the dominant, majority culture, disabled people may be able to bring new and valuable insights to the majority culture if and when they choose to re-enter it.

In the next section, I examine how disabled people have defined themselves as individuals and as a culture during the “second phase.” Through the act of separating from the majority culture to determine their value as a community, and beginning to express disability experiences through cultural production, people with disabilities are repairing the damage

inflicted on them by oppressive structures and images. Yet, as this section delves into how disabled people reclaim their power and voice through identity and culture, it also recognizes a destructive cultural heritage that continues to have real effects on daily lives. Thus, the following section bridges how disabled people have begun to fix what is broken and the overwhelming cultural forces yet to be overturned.

C. **Disability Culture, Identity, and Representation**

1. **Introduction to this section**

According to disabled artist and producer Pamela Walker, once creative disabled people shifted their focus from reacting against negative representations and stereotypes to acting (and writing) to create new images, a “Disability Culture was spawned” (1998, p. 3). Creating new depictions of disabled lives and experiences, based on personal histories, was a radical step toward closing the representational gap and starting to change the discourse around disability. In many ways, this project focuses on creating new images by, about and for disabled people. In this section, I discuss literature that supports disability culture as a communal and resistant act. As Walker notes, disability culture denotes a break from dominant culture representations of disability. The imagery and typical narratives developed by the mainstream often leave out much of the reality of disability experiences, while also creating negative effects for the lives of disabled people. These are aspects of what has been left out of the mainstream, or “the representational gap” of disability (Garland-Thomson, 1997). I explore literature about the representational gap, along with dominant narratives, discourses and stereotypes that have been perpetuated by mainstream depictions. Since disability culture arose during the “second phase” of the disability movement (Longmore, 2003b), defined by self-definition and self-determination, I also revisit the second phase, looking at literature on disability identity that

illuminates self-definition processes from this project. Finally, a thriving disability community and culture is needed to address the damage of mainstream culture, and begin to reframe disability from its cultural heritage. “Disability Culture” explores literature that investigates a subculture perspective. By developing and enacting a self-determined disability culture, disabled people and disability community are defining values, beliefs, customs, language, and artifacts. It is a disability culture that also reflects the diversity, multiculturalism, and multiplicity of voices, experiences, and viewpoints that comprise the disability community. It allows disabled people to construct cultural resistance and new perspectives that include fresh interpretations of the world. The disability culture literature explored here helps to explain this phenomenon, as well as to theorize and expand it for the future.

2. **The “second phase”**

As Longmore pronounced in 1995, the second phase of the disability rights movement involves redefining values and norms that have been imposed upon disabled people by mainstream society and culture (Longmore, 2003b). The second phase takes self-definition, disability experience, and disability culture as starting points. Longmore explains:

As they spurned devaluing nondisabled definitions, deaf people and disabled people began to celebrate themselves. Coining self-affirming slogans such as "Disabled and Proud," "Deaf Pride" and "Disability Cool," they seized control of the definition of their identities. This has been not so much a series of personal choices as a collective process of reinterpreting themselves and their issues. It is a political and cultural task. (2003b, p. 222)

This group definition comes out of a long history of being defined by others; in particular by medical practitioners, rehabilitation workers, and other service providers. This assertion of cultural and political identity by the group is expressed through cultural production, and has been an important, validating, and empowering process within the disability community. Longmore also tasks the community “to explore and to create disability culture” (2003b, p. 215). Thus,

“Disability Culture” as a form of activism became it is a major piece of the second phase of the disability rights movement (Longmore, 2003b).

By focusing on cultural production and self-representation, there has been a “cultural explosion” (Walker, 1998), with disabled artists creating more authentic and credible representations of disability experiences and identity. As they choose to seize “the means of artistic production,” these artists attempt to “radically transform” negative cultural assumptions about disabled bodies (Mitchell & Snyder, 2001, p. 382).

Along with alternative representations, creating alternative values is a collective process for the disability community. Some emergent values in the early part of the second phase include self-determination over self-sufficiency, personal connection over functional separateness, interdependence over independence, and human community over physical autonomy (Longmore, 2003b).

Additionally, Longmore calls for disability studies scholars to collaborate with the disability community on new research initiatives that “forge a link with disabled artists and writers” (2003b, p. 224) and galvanize new cultural definitions of disability. He also sees this link between disability studies scholars, disabled activists and artists as a way to: a) research alternative values as they are being generated by the disability community; b) to generate new research questions; and c) to validate the emergence and boundaries of disability culture. In effect, Longmore envisions disability studies doing the work of “disability-based cultural studies” (2003b, p. 224).

3. **Self-definition and disability identity**

In this section, I discuss a limited number of identity theorists out of a great amount of scholarship in this area. The scholars and identity literature chosen for this section

reflect how the artist participants represented identity processes in the study. Both artists present experiences of identity development in their works influenced by childhood memories with disability. Both artists also demonstrate the fluidity and reinterpretation of their earlier identities, and how they change over time. The theories selected here reflect these presentations of self and the effects of disability, gender, and social location on identity development.

Earlier in this chapter, identity development and barriers for an integrated and positive disability identity were discussed. Carol Gill (1994; 1997) and Deborah Marks (1999) argue that the powerful medicalization of disabled children and impaired bodies can have profoundly negative effects on young people with impairments as they begin to develop a sense of self. Repeated medical treatments can impose detrimental factors, causing “splitting” (Gill, 1994) in fragile psyches that lead to disintegration in the process of developing a sense of wholeness. While both Gill and Marks point out resilience and hope for re-integrating the self of many disabled individuals, these effects would not exist for nondisabled children or adolescents because they are usually not subjected to repeated medical interventions.

In Gill’s article, “Four Types of Integration in Disability Identity Development” (1997), she outlines four overlapping forms for re-integrating a “disintegrated” identity. These categories, which Gill detected from her observations and psychotherapy work with adolescents and adults with disabilities, describe features that help fulfill a “yearning for wholeness and belonging” she heard from many individuals (1997, p. 42). The first type of identity integration Gill calls “coming to feel we belong (integrating into society)” (1997, p. 42). In this type of integration, disabled people begin to feel that they deserve to belong, and have the “right to inclusion in society” (Gill, 1997, p. 42). In this type, disabled people claim entitlement to rights and emerge into society.

The second type, called “coming home (integrating into disability community)” (Gill, 1997, p. 42), involves openness to being with other disabled people. Gill points out that many people with disabilities avoid associating with other disabled people for many reasons, such as: avoiding stigma by association, fear of being segregated, rejecting the company of a devalued group, and feeling like participation with others like them will be “acquiescing to society’s unwillingness to provide access” (1997, p. 42). Yet, disabled people still find each other, despite isolation and attitudinal, transportation, and accessibility barriers. Getting together as a group often feels like coming home, and it fulfills the yearning for belonging.

The third type of integration, “coming together (Internally integrating our sameness and differentness)” (Gill, 1997, p. 43), is about putting the personal pieces back together to assemble individual identity as a whole, disabled person. Gill explains that fragmentation, which is caused by rejection of the disabled self, leaves the individual in a state of “disintegration.” Without re-joining disabled parts, an individual’s “self-image is riddled with significant gaps” (Gill, 1994, p. 3). The resulting identity cannot support resilient and stable self-esteem needed to form a “sense of worth and entitlement to a place in society” (Gill, 1997, pp. 43-44). Additionally, “disintegrated identity” impedes and undermines the stability of the previous integration types. Thus, this type of integration is important to each of the four types, since without it, the other types cannot hold up. “Coming together”, then, has a double meaning: the need to come together for an individual who has a disintegrated identity, and the need to come together as a separate group from the mainstream. Both processes are important for pulling the discarded pieces of disability together as a whole.

The fourth type of identity integration is called “coming out (integrating how we feel with how we present ourselves)” (Gill, 1997, p. 45). This type of integration is about claiming

one's identity as disabled. Once disabled individuals internally integrate the disabled parts of themselves (differentness) with the nondisabled parts of themselves (sameness), he or she can "come out" with a congruent sense of wholeness. With "nothing to hide" and greater self-acceptance, the final form of identity integration is presenting this self to the world. "Coming out" is powerful and empowering as it claims the wholeness of the individual and the affiliation with other disabled people while also claiming membership into society.

While Gill writes specifically about psychological processes that affect disability identity, post-positivist realist theorists of identity discuss identity that frequently arises from the experiences of marginalization. For example, Paula Moya, in her essay "Postmodernism, 'Realism,' and the Politics of Identity: Cherrie Moraga and Chicana Feminism" (Moya, 2000), argues for identity and experience as important organizing factors. She examines the work of Chicana writer/activist Cherrie Moraga, saying:

Unlike postmodernist feminists who understand the concept of identity as inherently and perniciously "foundational," Moraga understands identity as relational and grounded in the historically produced social categories that constitute social location." (Moya, 2000, p. 69)

Understanding "social locations" are critical to the "realist" identity, or Moraga's "theory in the flesh" (Moya, 2000). Social location is "the particular nexus of gender, race, class, and sexuality in which a given individual exists in the world" (Moya, 2000, p. 70). While Moya leaves out "ability" in this nexus, it should be added because ability and disability are also constituted socially and relationally, and grounded in "historically produced social categories" (2000, p. 69).

Similarly, feminist and disability studies scholar Rosemarie Garland-Thomson (2002) argues for a "feminist disability theory." She explains, "One way to think about feminist theory is to say that it investigates how culture saturates the particularities of bodies with meanings and probes the consequences of those meanings" (Garland-Thomson, 2002, p. 3). Thus, as post-

positivist realism demands that identity scholars interrogate the consequences of social location, feminist disability theory demands cultural investigations of identity. Both social location and cultural representation influence identity and its consequences for individuals. A feminist disability theory, which “introduces the ability/disability system as a category of analysis,” becomes part of feminism’s “diverse and diffuse enterprise” in which representational systems of gender, ethnicity, race, class, sexuality, and ability “mutually construct, inflect, and contradict one another” (Garland-Thomson, 2002, pp. 3-4). Garland-Thomson argues that these cultural structures “produce and sustain identities” whether they are ascribed to us or claimed.

Moraga’s “theory in the flesh” (Moya, 2000) has usefulness to disabled women. She wanted theory to claim knowledge from interpretations of violations. For disabled women, this might mean medical violations as well as obtrusive questions and staring encounters while in the public sphere. Such knowledge adds to our understandings of experiences that occur as a consequence of our social location. Moraga sees “flesh” or the body as a site for the material effects of social location. Physical effects may be vulnerability to pain, or pain as a daily consequence of embodied beings. Emotional effects may be preconceived notions or misrecognitions by those she encounters daily. Moraga’s theory in the flesh emphasizes experiences as mediated by the body: “experiences happen to us” and are mediated by theories that frame our view of the world. This “epistemic privilege” (Moya, 2000, p. 80) is personal experience that yields knowledge through experiences mediated by embodiment.

“Epistemic privilege” is an important concept not only to Moraga’s theory of identity, but also to post-positivist realist theory of identity. It is “a special advantage with respect to possessing or acquiring knowledge about how fundamental aspects of our society (such as race, class, gender, and sexuality) operate to sustain matrices of power” (Moya, 2000, pp. 80-81).

Thus, experience, determined by social location, is also interpreted through the theoretical frameworks used to negotiate it, and is subject to error and revision. Identities are grounded in experiences reconciled by theories of the flesh, or the physical realities of embodiment. Additionally, political consciousness can arise out of interpreted and re-interpreted experiences. In Moraga's theory, "Chicana" is the term she uses to describe her political consciousness, which encompasses her identity fused with her culture and mediated by experiences.

Performance and disability studies scholar Carrie Sandahl compares the term "crip" with the term "queer" in her discussion of crip-queer identities in solo autobiographical performance (2003). Both terms are "fluid and ever changing," rearticulated from their previously derogatory deployments. In its new form, "crip" signifies a politically aware disability identity, and a term of pride that can be used by people with both visible and nonvisible disability, and potentially by nondisabled allies. In her discussion of both terms, Sandahl points to Robert McRuer's definition of the term "queer." According to Sandahl via McRuer, queer is "a fluid designation for identities that 'are shaped and reshaped and that interrogate and disrupt dominant hierarchical understandings of sex, gender, and sexuality, but also race and class'" (McRuer, quoted in Sandahl, 2003, p. 26). Sandahl speculates, "that McRuer would agree to adding disability to this list" (2003, p. 26), along with both term's call to activism as political identity. I believe that the term "crip" has the potential to also be an identity designation inclusive of multiple identities that intersect in disabled individuals, and activate collective action.

The concept of fluidity is important for identity. Identity, as a psychological process of integration (Gill, 1997), or as an investigation of social location and epistemic privilege (Moya, 2000) requires fluidity and flexibility as it changes through reflective processes. In addition, identity shapes, re-shapes, disrupts, and interrogates dominant and cultural designations that are

ascribed to self and body, or that are claimed by individuals (Garland-Thomson, 2002; Sandahl, 2003). In this way, fluidity, flexibility, and change can be expected when discussing identity.

a) **Coming out**

Identity terms such as crip, queer, and Chicana claim agency, political, and cultural consciousness, signify “coming out.” “Coming out,” much like other concepts and terminology in disability studies, is borrowed from queer theory (Sandahl, 2003). To “come out” in queer theory usually refers to the process of publicly acknowledging one’s sexual orientation, but it can also be applied to gender identity, and transgender or transsexual identities. I have already used Gill’s (1997) definition for “coming out” as a disabled person.

Sandahl explains “coming out” as a “crip” (2003) in solo crip-queer performance as a way of performing disability identity through self-exposure. The crip and queer artists she investigates no longer choose to perform a version of able-bodiedness or heteronormativity, compulsory or otherwise. “They take center stage under the harsh spotlight of the stare, display their bodies, and speak unapologetically about impairment” (Sandahl, 2003, p. 41). “Crip” identity and coming out as crip is an “alternative to stigma management.” Rather than performing identity that is akin to passing, which helps nondisabled people feel more conformable, these crips present a “self-consciously crafted” identity (Sandahl, 2003, p. 41). Thus, self-consciously crafted and public identity is accepting of the multiplicity of identities that exist within one person, while also critical, of impairment, sexuality, and other non-dominant and non-normative identity categories. They claim differences without shame, but with holistic self-acceptance.

Autobiography and disability studies scholar G. Thomas Couser, in his book *Signifying Bodies: Disability in Contemporary Life Writing* (2009), explores disability memoirs and the

narratives that emerge within these life stories. Coming out has become a recurring theme in such writing. He defines the “coming out narrative” in this way:

The fundamental connection between narratives of coming out as gay and those of coming out as disabled is that both depend on and recount, the private acceptance and public acknowledgement of a stigmatized identity that is somatic in its basis. Both *conditions*... are given, not chosen; coming out, however, requires that both *identities* be consciously affirmed and freely elected. (Couser, 2009, p. 168, emphasis original)

Coming out requires two important processes, “private acceptance” and “public acknowledgement,” according to Couser. He points out that although these stigmatized identities, which he terms gay and disabled, are based in the body, each must nevertheless be intentionally claimed and presented. Yet, unlike other theories of coming out under discussion here, Couser does not indicate the necessity or presumption of the chosen identity aligning with its larger community’s political goals.

Ellen Samuels, however, notes that often, the public acknowledgement of stigmatized identity or identities may not always occur, or may occur over and over in daily encounters and in different ways. In her article, “My Body, My Closet” (2003), Samuels is primarily taking issue with the uncritical examination of “coming out” specifically, Swain and Cameron’s article, “Unless Otherwise Stated” (1999). Swain and Cameron submit that people with hidden impairments are less likely to come out, finding it easier to “pass” or maintain a “normal” identity, rather than to associate with the stigmatized group. Samuels disagrees:

Narratives of people with hidden impairments, like those of people with other nonvisible social identities, are suffused with themes of coming out, passing, and the imperatives of identity. (2003 p. 237)

Samuels suggests that people with hidden impairments typically *do* choose to come out, but it is a more complicated decision process than is explored in Swain and Cameron (1999). Depending upon what definition of coming out they are using, she asserts, they explain a one-sided

understanding that only refers to coming out as one's "true" identity, which must also entail aligning with the political analyses of the marginalized group. In other words, coming out for them is always about demonstrating that one is in agreement with the political goals of the group, limiting individual choice and agency. Samuels agrees that coming out can lead to political involvement and alignment with the larger group, but she also defines coming out to be about an internal shift, where one begins to accept oneself as different, but not necessarily making it public. Thus, coming out may exist only as an internal shift where the individual recognizes and fully accepts his or her differences from the dominant group.

Additionally, Samuels argues that coming out is not necessarily a static and singular revelatory event, but is often an ongoing decision about whether or not to come out to others, even after the initial internal shift, that occurs often on a daily basis. For examples, Samuels describes several stories of coming out from women in the disability community. Most of the stories are straightforward: women who had internally recognized themselves as disabled then intentionally began to associate publicly with other disabled people. But, for Carolyn Gage, who has a chronic illness, coming out "required her to construct a specific narrative explaining her body to a skeptical, ignorant, and somewhat hostile audience" (Samuels, 2003, p. 238). In other words, within our society, with its constant surveillance of bodies, hidden impairments tend to raise suspicion because others cannot see the functional difficulties the person experiences. Samuels, who is chronically ill and identifies as a lesbian femme, states that she has experienced the same kind of suspicion (2003). It is a daily challenge to explain, negotiate, and advocate for one's body against the assumptions of "normal" identity.

4. **Disability culture**

Writing about her personal experiences with disability culture, Gill (1995) describes how her work as a clinical psychologist taught her how “cultural affiliation mediated the effects of social devaluation” for people who belonged to a minority group. After witnessing such effects during her participation at a Jewish cultural celebration in the mid-1980s, Gill began speaking publicly about her thoughts on the existence of, and necessity for, disability culture. Using a family model, Gill spoke about disabled people as “orphan-like” members of a parent culture that was “able-centric” and rejecting toward them. She suggested, “We could oppose our social devaluation through developing a strong disability community-family and elaborating a proud disability culture” (Gill, 1995). Thus, disability culture emerged in the United States during the mid-1980s, in conjunction with the term “disability pride,” as a way to express and celebrate differences as disabled people (Gill 1994, 1995). This move demonstrated a break from the previous goal of assimilating with the dominant, nondisabled culture and society. Gill writes:

In promoting disability pride, disabled activists have borrowed from other minority pride ideologies in relinquishing the goal of assimilation into the majority (nondisabled) culture. There is great freedom in ending efforts to look or function like nondisabled people, and embracing one's own (disabled) identity without being tyrannized by majority (nondisabled) values. (1994, p. 13)

This freedom to express disability apart from the mainstream, without the need to assimilate into the parent culture, is an important task of disability culture, and a symbol of empowerment. Disability culture is a significant framework for disentangling disability from its dominant cultural heritage. In fact, the dominant culture is often the impetus behind expressions of disability culture. As Simi Linton says, “The cultural stuff of the [disability] community is the creative response to atypical experience, the adaptive maneuvers through a world configured for nondisabled people” (1998, p. 5).

However, some scholars have rejected disability culture (Peters, 2000). Linton notes that dominant cultural assumptions about disabled people, along with “entrenched” compliance with traditional definitions of culture, such as “intergenerational transmission of values, beliefs, customs, and other aspects,” interfere with research and scholarly attention to disability culture (1998, p. 103). Disabled people, like gay and lesbian groups, did not self-identify until adolescence or adulthood; a difference from ethnic minorities. With regard to disability identity, people may never identify with disability community—a larger, socially stigmatized and marginalized group.

Disability culture is a complex phenomenon that has been growing since the 1960s. In the *Encyclopedia of American Disability History* (2009), performance and disability studies scholar Petra Kuppers defines disability culture, which begins when groups of disabled people or disability community come together. She writes:

Disability culture speaks about the specific cultural utterances, behaviors, and practices that occur when disabled people are together—practices that differ from nondisabled people’s living. (Kuppers, 2009, p. 270)

Disability culture is often found during political meetings, gatherings of disabled people at Centers for Independent Living (CILs), during disability sports events, at conferences such as the Society for Disability Studies (SDS), at disability arts events, and during disability rights protests and disability pride parades. Kuppers points out that disability culture sites are usually accessible, and accommodation needs are freely met so that everyone feels welcome, comfortable and able to participate as desired.

Thus, disability culture can happen spontaneously or as a planned event or series of events. While this is clear, a concise definition of disability culture is more complex. Kuppers

starts with Raymond Williams' concept of culture as a "way of Life" (Kuppers, 2009, p. 269).

Utilizing her idea that disability culture requires "coming together," Kuppers states:

Disability culture can also mean the willed coming together of people who begin to understand themselves as a cultural minority, as a band that needs to create together rituals, codes, languages, art, and behaviors in order to strengthen their position. (2009, p. 269, emphasis original)

Kuppers draws on Gill's article, "A Psychological View of Disability Culture" (1995), noting that disability culture is "a strategy for survival" and "the cultural expression of long-standing social oppression," as a way to reclaim disability art and humor, and as claimed space to work on shared "language and symbols" while facing exclusion from education, access, silencing, and "the inculcation of self-hate" (Kuppers, 2009, p. 269).

While most scholars agree that disability culture began in earnest during the 1960s with the emergence of disability rights activism, which grew alongside the civil rights movement, began to move into what Longmore calls "the second phase" (2003b) during the post-ADA (Americans with Disabilities Act of 1990) moment, for the purposes of this study, I am situating disability culture from 1995 until the present (see Gill, 1995; Longmore, 2003b). Longmore's essay "The Second Phase" (2003b) originated as a keynote address for "This/Ability: An Interdisciplinary Conference on Disability and the Arts" at the University of Michigan, May 19, 1995" (2003b, p. 215). This conference, and Longmore's keynote, ignited discussions among disabled artists, scholars, and activists about disability culture *and* disability arts, and the role of artists, activists, and scholars in the ongoing disability rights movement. Longmore promoted and encouraged the second phase of the disability movement, launching a self-defined and self-determined affiliation amongst disabled people that continued political activism, and extended disability studies and arts. The disability was asked to reflect on disability as an identity, a

community, and a culture, and to determine its values, beliefs, and goals for the future. Disability arts and culture became more important for the movement.

Both Lomnicki and Wade's work can be situated in this phase of disability culture. Both actively contributed to disability culture during this time, performing disability arts in 1995. Wade wrote and performed *Sassy Girl: Memoirs of a Poster Child Gone Awry* in 1995, while Lomnicki began her career, co-founding Tellin' Tales Theatre in 1995.

Disability studies and education scholar Susan Peters (2000) explains that historical definitions of culture preclude categorizing disability as a distinct culture, with the exception of American Deaf culture. Such historical designations of culture could only be transmitted through such things as birth, ethnic heritage, or uniformities of language, customs, and values (Peters, 2000). However, more recent analyses of how culture develops found that definitions of culture include an enacted dynamic process (Peters, 2000). Linton proposes that anthropology could serve as an effective academic resource for studying enacted dynamic processes in the daily lives of disabled people. Anthropology could discover how "the interaction between cultural values and beliefs, social relations, and historical changes affect patterns of daily life and personal experience" for disabled people (Linton, 1998, p. 102).

In disability studies scholarship, "disability culture is a critical conceptual framework" for examining disability experiences and the cultural artifacts of that experience (Linton, 1998, p. 102). Linton argues that the cultural artifacts of a disability culture—language, customs, and arts—could have an impact on the mainstream, and therefore, anthropology should pay attention to disability culture. "To the degree that disabled people's culture moderates or overrides the cultural expectations and norms of the dominant group, anthropologists need to be alert to it" (Linton, 1998, p. 102).

In her article, “Is There a Disability Culture? A Syncretisation of Three Possible World Views” (2000), Peters contends that so far, disability studies has focused on the critique of “master narratives of the Other, without providing an alternative world view that would suit the lived experiences of disabled people” (p. 585). Her article outlines three possible worldviews and proposes a “syncretization,” or hybrid consciousness, of these worldviews for defining, developing, and enacting disability culture. Peters asserts that disabled people need to claim a “cultural identity” that can move the disability community toward reclaiming itself from the “Other” while also establishing disabled people as “subjects and active agents of transformation beyond objectified and marginalized Others” (2000, p. 585). In other words, claiming “cultural identity” establishes disabled people and disability culture with agency and as transformative subjects.

Peters proposes a “syncretic culture” for claiming cultural identity. She explains: Syncretism allows for an individual hybrid consciousness, which maintains tactical solidarity while not being swallowed up by universal cultural patterns and norms. An individual with such a hybrid consciousness is a border crosser; i.e. one who blurs cultural, political or disability borders in order to adapt to different symbolic and material constructions of the world. (Peters, 2000, p. 585)

As “border crossers,” disabled people become adept at navigating a material reality constructed for nondisabled people, filled with obstacles and misperceptions. But also, as border crossers, disabled people with “hybrid consciousness” are able to walk into and create a disability culture that exists separately from the mainstream. As Gill explains in her “Bicultural Framework of Disability” (1994), people with disabilities necessarily maneuver across boundaries of the dominant culture and their own experiences as disabled people. A “cultural identity” for disabled people makes crossing bicultural borders, and in most cases multicultural borders, more obvious and explicit. What is needed is a way to make such an identity more overt and understandable to the nondisabled majority. Peters says:

I will argue that this syncretic view of disability culture is necessary for deconstructing the hegemonic maps of difference created by society, for establishing ourselves [disabled people] as subjects and for producing our own cultural meanings, subjectivities and images. (2000, p. 585)

Thus, this “syncretic view of disability culture” dismantles current definitions of difference and disability, and constructs new definitions, images, and stories from empowered positions as cultural subjects.

In syncretizing three cultural worldviews, Peters is relying on four assumptions about culture. First, “the meaning of culture, as well as processes of identity development through acculturation,” is tied to certain worldviews, which she says have been confirmed by scholarly work and common ideologies. Second, each view of culture is tied to rules and values of a particular theoretical framework. Third, no worldview is more or less authentic than another. And the final assumption is that each discourse on worldviews has inherent limitations (Peters, 2000).

In the first worldview, culture as historic/linguistic, culture consists of discrete elements “based on the notion of culture as ‘depicted’ or received, rather than an enacted dynamic process” (Peters, 2000, p. 589). Yet, Peters demonstrates how elements of the historic/linguistic worldview are enacted in disability culture. She locates a common language of disability culture—how disabled people identify through words in everyday life and in written communication—that claims a cultural group. Peters also cites the following elements, including: historical writings on disability culture that can be traced textually; the evidence of a “cohesive social community” such as the one in Berkeley, California (2000, p. 590); political solidarity; acculturation within nontraditional family groups; pride and disability identity; and genetic links for certain impairments. These elements can be depicted, as well as enacted, in the process of developing culture.

For the second worldview, culture as social/political, Peters explains “disability culture is constructed/enacted in everyday [social] interactions and rests on the values of a radical democracy that is committed to social justice” (2000, p. 594). “Radical democracy” values differences, dissent, and social equality. In the social/political framework, collective identity is key, with the collective of individuals empowered to fight for social change and social justice.

In the third worldview, culture as personal/aesthetic, Peters explains that “voice and textual narratives” are vital to this worldview as disability culture (2000, p. 594). She adds:

Specially, through personal interpretations of life experiences, an individual creates a cultural identity as disabled. In this worldview, ideas and experiences are altered through the mind/body self-consciousness. The body becomes a metaphor for culture, where culture is created from whole body experiences, and the disabled body is the interpretive force for cultural identity. (Peters, 2000, p. 594)

This framework does not require a community of disabled people in order for cultural identity to exist. Through “decoding” and “re-centering,” an “embodied self” is able to filter cultural meanings and understandings of the world, focusing on interpretations of embodied experiences.

Peters notes that this worldview, although positively derived from a resistant perspective of the disabled body, is not typical when, for many disabled people, a negative perception of disabled bodies or stigma is internalized. Such internalizations may make some disabled individuals unable to “decode” their bodies from the dominant cultural inscriptions already imposed on them. Yet, Peters asserts that as disabled individuals from disability studies, the arts, activism, and other realms realize and pursue a disability aesthetic, living with disability and having a disabled body can be beautiful, valuable, and meaningful, even if not necessarily completely positive or negative. Beauty, value, and meaning are defined by the individual, and can be complex, nuanced, and full of seemingly contradictory definitions.

Culture as personal/aesthetic “constitutes the performative self, which is strategic and positional” (Peters, 2000, p. 596). This “performative self” of disability culture is usually what people mean when they “come out” as disabled. It is an assertion of pride and identity—acceptance of who they are and of the embodied, disabled self. Cultural identities involve a process of “personal identification,” with artistic appeal. In this worldview, one’s cultural identity may constitute both the physical body and ideas of the body as symbolic of disability culture and of subjective reality. “These [subjective] realities are not constructed universally, but through concrete and specific encounters, struggles, and engagements that are affective and ethically-based on values of self-pride” (Peters, 2000, p. 596). In other words, this cultural view is constructed via lived and embodied experiences, performatively enacted, and filtered through emotional resilience and entitlement as a value of one’s whole and embodied self.

Peters “syncretization” of these three worldviews encompasses the enacted elements of each for disability culture. This hybrid consciousness allows disability culture to fuse these three worldviews, granting individuals the opportunity to merge specific elements based on personal relevance. Additionally, as a hybrid model, the syncretic view accepts differences and encourages combinations of all three: disability history and language, disability activism and advocacy, and disability as a personal and aesthetic interpretation of embodiment.

a) **The cultural model of disability**

Before moving on from disability culture, I want to introduce what Sharon L. Snyder and David T. Mitchell call the “cultural model of disability.” In their book, *Cultural Locations of Disability* (2006), they begin with this model as a way to explicate disability from its recent moorings within other paradigms such as the social model of disability. According to Snyder and Mitchell, disability is “largely, but not strictly synonymous with sites of cultural

oppression” (2006, p. 6). Additionally, disability “is not purely synonymous with the processes of social disablement” (Snyder & Mitchell, 2006, p. 6), which is the social model of disability. Rather, a cultural model of disability allows for “social obstacles and biological capacities” (impairments) to have significance for how disabled people deal with their environments and beliefs (Snyder & Mitchell, 2006, p. 6).

In the cultural model, *impairment* is understood not only as “neutral,” as the social model defines it, but also “embodied revelation” (Snyder & Mitchell, 2006, p. 10), where impairment becomes potentially meaningful. “An embodied experience can be embraced while also resulting in social discrimination and material effects (such as pain, discomfort, or incapacity)” (Snyder & Mitchell, 2006, p. 10). For their purposes, Snyder and Mitchell assert that a divided understanding of impairment and disability becomes the political term *disability* (2006, p. 10). Thus, the cultural model holds this term, *disability*, to include previously separate notions of the body (impairment), which distanced the body from its social, political, and cultural consequences, as well as interrelated “material effects.”

As “embodied experience,” *disability* (Snyder & Mitchell, 2006) is similar to Peters’ (2000) explanation of culture as personal/aesthetic, where an “embodied self” influences and constructs cultural meanings. Additionally, the cultural model fuses embodied experiences with social barriers. “The definition of disability must incorporate both the outer and inner reaches of culture and experience as a combination of profoundly social and biological forces” (Snyder & Mitchell, 2006, p. 7). In this way, Snyder and Mitchell have put forward a model that coalesces the three worldviews that Peters suggested for disability culture. The term they use to signify this cultural amalgamation of historical/linguistic, social/political, and personal/aesthetic forces is *disability*.

The term *disability* recognizes that there exists a necessary distance between dominant cultural perspectives of disability (sometimes signified as “handicap”) as tragic embodiment, and a politically informed disability-subculture perspective that seeks to define itself against devaluing mainstream views of disability. (Snyder & Mitchell, 2006, p. 9, emphasis original)

Thus, *disability*, in this definition, already recognizes oppressive features of dominant cultural forces and distinguishes a “politically informed disability-subculture perspective” (i.e., disability culture) from those oppressive dominant perspectives. By combining physical, social, cultural, and political effects into one term, disability becomes an active and political term. As such, *disability* signals disability culture, complex meanings, embodied experiences, social and biological forces, and cultural and political subjectivity, agency, and empowerment.

The cultural model of disability, and its shortcut term *disability*, is exciting for scholars wishing to move beyond the social model and focus on cultural resistance and redress of disability oppression. With this model, I have a framework for theorizing political and cultural strategies that emerge from new and resistant representations of disability. It provides favorable effects for real disabled people and challenges a damaging cultural heritage.

The formulation of a cultural model allows us to theorize a political act of renaming that designates disability as a site of resistance and a source of cultural agency previously suppressed—at least to the extent that groups can successfully rewrite their own definition in view of a damaging material and linguistic heritage. (Snyder & Mitchell, 2006, p. 10)

Thus, the cultural model establishes the “cultural identity” Peters (2000) argued for, with cultural agency and the power to transform disability’s “damaging” cultural and lived heritage.

5. **Disability narratives**

The discourse surrounding disability—cultural representations in film, television, literature, and other media—often influences perceptions of disabled people in society, as well as the ways in which many disabled people view themselves. Mitchell and Snyder (2000a) point out

that disabled characters from literature and film are pervasive in Western culture. Yet, a disabled character functions as “an opportunistic metaphorical device” or “narrative prosthesis” within literary discourse (Mitchell & Snyder, 2000a, p. 47). Disability studies and American literature scholar Michael Davidson explains that disabled people’s “nontraditional bodies are sites of moral failing, pity, or sexual panic” (2008, p. 176) in literary discourse. The use of “narrative prostheses” allows authors to insert disabled characters as a way of ensuring “normalcy” and wholeness for a novel (Davidson, 2008). Moral failings in one character or sphere are signified by disability in another, giving the novel a sense of “totality” (Davidson, 2008, p. 176).

The need for a sense of “wholeness” and “normalcy” in literary discourse seems to drive some of the prevailing disability narratives in dominant culture. For example, medical narratives, which usually assume that ability will be restored by a “cure” bestowed by medical practitioners, fits nicely into what Caroline Gray calls “the assimilation narrative” (2009) where disability must be eliminated in order for the person to maintain value. Yet, just the threat of disability should be eliminated, not the people who possess it. In this way, disability becomes separate from the person, and the person is simultaneously tragic and hopeful.

Victoria Ann Lewis discusses the lure of stories about disabled people that are derived from the medical model because of their inherent dramatic structure (2006). She explains:

The seductive plot possibilities of the medical model, with its emphasis on a bodily transformation accomplished by an isolated effort of will, are irresistible in creating conventional dramatic structure. (Lewis, 2006, p. xxii)

Thus, “assimilation” narratives provoke dramatic works, and meet the needs of conventional audiences. Perhaps this is the reason that Gray calls assimilation narratives the most prevalent. But Lewis also gestures here to “overcoming narratives” when she references “an isolated effort of will.” Lewis adds that overcoming stories demand that disability be challenged by an act of

will on the part of the disabled character. All that prevents the disabled person from a full and meaningful life is an attitude adjustment.

In the “overcoming” or “hyphenation” narrative (Gray, 2009), disabled characters demonstrate “heroic efforts” to be normal, while nondisabled characters prod them because she or he is typically trapped in self-pity and resentment. In these scenarios, the perception of societal prejudice and discrimination is dismissed—even if this may actually be the cause of so-called “self-pity”—as paranoia about a maladjusted person that refuses to “accept his/her disability” (Lewis, 2006, p. xxii). Like the “cure” narrative, the story is individualized, and the disabled character is separate from the social and cultural forces that maintain his or her current status. In other words, this is an individual “problem.”

Additionally, portrayals of overcoming are structured to separate the disabled person from their disabled body as a way to emphasize the human spirit. Tanya Titchkosky, in her chapter “Overcoming: Abled-Disabled and other Acts of Normative Violence” (2007), explains that “human-interest” stories make “common, repetitive, and frequent” appearances in our culture (p. 181). The routine mass media depiction of “overcoming as a ‘human-interest story’ makes humanness interesting by working to exclude anything called disability from the nature of humanity” (Titchkosky, 2007, p. 181). Thus, in excluding disability, it becomes invisible, and cannot be perceived as “an ordinary and common fate of all,” which maintains disability as an individual tragedy. Instead, “human-interest stories” use inspiration to convert disability into triumph for the “universally human” spirit over tremendous adversity (Titchkosky, 2007, p. 181).

She writes:

The overcoming story proceeds by depicting an individual feature or trait as an enabling universally human *force*, such as courageous perseverance, reasoned tenacity, positive attitude, or sheer will. (Titchkosky, 2007, p.181, emphasis original)

Titchkosky intentionally uses the term “universally human” to indicate that this “force” belongs to all who are human. However, the human spirit is emphatically recognized while the disabled person, now disconnected from his or her impaired body and/or disability identity, is no longer needed for the story. As another form of “narrative prosthesis,” the disabled person becomes disembodied from the “universally human” spirit, and in this case, a “real” rather than fictional character disappears beneath the weight of metaphor in order to inspire readers of the story.

Similarly, Siebers points out in his essay “Disability as Masquerade” that many human-interest stories exaggerate disability for the able-bodied public in the service of reaffirming and reinforcing the supremacy of ability (2008). To achieve its dramatic story arc, Siebers argues that the human-interest story must demonstrate its “protagonist’s metamorphosis from nonhuman to human being” (2008, p. 111). Siebers explains:

Human-interest stories display voyeuristically the physical or mental disability of their heroes, making the defect emphatically present, often exaggerating it, then wiping it away by reporting how it has been overcome, how the heroes are “normal,” despite the powerful odds against them. (2008, p. 111)

Such human-interest stories, like many film and television portrayals of disability, lack any realistic representation of the experience. And because disability is socially misunderstood and culturally misrepresented, it is a simple matter to “conflate pathology with claims of exceptional talent” (Siebers, 2008, p. 113). Being exceptional or possessing “super” ability seems to come directly from disability; it is *because* of disability, not in spite of it. This conflation, Siebers argues, often creates the “cripple/supercripple” duality of many disabled heroes in human-interest stories (Siebers, 2008, p. 111). It is meant to be an inspirational tale that motivates nondisabled people to utilize their abilities.

Additionally, these stories maintain the ideology of ability, because disability is “overcome” and thus wiped away, leaving the disabled person invisible. Siebers explains:

Whence the desire that people with disabilities sometimes experience to overcome their invisibility and its attendant violence by exhibiting their impairments, and the paradoxical consequence that they become even more invisible and vulnerable as a result. In fact, owing to the ideology of ability, the more visible the disability, the greater the chance that the disabled person will be repressed from public view and forgotten.” (2008, p. 102-103)

The overcoming discourse of disability that persists in mainstream society and culture has insidious structures for repressing disabled people, keeping them invisible and vulnerable, and erasing them from “public view.” Narrative prosthesis, cure narratives, and the overcoming discourse are inherently limiting representations because they result in removing disability from public dialogue. People with disabilities are erased, avoided, and silenced in the public sphere. The possibility of having honest and valuable discussions about the realities of disability is extremely difficult in light of these pervasive narratives.

Ultimately, such narratives are detrimental to both disabled and nondisabled people. The responsibility to independently and triumphantly overcome disability removes any opportunity for civil rights, alternative community, or resistant subculture for disabled people. Furthermore, the overcoming narrative challenges nondisabled people to prove their ability to achieve—if they can do it, you can do it better. In his essay, “Screening Stereotypes,” originally published in 1985 (as cited in Longmore, 2003a), Paul Longmore explains this phenomenon: “If someone so tragically ‘crippled’ can overcome the obstacles confronting them, think what you, without such a ‘handicap,’ can do” (Longmore, 2003a, p. 139). The overcoming narrative absolves society and culture from responsibility, precluding opportunities for social change, social justice, and representational reform for everyone.

6. **The representational gap**

Cultural images of disabled people are sorely lacking. While disabled characters pervade our culture and mass media, these representations influence societal views and attitudes

towards actual people with disabilities. In her groundbreaking book *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997), Rosemarie Garland-Thomson perceives a “gap” between “disabled people and their representations” (p. 10). She explains: “Representation informs the identity--and often the fate--of real people with extraordinary bodies” (Garland-Thomson, 1997, p. 15). By exploring “how disability operates in texts” and in dominant culture (Garland-Thomson, 1997, p. 10), Garland-Thomson also explains how some of these gaps operate within social relationships and the material realities of life.

Representation has power to influence the lives of real people, often defining the social identities of people with disabilities and other differences while simultaneously defining those who are “normal” and unmarked. This unmarked subject, which Garland-Thomson calls the “normate,” is also the “cultural self”: white, male, able-bodied, and heterosexual. He is outlined in representation “by the array of deviant others whose marked bodies shore up the normate’s boundaries” and is also “the social figure through which people can represent themselves as definitive human beings” (Garland-Thomson, 1997, p. 8). The “disabled figure,” on the other hand, is a discursive construct “informed more by received attitudes than by people’s actual experience of disability” (Garland-Thomson, 1997, p. 9). Garland-Thomson states that the “disabled figure” “circulates widely in culture” finding a home in literary representation (1997, p. 9). These disabled characters, usually marginal and rarely central in literature, tend to be uncomplicated as devices that elicit responses from other characters or for “rhetorical effects that depend on disability’s cultural resonance” (Garland-Thomson, 1997, p. 10). Critics usually read such characters “metaphorically or aesthetically” without agency or political awareness (Garland-Thomson, 1997).

The gap between disability representations and lived reality demonstrates how these cultural figures shape discourse and its consequences. Social relationships are often disrupted or avoided because the nondisabled person may fear saying something wrong to the disabled person. The normate's perceptions have reduced the complex person with disability to a single attribute, removing the opportunity for a relationship (Garland-Thomson, 1997).

Consequently, the meanings attributed to extraordinary bodies reside not in inherent physical flaws, but in social relationships in which one group is legitimized by possessing valued physical characteristics and maintains its ascendancy and its self-identity by systematically imposing the role of cultural or corporeal inferiority on others. Representation thus buttresses an embodied version of normative identity and shapes a narrative of corporeal difference that excludes those whose bodies or behaviors do not conform. (Garland-Thomson, 1997, p. 7)

Thus, the nondisabled normate maintains his position within his material realities of social relations, ensconcing “normative identity” and reinforcing an exclusive narrative. If representation has such influence and power on the lived realities of human beings, then representation needs to be changed. Disabled characters, as they currently appear in culture, fall short because they are drawn by “omitting—and therefore erasing” factors and traits that may “mitigate or complicate” them (Garland-Thomson, 1997, p. 10). Texts often rely on cultural assumptions to fill in missing details, but cultural assumptions are created by representation. “Caricatures and stereotypical portrayals that depend more on gesture than complexity arise necessarily out of this gap between representation and life” (Garland-Thomson, 1997, p. 11). It is this “gap” between representation and lived reality that sparks my interest in this research, and propels my search for social change through cultural and representational reform.

Like literary representations, American film has also perpetuated stereotypes and caricatures of disabled figures. In Martin Norden's *Cinema of Isolation* (1994), the author does an exhaustive examination of disability in American cinema. A few of the most familiar

characterizations he discusses include the “sweet innocent,” the “saintly sage,” the “noble warrior,” and the “obsessive avenger” (Norden, 1994). The “sweet innocent,” a childlike character with a disability, is particularly situated to benefit a nondisabled character by receiving help from that nondisabled character. The sweet innocent uses innocence to humanize the other characters, helping them become better through a relationship with the disabled figure. The “noble warrior” is sentimental and patriotic, while the “saintly sage,” who is usually blind, uses wisdom and spirituality in the service of nondisabled characters. These characters often act as morality boosters, moving the story forward by aiding the nondisabled character evolve. Usually, these disabled characters are marginal and undeveloped in the film. The “obsessive avenger” unlike the previous characters, is angry about being disabled, and seeks revenge on nondisabled characters. He or she is a villain, and the disabled or disfigured body of this character gives this away. All of these film stereotypes, while involved with main characters, remain flat and uncomplicated sideline roles with little agency or humanity. They exist as props for the story the film wants to tell.

Another character, the “comic misadventurer” (Norden, 1994), has a disability that leads to many amusing interactions with nondisabled characters, usually at the expense of the disabled figure. For this character, think “Mr. Magoo” or “Wylie Coyote.” Sandahl and Auslander (2005) indicate that the comic misadventurer is one “whose impairments initiate physical comedy or whose body become the target for comic violence” (p. 3). Another character called the “inspirational overcomer” is “extraordinary” and “excels despite her impairments” (Sandahl & Auslander, 2005, p. 3). Other characters include the “monster,” feared by others due to horrible disfigurement, the “freak” or the “ultimate outsider,” and “the charity case,” a character that extracts pity and allows others to mark themselves as normal through his or her goodwill. “The

fates of such characters often include cure, death, or revaluation in the social order, a metaphorical quelling of the commotion disability stirs up in narrative” (Sandahl & Auslander 2005, pp. 3-4). In other words, disabled characters must “die” metaphorically in mainstream culture in order to appeal to mainstream audiences.

Thus, a paradoxical gap exists in the pervasive cultural representation of disability: disabled figures are everywhere—in human-interest stories by mainstream media, in Hollywood film and television, and in literature. Meanwhile, on the streets, in the world, and in our society, disabled people are overlooked, unemployed, and underrepresented in civic life. Their views, voices, stories, and experiences are rarely heard or seen in American media, and social interactions or community participation between disabled and nondisabled citizens are rare. And although reasons for this can still be traced to inequality of opportunity and inaccessible environments, as scholars we need to pay attention to reasons that stem from this representational gap. My project is an effort to look for creative, representational, and cultural strategies that close this gap and bring disabled people into public life in more meaningful and wholistic ways. The next section closes this chapter with an exploration of cultural resistance through artistic production as a potential strategy for closing this gap.

D. **Cultural Resistance: Strategies, Performance Art, and Disability Performance Art**

1. **Introduction**

This portion looks at literature specific to strategies that have potential for closing the representational gap. In this project, I argue that a powerful and explicit way to close this gap is through solo autobiographical performance art by disabled artists, I discuss literature on specific counter-strategies, performance art practices from queer and feminist theorists, and specific research on disability performance art from disability studies.

2. Counter-narratives and other strategies

In *Bodies In Commotion* (2005) Sandahl and Auslander argue for “manipulating and transforming stereotypes” as an important task for resisting dominant cultural portrayals. Unfortunately, the narratives available for disability are “frustratingly limited and deeply entrenched” in the dominant culture (Sandahl & Auslander, 2005, p. 3). “Disability counternarratives” may exist, however, if scholars (and artists) have the tools to uncover them. Mitchell and Snyder outline methodologies for uncovering disability counternarratives from the dominant culture, which are “poetical and narrative efforts that expand options for depicting disability experiences” (Mitchell & Snyder, 2000a, p. 164). In addition, disabled artists, writers, performers, and scholars have the opportunity to offer counternarratives into contemporary culture as a way to “re-read” disabled bodies and disability experiences, and to challenge pervasive disability stereotypes. Mitchell and Snyder address the importance for disabled artists to re-interpret social and cultural meanings of disability in their 2001 article:

Such a process of reclaiming the medically (and socially) authorized narrative of one’s body becomes the basis for disability art’s resignification of the disabled body: not an erasure of the discursive terms that define one as Other, but rather an effort to invert the power of even denigrating terminology into a redress of social ideologies of difference. (Mitchell & Snyder, 2001, p. 386)

Mitchell and Snyder call for disabled artists to “invert the power” of denigrating terminology by reclaiming narratives about disability and re-signifying the disabled body. Disability art, as an outgrowth of disability culture, can transform derogatory cultural assumptions about disability without erasing its “discursive terms.” Yet, I believe that what Mitchell and Snyder envision is that such a reclamation and inversion of power will have broader implications as “redress of social ideologies of difference” that are beyond disability. This makes sense because disability cuts across race, gender, class, sexuality, ethnic and religious boundaries, and as a result,

transforms the social ideology of disability, which has implications for a multiplicity of differences.

It is important to study how art works and artistic transformations reclaim narratives and re-signify disability. One way is through personal narratives, and the re-interpretation and reclamation of disabled bodies and lived experiences. Indeed, if disabled artists tell their personal stories without mainstream cultural inscriptions, their artistic lenses could provide deeper, more radical meanings that alter the “discursive terms that define one as Other” as well as powerful “redress” of the social ideologies and cultural prescriptions of difference more broadly.

Personal stories, such as coming out stories have power and agency as counternarratives. For example, in *Crip Theory* (2006), McRuer discusses one of Cheryl Marie Wade’s poems, “I am Not One of the (The Woman with Juice)” to illustrate how “coming out” as disabled can be a resistant strategy to compulsory able-bodiedness.

Talking back to able-bodied terms and containments, and terms of containment, [Cheryl] Wade speaks to ‘the last of your fears’ by employing conversely that crips cannot be contained; even the words most intended to keep disability in its place – such as, of course, cripple itself – can and will return as ‘a sock in the eye with gnarled fist’. (2006, p. 40)

McRuer cites Wade as an example of a radical crip, using the power of her artistic gifts, in this case her poetry, to come out as a disabled woman. She is talking back to the social and cultural tendency to put a euphemistic spin on disability. Wade uses the descriptive terms of discomfort and difference in an unapologetic way that claims her identity with all of its ugliness and able-bodied anxiety (McRuer, 2006).

In Sandahl’s discussion of crip-queer solo performers (2003), she notes that disability pride often accompanies publicly coming out as crip, which usually leads to activism. Sandahl uses Eli Clare’s words to illustrate this point: “Without pride, disabled people are much more

likely to accept unquestioningly the daily material conditions [of] ableism” (quoted in Sandahl, 2003, p. 44). Clare admits that disability pride is not an easy thing to “come by” because disability has been cloaked in shame, silence, and isolation. Clare is advocating for the idea that disability pride is closely associated with social and political consciousness, and leads to “individual and collective resistance to oppression” (Clare quoted in Sandahl, 2003, p. 44).

Furthermore, Sandahl points out that one of the ways that crip-queer solo autobiographical performers can present disability pride is by rearticulating the disabled body as both gendered and sexual. While able-bodied feminist and lesbian performers have also attempted to manipulate the male gaze by exposing their bodies in unexpected ways, critics of these performances note that the practice can inadvertently “replicate the very objectification they seek to challenge” (Sandahl, 2003, p. 45). However, for disabled performers, sexual objectification is rare. Crip artists may need to express their gender and sexuality in hyperbolic ways, perhaps following the model of drag queens, in order to claim sexual agency by recounting sexual experiences and gender identity onstage.

In their essay “Talking about Talking Back” (2000b), Mitchell and Snyder discuss the ways in which disabled artists and academics “come out” as disabled in their film *Vital Signs: Crip Culture Talks Back*. Shot with a disability perspective, the disabled artists and academics they interviewed for the film were presented so that their images loomed large on the screen, and that the interviewees controlled their “words, ideas, and images” (p. 198). This film can have a profound impact on its viewers, including me, in the way that it approaches disability. It puts disabled artists and academics whose work strives for representational change and juxtaposes new images with some iconic film clips of disability. As Mitchell and Snyder point out, this film embodies a “visual revolutionary praxis” (2000b, p. 199). Additionally, the film defines

disability culture by “explicitly argu[ing] for a growing cultural awareness based upon the experiences of being disabled” (Mitchell & Snyder, 2000b, p. 212), and it provides a public forum for disabled people to begin to transform public space; “a uniquely literal (and profoundly metaphorical) concern for the disabled community” (Mitchell & Snyder, 2000b, p. 204).

In *Disability Aesthetics* (2010), Tobin Siebers argues that disability, because it has always been part of the human experience, is also always part of aesthetics. He writes:

Disability aesthetics refuses to recognize the representation of the healthy body--and its definition of harmony, integrity, and beauty—as the sole determination of the aesthetic. Rather, disability aesthetics embraces beauty that seems by traditional standards to be broken, and yet it is not less beautiful, but more so, as a result. (Siebers, 2010, p. 3)

Thus, disability aesthetics offers a counterintuitive strategy for engaging with mainstream modern art. It privileges disabled, nontraditional aspects of beauty and rejects the presumed “healthy body” aesthetic.

Siebers explains that the human body is both the subject and object of aesthetic production. The original subject matter of aesthetics is the “affective sphere” of the body and the human body itself. He points out that there is a long tradition that has tried to “replace the underlying corporeality of aesthetics with idealist and disembodied conceptions of art” separating the sensations of art from the body and denying the “bodily character” of viewing art. Such a tradition limits the definition of art by devaluing the role the body plays in it. Siebers argues that many art works from the modern era have critiqued “the assumption of idealist aesthetics” (Siebers, 2010, p. 2) by engaging explicitly with the body. To do so, such works summon images of disability. “Most frequently they register as wounded or disabled bodies, representations of irrationality or cognitive disability, or effects of warfare, disease, or accidents” (Siebers, 2010, p. 2). In this way, modern art critiques idealist notions by engaging with work that depicts the human body as flawed, painful, frail, or injured.

Yet, Siebers explains that returning to the corporeal and affective aspects of aesthetics means accepting the role disability plays in it. Therefore, disability aesthetics “prizes physical and mental differences” and refuses health and the integrity of the body as “standards of beauty.” It does not support the “aversion to disability” traditionally required by notions of human perfection (Siebers, 2010, p. 19). “Rather, it drives forward the appreciation of disability found throughout modern art by raising an objection to aesthetic standards and tastes that exclude people with disabilities” (Siebers, 2010, p. 19). He further explains that disability is not a subject of art among many; is not a theme, nor an “autobiographical response embedded in an artwork”; and it is not a political act (Siebers, 2010, p. 20). “Disability is an aesthetic value” that contributes to knowledge about how certain bodies make us feel (Siebers, 2010, p. 20), capitalizing on disability as provocative and unsettling. In this way, disability aesthetics reinscribes the cultural meanings of disability. Yet, bringing these notions into the open, making disability aesthetics an obvious technique for construing meaning and feeling onto works of art, Siebers has exposed many of the critical mechanisms for creating negative bias and meaning in representation, and therefore revealing an entry point for resistance.

3. **Performance art**

Carrie Sandahl (2003) calls solo autobiographical performance a “hybrid” form that includes fusions of stand-up comedy, poetry performance, and one-person drama. These performances are usually done in front of a live audience, and sometimes performers interact with the audience. Venues may vary from theatres to art galleries, usually with a bare stage or “playing area.” Such artists tell stories from their lives, often episodically, while narrating and enacting personal stories in the “first-person past or present tense” (Sandahl, 2003, p. 28). Artists

usually portray themselves and may also adopt other characters from their lives. Stories are often “jarringly juxtaposed” to form an emotional and experiential collage (Sandahl, 2003, p. 28).

Sandahl states that what she calls “solo autobiographical performance” would be considered a subgenre of “performance art monologue” by theater scholar Michael Peterson, which tends to “privilege ‘reality’ over ‘fictionality’” and where the “author is present onstage in the body of the performer” (quoted in Sandahl, 2003, pp. 28-29). Performance art monologues have an “air of authenticity” to their work such that “audiences, critics, and marketers often consider solo artists authentic representatives of the social groups to which they belong” (Sandahl, 2003, p. 29). Because these artists take the stage alone and reveal their personal stories, audiences consider this “heroic”. These elements—the artist’s courage to expose personal details with monologue on a bare stage—“imbue the solo performer with tremendous power” (Sandahl, 2003, p. 29).

Performance studies scholar Marvin Carlson, in *Performance: An Introduction* (1996), says that although performance art had begun much earlier, it was during the 1970s that it started including autobiographical material. While I have seen a variety of definitions of “performance art”, Carlson’s definition is most helpful for the purposes of this research. He writes:

[Performance art’s] practitioners, almost by definition, do not base their work on characters previously created by other artists, but on their own bodies, their own autobiographies, their own specific experiences in a culture or in the world, made performative by their consciousness of them and the process of displaying them for audiences. (Carlson, 1996, p. 115)

For example, performance art by women during the 1970s exposed personal experiences, a collective past, and political activism using autobiography. The solo performance artists I have encountered in disability culture, including the two artists chosen for this study, use their bodies, autobiographies, and experiences. For many disabled artists, the “individual body” is “at the

center” of performance art practices, and putting the body, voice, and experience onstage to tell a personal story often provides opportunity for new and underrepresented experiences to be heard and seen. Carlson argues that performances are “made performative by [each performer’s] consciousness of them” alongside the “process of displaying [the performer’s body] for audiences” (1996). The “consciousness” surrounding the performer’s body and story is an important, deliberate part of the process of performance art that contextualizes the body, identity, and experiences being presented in a way that frequently resists and challenges dominant perceptions and perspectives.

Feminist performance has employed autobiographic material with social and political consciousness of the work. During the late 1980’s and early 1990’s, performance artists included more autobiographical narrative in their work, and “political and social concerns” were a main theme (Carlson, 1996, p. 117). Feminist autobiographical performances featured monologues: a resistant cultural form that permits expression and exploration of marginal identities and oppositional standpoints (Howell, 1999).

This sense of providing a voice and a body to common (and generally unarticulated) experience is very important to much modern performance, especially that created by and for marginalized and oppressed communities. (Carlson, 1996, p. 116)

Thus, monologue is part of the tradition of autobiography in performance art because it literally provides the voice of the body for marginalized individuals and groups. It allows the expression of oppositional perspectives within the context of a personal, performative narrative.

Queer performance artists, according to Sandahl (2003) use the “monologic apparatus” to “challenge instead of buttress hegemonic norms” and to build “alternative communities” (p. 29). Sandahl lists five reasons that artists choose solo autobiographical work, including monologue. First, she says it is cheap and quick to produce: artists do not need to rely on casting directors or

others to cast themselves in a solo performance. Second, “solo performance is about crossing boundaries” because it is open to everyone who chooses to do it “regardless of race, ethnicity, gender, or sexuality” and often regardless of disability (Sandahl, 2003, p. 28). Third, this art form seriously considers “the personal is political.” Fourth, queer performance artists emphasize visibility of identity onstage. These artists define their own identities while also defining and critiquing their communities. Finally, queer performance “witnesses” the personal stories of those “whose stories have been left out of mainstream accounts of history” (Sandahl, 2003, p. 29).

Providing a voice and a body for unarticulated experience such as transgender and transsexual identities is also important in modern performance art. Miller (1995) argues that women’s performance art challenges traditional gender representations through the unique, subjective artist, giving voice to women’s lived realities. Looking at Holly Hughes’ autobiographical *World Without End*, which explores the unlimited parameters of female sexuality and transgender roles, Miller explains how Hughes plays with identification and objectification, self and other, in the way that she names and sometimes separates her “male” body part from herself (Miller, 1995, p. 50). As both a separate character and part of the main character’s body, Little Peter “symbolizes patriarchal values and embodies the intrusion of the larger heterosexual culture” (Miller, 1995, p. 50). In this way, Hughes performs a marginalized viewpoint and comments politically and critically on heteronormativity, hegemonic gender roles, and limiting constructions of female sexuality.

There is an “explosive literality” central in much of feminist performance art, says Rebecca Schneider (1997). Her term, “explicit body” refers to unfolding the ways in which performance artists’ bodies elucidate social relations. Additionally, she is interested in how these

performances expose the “sedimented layers of signification themselves” (p. 2). In other words, feminist performance art reveals the underlying cultural meanings within mainstream social structures and representation. I contend that the “explicit” disabled body in performance art also exposes social relations, dominant cultural beliefs, and misrepresentations of disability.

Many of the earliest forms of performance art relied on the physicality of the performer. Erin Striff, in her introduction to *Performance Studies* (2003), explains how performance artists utilize her or his physical presence in the performance:

The performers themselves become the text to be read. We are, in fact, encouraged to read the artist as fundamentally present in his or her own work, frequently through the expressions of their bodies. (p. 9)

This notion of “presence” Striff touches on is important because, like other performance art, disabled bodies and psyches are at once presenting their physicality and representing cultural meanings. Similar to performance artists who focus on differences such as race, gender, sexuality, transgender or transsexual identities, disabled performance artists, with visible impairments, cannot escape this “presence” once they leave the stage. As Striff introduces Philip Aulander’s essay on body alteration and identity, she points out that the artists discussed in his essay cannot escape their performances of identity in “their post-surgical bodies every time they walk down the street, not just while appearing on stage” (Striff, 2003, p. 9). Performing on the stage allows them to control the interaction that their presence usually garners in the public sphere: staring, questioning, and ignoring.

“As anyone with a visible disability knows, persistent stares are one of the informing experiences of being considered disabled, “ says Rosemarie Garland-Thomson in her essay “Dares to Stares” (2005, p. 31). In her book *Staring: How We Look* (2009), Garland-Thomson examines “staring” from multiple perspectives, and defines staring as an encounter between

strangers, a momentary interpersonal relationship between the “starer” and the staree,” or “an interrogative gesture that asks what’s going on and demands the story” (p. 3). She argues that this “intense visual engagement” between unfamiliar people, typically “people who are considered different” (Garland-Thomson, 2005, p. 31), “creates a circuit of commutation and meaning-making” (2009, p. 3). The most “censured” form of staring, she argues, is looking at disabled people. For people with disabilities, staring can be “unwelcome exposure” that can challenge their “social management skills” (Garland-Thomson, 2005, p. 31). It makes visible their “presence” (Striff, 2003) in everyday performances.

Garland-Thomson make a distinction between staring and the gaze. The gaze, she contends, is an “oppressive act of disciplinary looking that subordinates its victim” (Garland-Thomson, 2009, p. 9). The stare is a form of “intense looking” or “social choreography,” enacting a visual exchange that marks the bodies involved. She writes:

Because lived staring encounters are spontaneous and dynamic...they can be pliable under the guidance of an experienced staree. Indeed, accomplished starees often develop a repertoire of strategies they use to choreograph staring encounters. (Garland-Thomson, 2009, p. 8)

Garland-Thomson’s use of the term “choreograph” acknowledges the performance and performative aspects of certain staring encounters in everyday experience. She points out that staring at disabled people comes as a result of what she calls “the ability system,” the “cultural narrative” that sees disability as “unexpected” or “uncanny.” In fact, Garland-Thomson says, “wide human variation is the norm rather than the exception. It is the ideology of ableism that tells us we should all look the same“ (2005, p. 40). Next, my discussion of the literature moves more specifically into disabled performers and performance artists. The social choreography of staring and staring management strategies will emerge as disability performance art—a powerful intervention on the staring encounter and the ideology of ability.

4. **Disability performance art**

Just as the staring encounter between disabled and nondisabled strangers implicate the body in notions of identity, dancer and scholar Ann Cooper-Albright uses dance performance to explore the ways that movement creates meaning, and “how physical bodies are both shaped by and resistant to cultural representations of identity” (Cooper-Albright, 1997, p. xiv). In her book, *Choreographing Difference* (1997), Cooper-Albright argues that dance comprises what she calls a “double moment of representation,” which destabilizes the relationship between somatic (embodied) identity and cultural identity where bodies “are both producing and being produced by cultural discourses of gender, race, ability sexuality, and age” (p. xxiii). She wants to articulate “how culture is embedded in experiences of the body and how the body is implicated in our notions of identity” (Cooper-Albright, 1997, p. 5). In other words, as bodies signal identity in society and culture, they also embody that culture. Performances, such as dance or performance art works that foreground the body, also foreground the cultural significance of embodied experiences.

Garland-Thomson points out that staring often involves “diagnosing impairment” as unimpaired strangers seek “a narrative that puts their disrupted world back in order” (2005, p. 31). In her essay on three disabled women performance artists, Garland-Thomson emphasizes how the gaze claims ownership while the stare seeks clarification. “Gazing says, ‘You are mine.’ Staring says, ‘What is wrong with you?’” (2005, p. 32). The gaze claims a sexual object, as in the male gaze, but “starers become doctors by visually probing people with disabilities” (p. 32). When unfamiliar people stare at someone with a disability, the “disabled body is at once the to-be-looked-at and the not-to-be-looked-at, further dramatizing the staring encounter” (2005, p. 31). In this way, the disabled body becomes simultaneously hypervisible and invisible—both

spectacle and object. Thus, staring “constitutes disability identity” as it visually communicates each position between the disabled and nondisabled individual.

In her 2000 essay, “Staring Back: Self-Representations of Disabled Performance Artists”, Garland-Thomson does a close reading of the performance artist Mary Duffy, who “foregrounds the body as an object both to be viewed and to be explained” through performance art (Garland-Thomson, 2000, p. 334). According to Garland-Thomson, “disability performance art is a genre of self-representation, a form of autobiography, that merges the visual with the narrative” (2000, p. 334). Disabled bodies on stage perform the medium and content of the work. The genre of performance art helps answer the question “what happened to you?” Garland-Thomson writes:

The disabled body on view *is* the performance. Rather than only telling the required disability story, then, disability performance acts out that story. (2000, p. 334, emphasis original)

The body and identity are intertwined in this art form, allowing the self to be narrated by the performer and the performer’s body to be viewed under the control of the artist. Such self-representation touches upon aspects of a more generalized disability experience and redefines that experience for disabled and nondisabled people alike.

In Mary Duffy’s performance, —an Irish woman born without arms—she centralizes her body as the performance, presenting herself as the living Venus. She opens her performance with a dark stage, and when lights come up, she is standing calmly in front of a black background, in the nude, lit as if a piece of art sculpture. When she finally begins to speak, she speaks of her embodied experiences and identity, telling her audience what words “you use to describe me”.

The words she cites are the verbal equivalents of the stare she sets up between herself and the audience. Yet, in this narrative, the words come from her own voice in performance rather than from the array of starers she has faced during her lifetime. By appropriating the words others use to describe her body, she upsets the dynamic of the stare. (Garland-Thomson, 2000, p. 337)

By “upsetting the dynamic of the stare,” Duffy stares back at the starers, and talks back to the questioners and the whisperers that she encounters in her daily experience. In addition, Thomson argues that her performance renounces this practice for her community, rejecting objectification, which the staring encounter promotes. Thus, Duffy “boldly reimagines disability on behalf of her community” (Garland-Thomson, 2000, p. 337).

Similarly, Garland-Thomson’s article “Dares to Stares” looks at the work of three women performance artists, including Duffy, whose work “mount[s] a critique about dominant cultural narratives about disability” (2005, p. 32). Staring encounters are social transgressions that, used in certain ways, have inherent power. The three women artists she analyzes, Wade, Duffy, and Sandahl invite the stare by exposing their impaired bodies in their performances as a way to engage the prohibited dynamic of staring, and to sharply challenge prevailing narratives about the disabled body. Inviting the stare makes the disabled body a “critical aesthetic medium” rather than a passive site for such things as charity, diagnosis, or freak show entertainment (Garland-Thomson, 2005, p. 33).

The artistic genre of performance lends itself especially well to the project of renarrating disability because the body is the artistic medium of performance. Thus, in these women’s art, the body that performs disability in the social realm is the same body that is the instrument of artistic performance. (Garland-Thomson, 2005, p. 33)

These artists “unleash and realign” the inherent power of the staring encounter. They “flaunt” their disabled bodies, constructing a new narrative of disabled female identity and subjectivity. “Such performances are forums for profoundly liberating assertions and representations of the self in which the artist controls the terms of the encounter” (2005, p. 33).

This kind of self-display and self-representation where the artist controls the terms of the encounter is important in disability performance art. As with feminist performance art, these artists perform “the explicit body” as a “form of cultural criticism,” using the body to “explicate

the bodies in social relations” (Garland-Thomson, 2005, p. 33). Gender and disability intertwine in the performances of these disabled women. While able-bodied female performers elicit the “male gaze” that objectifies and sexualizes them, disabled female bodies are pathologized. Yet Garland-Thomson points out that these artists--Wade, Duffy, and Sandahl--exploit this “transgressive potential in disabled female sexuality” as a means for constructing sexual subjectivity that is not pathological, victimized or passive (Garland-Thomson, 2005, p. 34).

Because I’ve already discussed Mary Duffy’s performance, I will focus on what Garland-Thomson says in regard to Cheryl Marie Wade’s performance of her poem, “My Hands,” and Carrie Sandahl’s autobiographical performance piece. All of these artists are featured in the video, *Vital Signs: Crip Culture Talks Back* (Mitchell & Snyder, 1996).

Garland-Thomson focuses on Wade’s performance of her poem “My Hands.” In *Vital Signs*, Wade is featured performing excerpts of her full-length piece “Sassy Girl: Memoirs of a Poster child Gone Awry” in which the poem is included. The performance piece mixes Wade’s original poetry with narrative, all autobiographical in nature, and all foregrounding her disabled body. This particular poem, however, focuses on Wade’s deformed hands, an identifiable aspect of this performer who also uses a power chair. This poem, like others in this show, centers on her body—Wade’s body dominates her poetry.

Looking at her poetry, Garland-Thomson notes that it is an “affirmation of her own body as whole and right” (2005, p. 36). This means that Wade claims an empowered identity as disabled woman, just as she claims her subjectivity and sexuality.

Wade controls the terms of the encounter. No victimized object of rude, intrusive, curious stare, Wade simultaneously rewrites the cultural narrative of the pathetic cripple and the pretty little lady. (Garland-Thomson, 2005, p. 35)

Wade's poem asserts her hands as beautiful, sexual, painful, and imperfect claiming a definition of herself that is complex and more realistic than typical cultural representations would allow. In this way she is using disability aesthetics to re-narrate how disabled people are perceived and received.

Sandahl's performance is much more interactive. Wearing a white shirt and pants, each garment features writing that explains what happened to her body in particular spots. There are also drawings and signatures of different doctors who have left their marks on her impaired body. As she walks around using her cane, Sandahl invites the stare, but on a more engaged level. She invites others to "read her body" with the actual medical knowledge and diagnostic information their stare seeks. In this way, she controls the terms of the engagement, having the option to ignore questions and directs starers to read her rather than to bother her.

All of these performances enact self-representation that engages the viewer on the artists' terms. Garland-Thomson points out that these artists act out individual versions of "positive identity politics" that claim their identities along with their power. She writes:

Wade, Duffy, and Sandahl forge an autobiographical form of feminist disability performance art that unsettles cultural presumptions about humanity, femaleness, disability, and self. Wade's performance alludes to the Black Power movement of 1960s positive identity politics; Duffy's rendering of herself from a freak to a Venus draws on the 1970s deconstruction of high and low culture; Sandahl's choreographing of interactive theater space deepens the current art form of the installation. By merging the visual and the narrative, body and word signify together in an act of self-making that witnesses the liberatory potential of disability performance art. (Garland-Thomson, 2005, p. 39)

Indeed, this liberatory potential of performance art is not only liberating for the performer, but also for the larger community that they represent, and in this case, these three women represent both disabled and female communities.

Kuppers claims disability performances are both cultural and political interventions (2003). She sees the ability of such performances to undermine certainties of dominant notions of disability, as well as to forge new ways of being in the world. She points out that tensions surrounding disability performances reflect discourses of the body in culture. Public assessment of disability performances depends upon issues of “performing” versus “being”. Being disabled onstage can be viewed as therapeutic and as an “authentic” portrayal. Performing, on the other hand, entails a split between performer and performance where “the ‘truth’ of the bodily expression is manipulated, cited, and rewritten by the performer” (Kuppers, 2003, p. 56). This is an important distinction if dominant cultural assumptions surrounding disabled bodies are to be interrogated. Through the performer’s “manipulation” and “rewriting” of their bodily experiences, they are able to re-present them through their cultural and political consciousness, rather than tacitly and passively accept the mainstream discourses of their experiences.

Kuppers’ analysis centers on her experiences and interpretations of disability performances as a spectator, using little direct engagement with the artists (2003). She does, however, draw on the dramaturgical processes that performance artist Matt Fraser uses to construct his “freak show” reenactment. Locating his historical role model, Fraser performs “Sealo the Seal boy,” a real freak show artist with the same disfigurement as Fraser (shortened arms with tiny “handsies,” as Fraser refers to them). As Sealo, Fraser performs as his freak show twin did in his time. In this way, Fraser reaches back to his “roots” and touches on disability as a “cultural minority experience” (Kuppers, p. 31) rather than a singular, individual one. In this performance, Fraser manipulates his audience, who become the audience of time past, to laugh in all of today’s politically incorrect places.

Sandahl analyzes four solo autobiographical performers with intersecting crip-queer identities in her article (2003). As I discussed in earlier sections, Sandahl's analysis focuses on autobiographical works from these artists, and draws on personal conversations with each of them. Sandahl puts forth two intersecting components within each performance art piece: queering and crippling. "Queering" spins mainstream representations to "reveal latent queer subtexts" (Sandahl, 2003, p. 37) or to deconstruct heterosexism. "Crippling spins mainstream representations or practices to reveal able-bodied assumptions or exclusionary effects" (p. 37). Like queering, crippling exposes "the arbitrary delineation between normal and defective and the negative social ramifications of attempts to homogenize humanity" (Sandahl, 2003, p. 37). Both of these practices also "disarm what is painful with wicked humor, including camp" (Sandahl, 2003, p. 37). The artists in Sandahl's study "crip the queer," expanding and critiquing what it means to be queer, and also "queer the crip" which means they critique and expand what it means to be a crip.

Sandahl's analysis of the ways these strategies are employed by the performance artists is richly intricate. By working with both of these modalities at the same time, these artists produce new ideas about both disability and homosexuality. For example, Greg Walloch, a performance artist with cerebral palsy, "queers the crip" in his "Walking Inspired" performance in *Crip Shots* (Kilacky, 2003) performance. As he walks for an imagined audience of doctors across the stage, he sexualizes the experience by telling us about his uncontrollable erection. At the same time, he "crips the queer"; his walk also mimics a fashion runway where the model, wearing only his briefs, limps across the stage with his crutches.

Sandahl notes that each of these artists employs specific strategies that are also sites of activism. First, their use of the "tainted" terms "queer" and "cripple" or "crip" reclaims and

redefines the terms of oppression in their performances. Sandahl uses the term “taint” because such terms are still considered dangerous in certain contexts, but she asserts that within a “theatrical frame,” it is safer to “rehearse” these identities and all the “contradictions” their bodies inhabit through performance (Sandahl, 2003, p. 51).

Second, these performance artists “come out crip” as well as queer, proclaiming their identities while also displaying their bodies in their performances. This is a radical move, since Sandahl notes that the only other options available to disabled people have been either the “charity case” or the “overcomer.” The charity case must perform, or even exaggerate, their impairments in order to receive government services or charity. The overcomer, however, performs his or her impairment in a way that signals impairment is of no consequence. These artists perform “alternatives to stigma management” (Sandahl, 2003, p. 41). Therefore, coming out as a crip, both onstage and in everyday life, enacts a performance of the self that accepts impairment while acknowledging the social and cultural critiques that keep disabled people oppressed.

A third strategy of disability performance art, according to Sandahl, is performing “crip pride” in the form of “sexualized public display” (2003, p. 44). Sandahl points out that sexuality is not typically afforded to crips, which is why proclaiming gender, sexual orientation, and sexual agency with pride is a public demonstration of what is usually private. These artists claim their sexuality and gender, describe some of their sexual experiences, and put a sexual spin on what are usually painful experiences. Sandahl says: “The power of these performances lies in their ability to assert pride while drawing the audience’s attention to the political and social issues of being crip and queer” (2003, p. 49).

The final strategy is “bearing witness.” Sandahl finds Clare helpful in discussing how performing pride encompasses the responsibility to also bear witness. Sandahl quotes Clare to help describe the process of “bearing witness:”

Both witness and pride strengthen identity, foster resistance, cultivate subversion... Yet, we also need to remember that witness and pride are not the same. Witness fuses grief and rage with remembrance. Pride pairs joy with a determination to be visible. Witness demands primary adherence to and respect for history. Pride uses history as one of its many tools... We cannot afford to confuse, merge, blur the two. (Clare, quoted in Sandahl, 2003, p. 49)

Thus, bearing witness acknowledges the oppressive, painful histories of individuals in disability community, as well as the wrongs perpetrated on the community as a group. The distinction that Clare makes here is that “witness” requires reverence while pride is inherently irreverent because it claims self-respect and satisfaction for a life and a body that has been denied such attributes. Bearing witness in acknowledges those who have come before us, those to whom we owe a debt, and to those who risked much more than the performer risks in his or her performance.

III. STATEMENT OF THE PROBLEM/CONCEPTUAL FRAMEWORK

A. Introduction

In her 2006 article “The Authentic Disabled Voice,” Chicago-based disability rights activist and artist (filmmaker, author, playwright, and actor), Susan Nussbaum, proclaims, “The dominant culture is obsessed with disability” (2006, p. 3). Yet, such characters are “flattened-out” and “perpetuate backward notions about real disabled people” (Nussbaum, 2006, p. 3). Nussbaum is expressing the crux of Garland-Thomson’s notion of the “representational gap” (1997). The ubiquitous and unrealistic representations of disability have very “real” effects on the lives of disabled people. Nussbaum notes that common representations of disability are boring, lack substance, and contain little consideration of lived realities (Nussbaum 2006). She contends, “As long as the writers of disabled characters are not themselves disabled, disabled characters will be written largely as metaphors – to symbolize, rather than behave and interact” (2006, p. 4). Thus, Nussbaum pinpoints the central problem inherent in the dominant culture’s depictions of disability: disabled characters are portrayed in ways that disregard the full humanity and participation of people who experience disability, and society reflects these limiting depictions and understandings to project skewed perceptions of actual disabled people. As Garland-Thomson puts succinctly, there is a “gap between representation and reality” (1997, p. 12).

The “gap” between disability representational and reality is the problem this research project seeks to address. The problem involves an inverted relationship between mainstream depictions and their effects on lived experiences: the more disabled characters are represented in mainstream culture, the less disabled people are included, understood, relevant or included in society. Dominant cultural representations negatively influence the perceptions and attitudes

towards people with disabilities in society (Garland-Thomson, 1997). This chapter discusses this problem in more detail, including its attributes, and the corresponding issues it creates.

Additionally, conceptual frameworks that underlie and support this project are discussed.

B. **The Problem**

1. **The gap between representation and reality**

Between art and life there is typically a gap where representation does not accurately depict lives and experiences of actual people. Yet, for disabled people, this is even more important, because others have historically determined disabled people's lives. Doctors, medical professionals, institutions, family members, and cultural representation have pre-determined, without the input of disabled people, how their lives, their bodies, their images, and their identities will be understood. Thus, the representational gap is a critical problem in the lives of people with disabilities, and therefore finding solutions and strategies for self-determination, self-representation, and disability cultural depictions is an important goal of disability studies, and of this project.

In *Extraordinary Bodies* (1997), Rosemarie Garland-Thomson explains representation's power to influence the lives of real people, and define the social identities of people with disabled bodies, gendered and racial bodies, and other bodily differences. Simultaneously, representation outlines the boundaries of those who are "normal" and unmarked. The "normate" is defined in representation by the "deviant others" whose bodies outline his (Garland-Thomson, 1997, p. 8). In other words, without the "deviant others" of representation, the "normate" would not exist.

The "disabled figure," discussed in the Literature Review, is more explicitly described in representation than the normate. Disabled figures, however, have none of the complexities or

other social and existential “realities” based on actual experiences of disabled people. They are typically marginal and uncomplicated, as Nussbaum asserts. They elicit responses from other characters, and are frequently intended for their “rhetorical effects that depend on disability’s cultural resonance” (Garland-Thomson, 1997, p. 10). The normate and disabled figure work together in both representation and social relationships. The normate coexists with disabled figures, and other “extraordinary bodies,” to reify the power of what is constructed as “normal” and to objectify all others.

The resulting “gap between representation and reality” (Garland-Thomson, 1997, p. 12) demonstrates how cultural figures shape the discourse around “disability” and “normal” in both cultural representation and in society. Garland-Thomson explains that “the actual experience of disability is more complex and dynamic than representation usually suggests” (1997, p. 12). This alludes to the idea that discourses surrounding disability in dominant culture are far less developed than disability studies, gender or race discourses because of how disability has been limited by cultural representation.

Yet, representation frequently obscures these complexities in favor of the rhetorical or symbolic potential of the prototypical disabled figure, who often functions as a lightning rod of fear, pity, discomfort, guilt or sense of normalcy of the reader or a more significant character. (Garland-Thomson, 1997, p. 15)

Thus, comprehending disability, and the experience of being disabled, is difficult in mainstream contexts because it is frequently obscured by representation. Disability’s “rhetorical or symbolic potential” often results in “fear, pity, discomfort, guilt or sense of normalcy” in social relationships between disabled and nondisabled people. For example, social relationships are often disrupted or avoided because a nondisabled person fears saying the wrong thing to a disabled person. Or, he or she chooses to ignore people with disabilities altogether out of discomfort. Thus, the “normate” of the social realm develops perceptions that are internalized

from culture, and these perceptions reduce the person with disability to a single attribute, physical difference, ignoring the opportunity for a “real” social encounter between the two (Garland-Thomson, 1997).

2. **Perspective shapes perception**

In *Disability Rhetoric* (Dolmage, 2014), the author lays out an “archive” of disability myths, stereotypes, narrative tropes, and metaphors that function as disability rhetoric, which permeate what Garland-Thomson has called “the representational system” of disability (Dolmage, 2014, p. 31). Since “representation structures reality” (Dolmage, 2014, p. 31), this archive—a listing of each “myth” with a brief description and examples—structures the social and cultural “reality” that has helped shape commonly held perspectives about disability. Disability rhetoric helps to frame “some of the myths of disability that are ubiquitous across all cultures and eras and that condition our understanding of disability (and thus of all identity and all bodies)” (Dolmage, p. 31). In other words, these myths, stereotypes, metaphors, and familiar narratives shape and condition how people, both disabled and nondisabled, understand disability in society and culture.

In Nussbaum’s article (2006), she hints at a possible solution to the problem of representation, suggesting that “the writers of disabled characters” should be “themselves disabled” (p. 3). I agree with Nussbaum, because the daily, lived experience of having impairment(s) and disability can profoundly influence how one understands and interprets the world. However, not all people with disabilities are the same, nor do all share a political and personal understanding of disability. In order for characters to be written differently, even by disabled writers as Nussbaum suggests, such writers would require a different perspective—an

understanding of disability that has shifted in a way that resists and challenges disability rhetoric (Dolmage, 2014).

The lack of a “disability perspective” is a corresponding problem with the representational gap. The literature includes interpretations of disabled performers by Koppers (2003), Garland-Thomson (2005), and Sandahl (2003). Because the analysis of these performances lacks qualitative interviews to help divulge the relationship between how the artists’ perceived and represented their experiences, these studies do not address the artist’s intentions, strategies, or perspectives.

Along with disability rhetoric, social constructionism plays a large role in how disability is understood. Social constructionism, according to Marks (1999), defines disability as “neither ‘natural’ nor essential, but rather that it is socially produced,” viewing the “perceptions of and responses to differences” as contingent, or “historically and culturally specific” (p. 78). Thus, social constructionism is produced with the help of cultural representations, alongside rhetoric, and reinforced in social and historical contexts that also shape conceptions of disability.

Social constructionism has “been an important theoretical backdrop for critical theories of disability,” and “shows that our values and ways of seeing are a social accomplishment” (Marks, 1999, p. 79). Marks recommended that disability studies scholars concentrate “on the way in which the labels are produced and reproduced in social interactions within institutional and cultural contexts,” rather than focusing on “disabled people in the abstract” (1999, p. 79). In other words, focus on perceptions of “disability,” or how it is understood and constructed in social practices. Marks explains:

Knowledge and social action go together. Thus, rather than seeing disability as being a consequence of individual differences, it can be understood as a result of perceptions rooted in social practices which mark out some differences as being abnormal and pathological. (1999, p. 79)

Thus, the way in which people understand disability is a result of social interactions and social practices, but also, social practices and relations are shaped and influenced by the ways disability is represented. Disability rhetoric influences social constructions of disability, which affect how disability is perceived. Without examining or questioning disability's rhetoric, representational system, or social practices, which shape how it is understood, perceptions are unwittingly steeped in the "ideology of ability" (Siebers, 2008) or "compulsory able-bodiedness" (McRuer 2006). In other words, mainstream perceptions of disability thrive within what Marks calls "those normally hidden processes and structures which produce disability and 'normality'" (1999, p. 187). Making these hidden structures visible is what this project, and "much of the work of Disability Studies scholars" is about.

Returning to Nussbaum's example of disabled characters written by disabled artists, such artists would arguably need a view of disability that is cognizant of how ideas and practices surrounding disability are produced in society and culture. Such a writer would need to project awareness, or perspective informed by disability culture, in the writing of such characters. Without such a perspective, simply substituting the nondisabled writer with a disabled one would have little or no effect. This is because people with disabilities are frequently just as enmeshed as nondisabled people in mainstream concepts and practices. Many people with disabilities share negative and limiting views of disability and disabled people with their nondisabled peers, and as a result, characters they create would likely maintain the representational gap, the problem that this project seeks to address.

In her article, "Disablistic Practices in Womanhood," Reinikainen (2008) discusses how she dealt with the problem of disability perspective in her qualitative research study involving autobiographical writing. Her study examined autobiographical texts, or self-representations, of

20 disabled women. The inquiry was seeking “the *political*” in disabled women’s personal accounts (p. 20, emphasis original) The author argues that much of the research that focuses on personal experiences of disabled people fails to address the social, cultural, and political aspects of these experiences. Research on disability experience with the goal of social change, Reinikainen argues, needs to consider what many European and Canadian scholars call “disablism,” which results in “disablistic practices that are oppressive, exclusive, and disabling to disabled individuals” (p. 20). Thus, the author looked for “socio-cultural and institutional practices” (p. 21) of “gender and disability” by examining autobiographical texts. She looked specifically for references to “disablistic” traditions of exclusion and isolation.

I found Reinikainen’s article helpful in framing the concepts in my research, which also looked for latent meanings and underlying concepts that reflected “disablistic” practices, but I called these practices and concepts “structures of ableism.” Reinikainen notes that her own perspective influenced and guided her interpretations of the texts during the research process. As a result, she was able to recognize the political, “socio-cultural,” institutional, and “disablistic” practices referenced in the autobiographical texts that were selected for her study.

For example, Reinikainen (2008) acknowledged how the narratives available to the women writers of these autobiographical texts are extremely limited. The personal accounts of disabled women’s experiences were to address “womanhood” (Reinikainen, 2008). Yet, the narrative models, available from mainstream culture and representation offered few way to present disability experiences in any “*culturally understandable way*” (Reinikainen, p. 22, emphasis original). Thus, the woman themselves had not been exposed to alternative models of autobiographical storytelling, and the dominant culture would likely not understand alternative depictions of their experiences. Thus, the available, culturally recognizable models that these

women used included narrative themes such as personal tragedy, individual “abnormality,” and rehabilitation following an accident (Reinikainen, 2008, p. 21). The women’s accounts were typically accompanied by feelings of shame about an “imperfect body,” functional limitations, dependence and incapacity, and trying to hide their impairment or to “pass”. Additionally, medical discourse colored these texts, suggesting how medical discourse about disability has dominated and explained disability, and has been the dominant representational method for disability for the general public (Reinikainen, 2008).

Similar to the women’s narratives in Reinikainen’s study, Marks (1999) warns how personal narratives tend to follow the available models from mainstream culture, maintaining disability’s entrenched negative and uncomplicated stories. She notes that such narratives risk being perceived as a

form of self-subjugation, affirming a fixed ‘disabled’ identity and viewed as either representing all disabled people, offering a model along the lines of ‘triumphing over adversity’ or reinforcing disabled people’s positions as pathological objects available for voyeuristic gaze. (Marks, 1999, p. 183)

However, Marks explains that personal narratives of disability experience can be a potentially political act of resistance. Alternative autobiographical narratives, “which are written within a highly theorized politicized context and which examine complex identities and experiences,” offer accounts of disability that are personal and political, affirming a “multiform reality” of experience that integrates both “self and society” (Marks, 1999, p. 183).

Additionally, “aesthetic resistance” (Marks, 1999, p. 182) is another form of self-representation that can be used politically and in an affirming way. In a photo layout in a British fashion magazine, disabled celebrities were featured as models, with written captions for each model. Mat Fraser, a visibly disabled performer and writer with shortened arms, is included, and his caption states “the fundamental problem is that people with disabilities are invisible . . .

You've got to declare yourself disabled and beautiful" (1999, p. 183). Aimee Mullens, a model with lower leg prostheses said, "it's my mission to challenge people's concept of what is and isn't beautiful" (1999, p. 183). Mullens claims beauty *because* of disability, not in spite of it. In this way, these models enact alternative narratives to dominant culture's notions of what it means to be disabled, claiming themselves and their different bodies in the process, and resisting the negative and pervasive constructions of disability.

Self-representation, which both engages with and disrupts disablist culture, thus offers a space for new identities. What has been constituted as disability and is subsequently hidden, displayed or excluded can perhaps begin to be respected and included within a transformed social and cultural environment. (Marks, 1999, p. 188)

C. **The Research Problem and How to Fix It**

If the dominant system of representation perpetuates how disability is understood—“backward notions” of disabled people through “flattened out” characters (Nussbaum, 2006)—and this understanding makes interactions between disabled and nondisabled people more difficult, distressing, or distancing, then cultural representation needs to reflect the complexity, diversity, and humanity of disabled people. New representations risk recreating and reinstating the current “representational system” and the ways in which it structures reality. The same social and cultural practices that emanate from long-standing systems of oppression, ableism, and the need to be “normal” are left unquestioned and unchanged. This research project explored the relationship between “real” lived disability experiences and their artistic representations. Each artist in the study simultaneously lives and represents disability, disability experiences, and themselves. What they portray in their work harkens to common elements experienced by other disabled people, which connects to others, creating disability culture and community. The research formalized conversations between the researcher, the artist, and their autobiographical performance work to establish interplay in these conversations, and between my analysis and the

artists' interpretations. The interplay revealed new kinds of representations that resist dominant ones, claimed disability in body and identity, and created disability culture and diverse communities.

By examining the gap between representation and “reality” through the autobiographical work of disabled performance artists, this research project exposed many systemic practices stemming from social and cultural structures. The artists interpret their experiences from a “politically informed disability subculture perspective” (Snyder & Mitchell, 2006), which demonstrates an awareness of the “ideology of ability” (Siebers, 2008) and “compulsory able-bodiedness” (McRuer, 2006). Additionally, the research demonstrated new representational methods and strategies used by the participating artists.

Revising how disability representations are produced, and putting them into the hands of culturally conscious disabled artists, could eventually change perceptions and treatment of people with disabilities in the social realm. My curiosity, and the problem as I see it, is how the representational gap can be narrowed. How might self-representational methods and strategies, from a disability culture perspective, work to repair this gap, resist social and cultural constructions of disability, and “create culture anew” (Garoian, 1999)?

Disabled artists are forging new cultural depictions and representations about themselves, essentially making over disability in their own resistant, creative, and empowered images. The artists in this study are no exception, and in fact, are excellent examples of self-definition and self-representation. This research raised questions about what these artists accomplished through their performance works, such as: How do these images and representations differ from dominant cultural representation of disability? What new meanings and perceptions could impact the daily lives of “real” disabled people? What effect could more complex, nuanced, and

politically informed representations have on disability discourse and on social relations between people with disabilities and others?

D. **Conceptual Framework**

My perspective as a researcher, including the conceptual frameworks that helped shape and direct my analysis, also influenced and guided my interpretations during the research process. In this section, I discuss these frameworks, including how they were applied to this research in light of the research problem. My understandings of representations depicted in the autobiographical performance work of artists in this study and of their conversations about their work were informed by feminism, social constructionism, disability studies, personal experiences of impairment and disability, and my personal “politically informed disability subculture perspective” (Snyder & Mitchell, 2006).

Solo autobiographical performance art provides an “air of authenticity,” particularly through the use of monologue. According to Carrie Sandahl, “audiences, critics, and marketers often consider solo artists authentic representatives of the social groups to which they belong” (2003, p. 29). This project was not interested in locating an “authentic disabled voice,” but rather an authentically derived performance based on the particular lived experiences of these two artists. Disabled people are diverse in race, class, religion, gender, sexuality, and impairment type, and perspectives and experiences vary between individuals. Yet, common experiences of oppression may be shared, they are not exact. Many experiences occur among disabled people to support common conceptions, values, and beliefs. Frequently, what disabled individuals share connects them culturally, and I do seek to define some of the boundaries of a “disability culture” in how each artist constructs this culture through her represented experiences. The performance art work itself—text, video, field notes from live performances—is an artifact of this culture, and

treated in this project as such. But it is also treated as an autobiographical document accompanying the interview data. The performance is considered more “authentic” because it relies on the artists’ experiences for content, while each artist’s body also validates these experiences on the performance stage. In this way, the performance art piece is used here because of its “air of authenticity” and as a means to represent the individual artist, as well as to act as a representative artifact of disability community and culture.

Art education scholar Charles Garoian’s “performance art pedagogy” (1999) has been instrumental in shaping this study. His “pedagogy” works as a model for seeking resistant and radical qualities in how performance art utilizes personal history and memory. Garoian states that performance art is “predicated on a history of cultural resistance” (1999, p. 10). He explains that performance art “is the genre of choice for artists of marginalized cultures who have found the strategy of radical critique necessary to aestheticize issues surrounding ethnicity, sexual orientation, gender, race and class distinctions” (Garoian, 1999, pp. 18-19). Disability intersects and overlaps with these issues, often creating its own issues of cultural and social marginalization, and as such, disabled artists have also used the genre of performance art as cultural resistance and radical critique. Garoian’s work provides a set of conceptual categories that helped guide the gathering and analysis of information in this study, as further described in the Methods chapter.

Disability performance invites discussion, interaction, and engagement with the public as a means of claiming agency and subjectivity. Interaction and discussion is needed because, as Koppers (2003) notes, “disability can preclude communication as its conception structures what kind of social involvement is not proper” (p. 5). Yet, disabled artists, although often unknown and unseen in the social realm, resist disability’s conception to prevent communication by

claiming public space and participation, and by reinventing the cultural practices and social consequences that have constructed their personal invisibility as disabled people. Kuppers states:

Disabled performers are often aware of the knowledges that have been enacted around them: tragic, poor, helpless, heroic, struggling, etc. in the laboratory of the performance situation, these knowledges can be re-examined, and questioned again and again...the disabled performer in contemporary art signals a historical moment where a culture is examining its bodies, sorts and counts its differences, allocates new quarters, and reinvents itself. Performance is a place where cultural uncertainties can find expression—the unknown is framed by the conventions of the stage or the gazing scenario. (2003, p. 3)

By questioning and re-examining the pre-existing discursive field of disability through performance, mainstream culture can “experience its bodies,” reinvent itself, and re-frame the “unknown” as something familiar, or even “interesting” as Cheryl Marie Wade might say.

My personal experiences as mobility impaired, visibly deformed, and a legally blind, guide-dog user, often lead to miscommunication and misperception in the social/public realm. The effects of these experiences include: being ignored in stores when I need to find someone for assistance; being openly avoided in train cars, buses, elevators, and other shared spaces; the demand that I respond to obtrusive questions regardless of the fact that I am involved in another task; being physically touched and manipulated under the guise of “assistance”; being verbally and loudly directed, regardless of whether or not I need help; and many other frustrating occurrences that disregard my adulthood or autonomy. These incidents offer examples of the “real” lived impact of the “representational system” and its constructions of disabled people as helpless, simultaneously hypervisible and invisible, scary and angry, and cheerful and passive. In addition, these constructions of disability demand that I behave in accepting, passive, and grateful ways, without objecting to mistreatment. But also, these constructions demand that I act as “normal” as possible, not take exception to inaccessible or unwelcoming environments, and try to demonstrate independence as much as possible. These social expectations are often

contradictory and incoherent, and go largely unnoticed by the majority of people who take ability, and able-bodied privilege, for granted.

Since ability and able-bodied privilege is so ingrained and pervasive, a politically informed and culturally conscious disability perspective is required in order to shift away from the internalized, habitual, and unseen structures that maintain ability as the standard, as “normal”, and as human. Marks reminds us that: “Much of the work of Disability Studies scholars has been to make visible those normally hidden processes and structures which produce disability and ‘normality’” (1999, p. 187). In order to do this, I also make my perspective as a disability studies researcher visible.

Reinikainen’s article (2008) helped me to frame my interpretive perspective, which is also expressed in the perspectives of each artist. She explains the ways in which her analysis emphasized the “social and cultural nature” of interpreting experiences. She writes:

Experiences of disability and womanhood are always produced in interaction with other people, with material and social circumstances, with cultural constructions, ideas, images, and stereotypes of disability and womanhood. This point of view makes it possible to interpret those ideas of womanhood negated by disability, which were constantly expressed in the analyzed texts, as references to our cultural stereotypes of the genderless disabled versus the ideal-bodied ‘real’ woman. (Reinikainen, 2008, p. 22)

Reinikainen’s statement above helped me to frame my interpretive perspective, which I am calling politically informed and culturally conscious. The way it is expressed here reflects how Reinikainen frames her next caveat about analyzing autobiographical texts. She writes:

The conventions of autobiographical writing on disability play a part in prescribing what and how disability or experiences of it can be narrated. The available narrative models of presenting disability offer a limited range of possibilities for narrating experiences of disability in a culturally *understandable* way. (Reinikainen, 2008, p. 22, emphasis original)

Reinikainen’s perspectives are drawn from her personal experiences with disability, as a disability scholar, and as a feminist. Her interpretive framework is guided by feminism, as is my

own. The most important thing I take from feminism is standpoint theory. Garland-Thomson (1997) concurs, stating, “Perhaps feminism’s most useful concept for disability studies is standpoint theory” because it acknowledges the complexities of “physical existence” (p. 24). In addition to emphasizing the body’s complexities, she argues that feminism’s standpoint theory has much to offer disability studies. She explains:

Emphasizing the multiplicity of all women’s identities, histories, and bodies, this theory asserts that individual situations structure the subjectivity from which particular women speak and perceive . . . feminist standpoint theory has reformulated gender identity as a complex, dynamic matrix of interrelated, often contradictory, experiences, strategies, styles, and attributions mediated by culture and individual history . . . Acknowledging identity’s particular, complex nature allows characteristics beyond race, class, and gender to emerge. (Garland-Thomson, 1997, p. 24)

This study looks at and interprets the autobiographical performance work and lived experiences of disabled women artists with an eye toward the complex and interrelated nature of identity, “mediated by culture and individual history.” The feminist theories and methods that look at identity and experience through interactions and interrelatedness informed this research project from its inception to its results.

IV. METHODS

A. **Introduction**

While Garland-Thonson’s concept of the “representational gap” illuminates a problem and raises questions about representation, this dissertation project, and my contribution, uses critical theory within a social science study to find practical methods and strategies for creating representations that narrow this gap and could eventually improve the lives of actual disabled people. In order to elucidate the relationship between lived disability experiences and their artistic representations, this project concentrated on and analyzed the autobiographical work of two solo performance artists with disabilities. The research process included qualitative analysis of performance texts (scripts, videos, live performances where possible), and qualitative interviews with each artist. By researching disabled performance artists and their autobiographical work, I could examine the interplay between personal history and its representation for each artist. This study investigated what these artists uncover about themselves and about disability through their artistic processes. In other words, if performance is a way of knowing, what knowledge—identity, culture, politics, consciousness, meanings—have these artists’ performance works revealed? How do personal experiences influence the performances and vice versa? Data from qualitative analyses of performance works, in conjunction with data gathered from individual interviews, reflect this interplay between experiences and self-representations, which could reduce the representational gap—the core problem addressed by this project.

This chapter explains the methods used for this study, data collected, and the processes used to analyze the data. In addition, I situate myself in this research as a disabled woman, scholar, and artist.

B. Methodological Goals

In his book, *Performance Ethnography* (2003), Norman Denzin argues that, among other things, performance is a way of knowing, a way of being, and a methodology. Dwight Conquergood explains how knowledge has been privileged in modernity through science and reason. He cites Michel de Certeau's phrase, "what the map cuts up, the story cuts across," which Conquergood explains is about "transgressive travel between two different domains of knowledge: one official, objective, and abstract—'the map;' the other one practical, embodied, and popular—'the story'" (2002, p. 145). He argues that this "travel" between different ways of knowing "carries the most radical promise" in the field of performance studies. Performance studies bridge different knowledge sources, such as empirical and embodied knowledge. The "map" delineates, divides into boundary areas, and contains; the "story" can meander, process emotional experiences, and inhabit multiple jurisdictions at once.

This research project aims to travel across borders of different ways of knowing. By bridging qualitative research methods with theories and concepts borrowed from performance studies, cultural studies, and critical theory, this project will travel between disciplinary boundaries. I seek new knowledge between embodied experiences and representations of the self, between the story told about the self in art and the meanings accumulated from life, and between dominant cultural notions of disability and disabled artists' reimagining of culture and representations.

"Performance is always a doing and a thing done" according to performance studies scholar Elin Diamond (1996, p. 1). She explains that performance is not the difference between truthful and fictional representations, "but...different ways of knowing and doing that are constitutively heterogeneous, contingent, and risky" (Diamond, 1996, p. 2). Diamond explains

that the prefix “re” in performance, as in “re-presentation,” recognizes two things: a repetition, and the “pre-existing discursive field.” The pre-existing discursive field includes embedded features of previously performed gender attributes, social histories, and aesthetics, as well as consciously and unconsciously acknowledged “political and cultural pressures” (Diamond, 1996, p. 1). For example, “re-inscribe” or “re-signify” includes the doing (inscribe, signify) and the thing done (re), the repetition of experience that is aware of the pre-existing discursive field during the performative present. At the same time, “inscribe” and “signify” indicate and “assert the possibility of materializing something that exceeds our knowledge, that alters the shape of sites and imagines other as yet unsuspected modes of being” (Diamond, 1996, p. 2). In this way, representation through performance offers a method to demonstrate and depict the past—the cultural, social, political, and embodied experiences in discursive context—while constructing new possibilities for the future. Autobiographical artists represent lived experiences, infusing performance work with their personal “realities,” and these representations acknowledge a pre-existing discursive field that has influenced perceptions of reality, and in turn, influence new ways of being.

The “pre-existing discursive field” in disability performance contains embedded aspects of cultural notions of disability. Performance and disability studies scholar Petra Kuppers, analyzing disability performances in *Disability in Contemporary Performance* (2003), argues that disabled artists “understand the pervasiveness and persuasiveness of medical knowledge and social differentiation based on medically and culturally controlled difference” (p. 4). Kuppers finds that these artists “turn to subversion” and use strategies to “dissolve the stability of categories, and posit openness and change” through their artistic works (2003, p. 4). Thus, the

cultural categories surrounding disability are restrictive and controlled in ways that can cause artists to turn to radical approaches. She says:

The aesthetic vehicles used by these artists to engage social fears and containment procedures...explode traditional art's boundaries, challenging the notion of genre, creating uneasy hybrids of art and the everyday. (Kuppers, 2003, p. 4)

Disability, like race and gender, "structures people into separate categories" (Kuppers, 2003, p. 5). By exploding such categorical boundaries, disabled artists subvert them and create new ones.

The literature about performance art indicates the potential of autobiographical work to move across and between boundaries of art and the everyday, creating "uneasy hybrids" between the two (Kuppers, 2003). To accomplish this in this study, I needed to analyze both kinds of data: lived experiences and their representations. Thus, I turned to individuals who could offer both types of data: disabled performance artists. In these artists and each solo autobiographical performance, disability experiences and their depictions in art could be investigated together. Using qualitative, in-depth interviews with each artist about their selected solo performance work, and qualitative, thematic analyses of the work itself, this investigation focused on the interplay between the performance work and the interview material thereby facilitating an intensive exploration between each artists' life and art.

C. **Situating Myself in the Research**

In qualitative research in disability studies scholarship, the primary research instrument is the investigator. As a disabled woman, artist, and scholar, my perspectives and lived experiences shape the ways I have designed this study, the ways I interpreted and analyzed the data, and the ways I create meanings from the findings. My "research identity," as Butler-Kisber describes it (2010, p. 19), demands that I acknowledge my beliefs and perspectives influencing this inquiry. First, I believe that human beings create their "realities": that is, humans make up meanings of

things and events around them as a way to make sense of their existence. Other human beings frequently influence these meanings and the meanings already created in society, in cultural representations, and through our interpretations of media. Also, we construct meanings through the interactions we have with powerful figures in our lives, such as family members, medical professionals, clergy, friends, and teachers.

From a young age, I was isolated from my family and exposed to multiple medical interventions because of my impairment and disability. I had internalized many of the dominant cultural assumptions, medicalized notions, and ableism this study attempted to reimagine. As Sandahl (1999), Gill (1997), and Marks (1999) explain, and Lomnicki and Wade represent, I, too, had separated my body from myself and chose to reintegrate my own fragmented psyche. Disability arts and culture, as I indicate in the Introduction chapter, shifted my internalized ideas of disability, and re-directed my personal journey. Disability performance offered a different paradigm for thinking about my own body and personal experiences, and because it left me personally transformed, I believe it could transform others.

I relate and empathize with the work and experiences of these two artists, and therefore, I am aware of my difficulty in distancing myself from this research. I am unable to interpret this material objectively, finding instead it has become part of how I create meaning. Because I cannot separate myself from the research process, nor do I believe anyone can be truly objective, I have tried to be clear and open about my personal perceptions within each aspect of the research.

However, I was concerned about rigor and incorporated several elements to ensure it. First, this research incorporated several points for member checking. Research participants were asked to check in at specific points in the analysis process. An intensive member check was

incorporated into the second interview, again during the third interview, and then following the completion of data analysis. Although in some, my interpretations were not compatible with their feedback, in others we discussed their disagreements and my interpretations. This will be discussed more in the section on analysis. Second, I adhered to the participants' voices by recording and transcribing each interview. And third, rigor was achieved through prolonged engagement with each participant, developing a research relationship over several years with each in-depth interview.

Finally, several paradigms shape the design, methodology, and meanings in this research, including: social constructivism, participatory/advocacy, feminist, and disability theory. Please refer to "The Statement of the Problem" chapter for descriptions of these paradigms.

D. **Methodology Overview**

This research project examined solo autobiographical performance work and formalized conversations with two disabled performance artists: Cheryl Marie Wade and Tekki Lomnicki. These artists were selected based on two initial criteria. First, the artist should have performed at least one solo autobiographical piece that foregrounds lived disability experiences. Second, the artist should be willing and available to complete three interviews of one-hour in length. Other criteria factored in to deciding on these two women. For example, I had previously seen video excerpts of Wade's work and found it very powerful. Also, I had seen Lomnicki's performance work, *Blurred Vision*, and other works of hers that supported her appeal. I could tell from what I had seen initially that they met my criteria. Working with two disabled women appealed to my interest in feminist disability studies, and the intersections of disabled and woman identities. Finally, the selection of these two disabled women artists had done work that had impacted me

as an audience member. I could relate personally to their work, and felt that I could relate to them and their works on multiple levels.

My overall methodological goal was to complete an interdisciplinary project that used qualitative techniques with theory and conceptual frameworks from the humanities. Through this process, evidence would demonstrate how disability could be represented from the perspective of those who lived it *and* represented it. Understanding and incorporating their perspectives into the research was an important piece of the process. Others, including medical professionals, family members, and social workers, often determine disabled people's lives, while self-determination, including perspective, choice, and voice, is seldom a consideration. For this reason, it was important to integrate not only the voices of these artists, but to actively pursue their participation, perspectives, and feedback into the research. Thus, my findings provide a textured picture of these artists and their performance work that explores and illustrates the relationship between personal experiences of disability and how disability is represented from artistic, culturally conscious perspectives of disabled women artists.

After recruiting disabled performance artists who had written and performed at least one solo autobiographical work, I applied qualitative techniques with two distinct data sets—interviews and performance texts—in interactive ways, creating interplay between the data. The first data set comprised transcriptions from individual, semi-structured interviews with each of the artists. At the end of the first qualitative interview with each artist, I requested they choose a solo autobiographical performance piece for us to work with in the study, or choice in representational work we discussed. The second data set was the video and script of each artist's chosen performance piece, which I analyzed using thematic techniques discussed below. After my first analysis of Wade's choice, *Sassy Girl: Memoirs of a Poster Child Gone Awry* (1995),

and analysis of Wade's first interview, I went back to Wade to present my initial findings and get her feedback, further interpretations, and insights about the work. This began the interactive analytic process between the data sets, the artists, and the researcher. A total of three interviews were conducted with each artist, and at least two feedback sessions that occurred in the final two interviews. Lomnicki chose *Blurred Vision: The Relapse* (2005, unpublished manuscript), and this process was also completed with her performance work. One additional feedback session had been planned where each artist read her findings chapter and offered feedback, but this only happened with Lomnicki. I explain these methods more fully, detailing the interactive processes between the artists, their performance piece, and me, later in this chapter.

Before data collection, I organized my research around a set of categories, also called a template, derived from the literature. "Template analysis," according to Reynolds (2003), "essentially approaches qualitative data analysis with a 'start-list' of themes or categories that are anticipated from the outset" (p. 551). Templates, and template analysis, also provide the researcher with "a few pre-defined codes, which help guide analysis" (King, 2004, p. 259). Since these "pre-defined codes" can be obtained from several sources, including academic literature, the researcher's personal experiences, informal or anecdotal evidence, or exploratory research (King, 2004), I chose academic literature from disability studies and performance theory, which aligned with my personal experiences of viewing performance art by disabled artists. This literature guided the template design, which I outline and define next.

1. **The template: Four research categories**

According to Hsieh and Shannon (2005), "using existing theory or prior research, researchers begin by identifying key concepts or variables as initial coding categories," which can be used for "direct content analysis" (p. 1281). This template structure provided a place for

my research to begin: questions to ask, initial “codes” identifying themes or “variables” I wanted to address, and a straightforward technique for analysis. I wanted this template to guide my project, but not to limit it. Therefore, these categories are a starting point—a way to delineate the components of the relationship between life and performance art—and also a jumping off point.

Additionally, these categories provide “sensitizing concepts” (Bowen, 2006), which suggest direction for the research as “interpretive devices” and “a starting point for a qualitative study” (p. 2). Sensitizing concepts are embedded in the researcher’s disciplinary emphasis and inclination for certain perspectives, offering ways of organizing and understanding experience. Thus, the categories selected for the template also act as sensitizing concepts, which deepened my perception and guided me through the analysis. I used these categories as sensitizing concepts and initial codes, allowing other themes to emerge from the data, and providing a kind of hybrid methodology with both open and structured dimensions.

My initial template was a start-list of four categories: interrogating cultural assumptions, re-articulating experiences into art, disability identity or self-representation, and disability culture. These categories were derived from different literature sources prior to data collection. A primary source for the categories was Charles Garoian, who, in *Performing Pedagogy* (1999), argues for a critical performance art pedagogy in which teachers are artists and artists are teachers, and students are spectators and spectators are learners. His ideas about performance art resonate with me as an explicit form of knowledge transfer between art and life. “Performance art has enabled artists to critique traditional aesthetics, to challenge and blur the boundaries between the arts and other disciplines and those that separate art and life” (Garoian, 1999, p. 19). Garoian’s “performance art pedagogy” addresses the phenomenon of performance art directly, and reveals how the relationship between art and life could be broken down into manageable,

culturally valuable and resistant parts. This appealed to me, not only because it addressed the “what” of this project—the relationship of art to life—but also the “why,” or the cultural and political relevance of “authentic” representations of disabled people. Garoian’s framework speaks to the need to interrogate dominant cultural impressions and expectations, identities, and ideologies about experiences and reality, while “constructing culture anew” (1999, p. 5).

“Performance artists use memory and cultural history to critique dominant cultural assumptions, to construct identity, and to attain political agency” (Garoian, 1999, p. 2). Thus, his framework potentially asserts and inserts the body, voice, and presence of marginalized people.

To clarify Garoian’s performance art pedagogy further, students are considered both artists and spectators, creating performance art works as individuals and as co-collaborators within the classroom as stage. In this way, the transformations, resistances, and new cultural forms that come out of performance art can directly impact the students as both spectators and artists. My project focuses on how disabled performance artists transform and challenge the dominant culture, how personal artwork is a transformation of their experiences, and how the art transforms them. Garoian argues that when the “pre-existing discursive field” of performance is “juxtaposed against existential experiences,” it “makes it possible to expose and interrogate cultural inscription and to re-consider and construct culture anew” (1999, p. 5). In other words, in the context of solo autobiographical performance art, each artist puts her lived experiences against the “pre-existing discursive field” of dominant disability ideology to create “liminal” space. Liminal space, or the threshold between boundaries, such as ableism and its associated “isms,” can be exposed and interrogated, and the problem of disability, both in representation and in the everyday, can be contested while it is simultaneously re-constructed.

Garoian's ideas aligned with many disability studies concepts. This research sought to understand the knowledge that comes from challenging or blurring the boundaries separating art and life, or as Koppers says, exploding boundaries to create "uneasy hybrids of art and the everyday" (Koppers, 2003, p. 4). But also, this research sought to blur boundaries between disciplines. Disability studies literature, combined with the framework of "performance art pedagogy," worked together to create and scaffold my template of four initial research categories.

Next, I will define and describe the four categories of the template. Each category generated questions for both artists and for analyzing solo autobiographical works, which also guided the research process. These questions follow each category's description.

a. **Category 1: Interrogating cultural inscriptions of disability**

This category looks at how performance art questions how the dominant culture assigns particular meanings and labels to disabled bodies and identities. I am interested in the ways that disabled performance artists investigate and appraise disability stereotypes, metaphors, and cultural myths. This category stems from Garoian's (1999) idea that "performance artists use memory and cultural history to critique dominant cultural assumptions" (p. 2), and make it possible to "expose and interrogate cultural inscription" (p. 5). Thus, each performer may be working with personal histories and experiences to examine, subvert, and critique the cultural ideas, images, and expectations of being disabled.

In addition, this category stems from disability studies and feminist scholar Rosemarie Garland-Thomson (1997), who argues that the representational system creates negative effects in the lives of disabled people or "extraordinary bodies." Garland-Thomson argues that the ubiquitous "disabled figure" promotes a "representational gap" that impacts the experiences of

actual disabled people. She contends that the “disabled figure” is flat, uncomplicated, narrowly defined, and typically used as a narrative device; while people with disabilities have “more complex and dynamic” lives (Garland-Thomson, 1997, p. 12). Many disability studies scholars (see Longmore, 2003a; Mitchell & Snyder, 2000; Norden, 1994; Sandahl & Auslander, 2005) have delineated cultural inscriptions of disability, including their uses as metaphors, stereotypes, myths, and narrative tropes.

Interrogating how disability is represented by the mainstream includes the pervasive cultural assumptions of what it means to be disabled, which appear in the social and public spheres. Cultural assumptions affect the lives of disabled people. The dominant culture tends to strengthen and perpetuate “compulsory able-bodiedness” or normalcy, making cultural resistance to such practices into political acts (McRuer, 2006). Therefore, the knowledge sought from this category incorporated questions about political or resistant perspectives and political agency.

From this category, certain questions arose about how the artists question or critique cultural views on disability. Questions included: What aspects of their work commented on or interrogated dominant cultural notions of disability, such as stereotypes, metaphors, or common disability narratives? How do cultural assumptions/oppressive acts play in in daily life? How has the artist dealt with them? What aspects of the performance work questioned or acknowledged disability culture? How and why did they choose these aspects? In addition, I asked the artists if and how she portrayed/enacted a political perspective or agenda in her performance work or everyday experiences.

Similar questions were considered for each autobiographical performance text. What stereotypes, myths, or narratives do the performance texts work with/against? How so? What

aspects of disability culture are acknowledged? How is an alternative culture presented? Does the performance enact, or speak to, any political perspective?

The way in which disabled performance artists interrogate and expose cultural inscriptions and assumptions of disability is particularly relevant to this project. Examining the means by which disabled performance artists question disability stereotypes, preconceived narratives, and other cultural myths through representing their own experiences, memories and histories are a valuable form of cultural resistance and critique. Portraying aspects of what may be considered “disability culture” also signals a critique of the dominant culture. It asserts political agency and identity, and begins to dismantle dominant notions while constructing new cultural images and ideas. In addition, disability performances demonstrate awareness of a pre-existing disability culture and community, and proclaim these ideas, images, language, meanings, and cultural knowledge.

Each of the categories in the template overlaps and interconnects with one another. Both the insertion of disability culture, and the presence of the performance artists’ disabled bodies are woven into all of the categories. For example, category 1 requires that the artist represent her lived experiences in order to interrogate dominant culture. The visibility of each artist’s disabled body makes her experiences explicit, while the contrast of alternative values and beliefs reveal a critique of dominant cultural values and beliefs. Thus, disability culture elements provide contrast and foundation for every category. The disability culture and the visibly disabled body undergird each experiential and performative theme. I define the next three categories below, including overarching category disability culture, and the disabled body in performance that runs throughout the template.

b. **Category 2: Transforming experience into art**

Invoking the idea that the personal is political, solo autobiographical performance art is also a personal, political, and interdisciplinary art form where artists take the raw material of their lives and convert it into artistic expression. A doing and a thing done, disabled performance artists re-articulate personal histories and memories through their reflective, reflexive, political, and artistic lenses, working with the tools and techniques of their craft to re-present experiences to their audience.

For this category, Garoian discusses the concept of “re-presentation” in performance art pedagogy, which assumes that identities and ideologies are unfixed and in “continual formation” (1999, p. 5).

Artists...invoke their personal memories and histories through performance, [and] engage in storytelling: a testimonial process that, according to performance theorist Elin Diamond [1996, p. 1] is the doing of ‘certain embodied acts, specific sites, witnessed by others’ and ‘the thing done, the completed event framed in time and space and remembered, misremembered, interpreted, and passionately revisited across a pre-existing discursive field. (Garoian, 1999, p. 5)

The transformation of experiences in performance art includes the original act, shaped by an earlier discursive field, then reinterpreted and remembered/misremembered, and reshaped within the performative present. Thus, performance art reflects the artist’s “experiences of reality and their desires to transform that reality” (Garoian, 1999, p. 10).

In disability studies contexts, Snyder and Mitchell (2006) re-employ the term *disability*, to express embodied experiences, cultural meanings, disability culture, and political and cultural subjectivity. Their concept, the “cultural model” of disability, declares *disability* asserts “a politically informed disability-subculture perspective that seeks to define itself against devaluing mainstream views of disability” (Snyder & Mitchell 2006, p. 9).

Using the cultural model, the second category looks for this anti-ableist perspective in the re-articulation and re-presentation of disability experiences in the work of these two artists. This perspective allows a critique of dominant viewpoints, and the re-positioning of embodied experiences from the margins to a central position that privileges disability. If I were to create a hybrid between Garoian and Snyder and Mitchell, this *disability* perspective with all of its embedded meanings would be the frame and “pre-existing discursive field” across which experiences are “interpreted, and passionately revisited.”

Performance art moves between private and public, creating a liminal third space. It uses the private to examine the public, and the public to examine the private, or what Garoian calls an “ethnographic performance”—a strategy that relies on embodied experiences to challenge and re-frame cultural meanings associated with different bodies (1999, p. 43).

With these ideas in mind, the following questions arose. To each artist, I asked: What is the relationship between lived experiences and how these experiences were represented on stage? Other potential questions included: What raw material was used to construct this performance work? How were experiences/episodes chosen? How did experiences change for the performance stage? How did putting experiences on the stage affect meaning(s) of the experiences? How did this process transform you?

I explored the following questions in my analysis of the performance texts: What experiences are represented? How do the representations of experience affect their meanings? What experiences were specifically chosen to tell this story? How much did the raw material change through the artistic process? What perspective(s) are expressed in the work?

c. **Category 3: Self-representation and disability identity**

The re-articulation of disability experiences through the artistic imagination, and through a politically informed disability subculture perspective, builds upon knowledge of disability history, cultural values, and political goals. Such an informed and self-aware disability identity, and the representation of personal disability identity, is what interests me in this category. Additionally, because these artists have multiple identities, I am interested in their self-representation within the performance and in everyday life.

In Garoian's performance art pedagogy, performance art can yield six overlapping and interconnected strategies, which link to the "explicit" body. These strategies allow artists (or students and spectators) "to interrogate and intervene [in] socially and historically embodied culture" (Garoian, 1999, p. 12). Often, identity is cultural—shaped by the cultural inscriptions of our bodies within our social locations. These strategies or interventions in performance art ultimately reclaim the self and the body from their culturally inscribed identities. The six strategies are: the "ethnographic" strategy, which involves examining the body's "physical, historical, and cultural terrain"; the "linguistic" strategy, which reveals and critiques stereotypes and cultural metaphors that are inscribed on the body, and can create a "language of identity"; the "political" strategy allows the reclamation and repositioning of the body as a means for political agency; the "social" strategy promotes community and critical citizenship through collaboration, or the body in social relationships; the "technological" strategy utilizes the body as a cultural instrument to critique and intervene in techno-culture and mass media; and finally, the "ecstatic" strategy questions the dialectics of pleasure and desire through the aesthetic experience of the body (Garoian, 1999, p. 12).

I am interested in a nuanced analysis of self-representation that blends the performative elements, which Garoian delineates above, with disability studies approaches to identity. With these ideas in mind, the following questions about this category were developed. To the artists and interview data, I was interested in the following questions: How do these artists construct their identity in their work? Is the identity performed on stage the same or similar to their identity in everyday life? Is there a performance identity that is only available when the artist is on stage? Does performed identity spill into lived experience? How does performance influence, change, or fortify each artist's off-stage identity?

For the autobiographical performance, I wanted to look for identity elements and how they were portrayed. What elements—embodied, linguistic, political, social, technological, or aesthetic—were used in the self-representations within the work? Is identity mediated by artistic, theoretical knowledge, and/or reappraisal of disability experiences? How does identity change or stay the same in the performance work?

d. **Category 4: Creating disability culture**

Garoian explains that performance art has enabled artists to critically examine cultural assumptions, offering an opportunity to question, appraise, and respond to contemporary culture while also “creating culture anew” (1999, p. 19). In this category, I am interested in how these performance artists, after challenging and examining dominant culture, “re-consider and construct culture anew” (Garoian, 1999, p. 5). Although disability culture is an important fundamental aspect that interconnects the other categories, as the disabled body does, this category looks at the noteworthy ways disability culture is constructed in the autobiographical performance works of these disabled artists.

Gill (1994) points out that disabled people, with a “politically informed disability subculture perspective” (Snyder & Mitchell, 2006), necessarily negotiate mainstream society’s cultural norms and disability culture’s ideas, beliefs and values. She proposes a “bicultural framework,” similar to people with bi-racial or multi-ethnic backgrounds, where both cultures are acknowledged and negotiated. Yet Gill also notes that frequently it is a better approach to embrace “one's own (disabled) identity without being tyrannized by majority (nondisabled) values” (Gill, 1994, p. 13). In this way, disabled people may opt to relinquish “the goal of assimilation” (Gill, 1994, p. 13) by adopting disability community as their cultural “home” (Gill, 1997). Disability culture is built upon communities of disabled people that identify as disabled and share a desire to express this identity, their experiences, and elements of disability culture.

Peters (2000) argues for a “hybrid consciousness” of disability culture in which disabled people claim a “cultural identity” that can move the disability community toward reclaiming itself from the “Other” while also establishing disabled people as “subjects and active agents of transformation” (Peters, 2000, p. 585). She calls for a syncretic cultural worldview that blends elements of three pre-existing paradigms of culture into a hybrid consciousness, and allows disability culture to be defined, developed, and enacted over time. Disabled people are practiced “border crossers” (Peters, 2000), living and maneuvering between the dominant world and the disability community, between accessible and inaccessible environments, and negotiating dominant cultural “norms” and their own interpretations of their experiences. Peters’ use of the term “border crosser” gestures back to performance theory, and the liminal space where culture and experiences can be disrupted and changed.

Peters (2000) argues that disability culture as personal/aesthetic constructs a strategic and positional performative self. This “self” has fully “come out” as disabled and also claims

“disability pride”—wholly accepting of self and differences. The disabled body in performance art becomes symbolic of a disability cultural identity, or a metaphor for disability culture. Life experiences are reinterpreted through what Peters (2000) calls “mind/body self-consciousness” where the body, or embodied experiences, become the interpretive frame. This paradigm relies on several of the categories in this template, including transforming experiences, disability identity, disability culture, and the disabled body.

With this category in mind, I asked each artist to talk about disability culture in her solo autobiographical work. What disability cultural elements are expressed in the work? How so? How did she utilize the visibility of her disabled body to symbolize, enact, or define culture in the performance? What did the artist want the work to respond to from mainstream representations?

To the performance texts, I posed the following questions: How does each artist frame and construct an alternative worldview to dominant culture? What elements from disability culture are depicted? How are these elements depicted? How does each autobiographical work relinquish the goal of assimilation with the dominant culture (i.e., the desire to be like nondisabled people), if it does? How is disability culture utilized as a critical conceptual framework for the artists to represent their experiences in the performance work? Are there scenes of “coming out” or “disability pride”? How is disability culture performed?

e. **Overarching category: The disabled body in performance**

In each of the four categories is the presence and presentation of the disabled body. This category is separate from the previous four because it emerged as a result of constructing the template. Like the performance art strategies that Garoian lists above, the

disabled body is connected to each of these categories as an important dimension of the artists' experiences both on and off stage.

Once disabled artists seized “the means of artistic production” they began to “radically transform” negative cultural assumptions about disabled bodies (Mitchell & Snyder, 2001, p. 382). Garoian takes note of feminist performance artists who “reclaimed the self and the body” by making the body “explicit”—the “stage”—in performance (p. 43). This idea reflects Rebecca Schneider’s concept of the “explicit body” as the site of lived experiences and social relations (1997). Thus, the body on stage reveals cultural meanings through its “explosive literality” and through its focus on embodied experiences. By explicitly placing their disabled bodies in the performance frame, alongside transformed representations of their experiences, disabled performance artists resist and critique dominant notions of disability, reclaim self and body, symbolize and create disability culture, and transform their experiences from “tragic embodiment” to creative, innovative, and alternative ways of being in the world.

As an overarching category that appears in each of the previous categories, it was important to include questions about the disabled body in performance. For the artists, I had questions for them such as: How does visibility or invisibility affect lived experiences? How did you use your visibility in the performance? Does one performance influence or change the other (i.e., lived disability performance and artistic performance)?

For the performance texts, I had questions such as: How does the presence of the visibly disabled body influence the performance and the self being represented? Does the disabled body affect representation? Does it enhance or detract from the identity being portrayed? How is its presence (and power?) wielded in the performance work, and how so in daily life?

In the next section, I provide detailed descriptions of how data were collected and interpreted in each data set: qualitative interviews and thematic analysis of performance texts. The section also includes descriptions of the interactive processes between data sets, which includes how feedback was incorporated into further analysis of the data.

2. **Data Collection**

a. **Data set 1: Qualitative research interviews**

For this data set, data collection involved individual interviews with each artist. Utilizing semi-structured interview techniques, each artist was interviewed three times. The first interview looked at their performance work in general, and the representation of lived disability experiences. Prior to this interview, an interview guide was prepared using my template, but I started with the overarching category, “the disabled body in performance,” rather than following the template in order. Below, I outline the interview guides prepared for all three interviews. Thus, one additional item closed the first interviews: What solo autobiographical performance work would you like me to analyze?

Between the first and the second interviews, I used thematic qualitative methods to analyze the solo autobiographical performance texts I had received from each artist. This data set is discussed in detail in the section entitled “Data Set 2: Qualitative Analysis of Performance Texts.”

For the second interviews, I presented my preliminary thematic analysis, or first pass, of the artist’s solo performance. Additionally, the second interview included analysis from the artist’s first interview. This began the interactive interpretive process of looking at both my initial categories of inquiry and emergent themes that arose within the data as a whole. During the second interview, the artists were told that I would begin by talking through the initial themes

I found in their performance piece, along with statements about how or why I interpreted these themes, particularly if I had pulled out specific themes or concepts from the first interview and performance analysis combination. I asked each participant to jump in at any time with comments, disagreements, or any other feedback about my analyses. These interviews became a deeper conversation and analysis of each solo autobiographical performance piece.

Prior to the third interview, I analyzed the second interviews with each artist, reviewed the first interview and analysis, and analyzed each performance again. Analyzing the performances this time incorporated the artists' feedback about my first analysis of their solo work, which caused a closer look at any additional themes added or removed, and analysis of our conversation about the work in the second interview. Thus, analyses took into account the entirety of both data sets, so that the third interview consisted of my findings, requests for comments from the artists, and my request for clarification, comments, and final thoughts about the research process from each artist.

A final check-in with each artist was planned to request feedback about the accuracy of the data gathered from the entirety of the research about her and her work. In other words, she was asked to read and respond to the chapter written about her in this dissertation. Only one artist, Tekki Lomnicki, was available for this final feedback opportunity.

b. **Interview guides and questions**

1) **Introduction**

In this section, I provide the initial interview guides, the categories used from the template, and the questions planned from each category. After outlining each guide, I provide a brief description of how the interview went in practice, including how the categories were covered. The interview guides were meant to guide flexibly my questioning

during the actual interviews, reminding me of each category I wanted to cover, not as a script to follow. Semi-structured, in-depth interviews, as these were, permit information to flow conversationally because the interview process remains open and flexible (DiCicco-Bloom & Crabtree, 2006). The guides provide prompts for less talkative participants while allowing more talkative subjects to speak freely, and giving the investigator reminders, if needed, to move the conversation in new directions.

2) **Interview 1 outline**

a) **Category: Disabled body**

Main question: **What is the relationship between your lived disability experience and the performance work that you do?**

Prompts/additional questions: **How does the visibility (or invisibility) of your disabled body influence your work and the identity you represent in the performance? How does it enhance or detract from the identity being portrayed?**

b) **Category: Transforming experience into art**

Main questions: **What does it mean to you to transform your experiences with disability into art? What filters or artistic processes do you use to transform lived experience?**

c) **Category: Identity and self-representation**

Main question: **What identity or identities do you portray in your work?**

Prompts/additional questions: **How do you construct identity in work? Do you perform this identity (identities) in your everyday life? Describe them.**

d) **Category: Interrogating cultural inscriptions of disability**

Main question: **What aspects of your work comment on or interrogate how the dominant culture looks at disability?**

Prompts/additional questions: **In what ways are you politically active in your everyday life, if at all? What political agenda or political perspective do you have, if any, in your work?**

e) **Category: Disability culture**

Main question: **What aspects of your work express disability culture?**

Prompts/additional questions: **Do you portray disability culture in your work? If so, how?**

Interview 1, for both artists in this study, went according to plan. The initial question began a longer conversation about disability experiences and the artists' performance work, leading naturally into other topics. For example, Wade brought up the topic of transforming her experiences for performance without my asking, which seemed to flow directly from my initial question. She spoke about how experiences needed to be synthesized or fictionalized. She also talked about how performance work had transformed her and how she performed her identity in the world. This became an emergent theme, and prompted me to ask more about transformations.

Similarly, Lomnicki offered how she transformed her personal experiences for the performance stage. Both artists brought up the presence of their visibly disabled bodies as part of experiences in life and art, and both indicated inclusion of disability culture elements in the works.

3) **Interview 2 questions**

This interview focused on my analysis of the performance work recommended in the first interview. As a result, this interview guide was more like a prompt for a feedback session, leaving enough room in my questions for categories and new themes to emerge from the artists.

a) **Presentation of themes**

As you know, I analyzed the performance piece you sent to me. In my analysis (of *Blurred Vision*, of *Sassy Girl*) I found the following: (I described my findings to each subject). As I list the themes I found, feel free to jump in at anytime with questions, comments, or whatever.

b) **Questions to gather feedback**

In what ways does my analysis correspond or not correspond to your own views of this performance work? What aspects have I missed? What, if any, aspects surprise you? Were there any particular strategies or reasons for the way you presented this piece? If so, what were they?

Interview 2 went as planned with each artist. Both of them started out quietly listening, and I did remind them to jump in anytime. They did, and once they did, the conversation about the performance work began to flow. Both artists added to my analysis with themes of their own, and added to the discussion with ideas about their creativity and approaches to the performance work. For example, one of my first comments to Wade about *Sassy Girl* is, “you take us through this journey from where disability begins in your life to where you stand currently.” First she corrected me, saying, “Yeah, where I stood currently when I wrote the show” and then, she continues by expounding on my statement with analysis of her own:

What I tried to do is to evolve that story: to tell it more deeply, to tell more about this evolution, to tell more about the struggle of getting to a place where you can, I won't say peacefully coexist with your disability, because I've never peacefully coexisted with it. But, where you accept it and don't give up on, you know, living a life, even if it's hard. (Wade, Interview 2)

Wade added insights into her process of creating the performance, her intentions for the piece, and her psychological acceptance of disability. Another example from Lomnicki adds similar insights. I was presenting my initial findings from *Blurred Vision*, and said, "the play deals with childhood fantasies, like wanting to become a nurse who moonlights as a cop, the girl from Ipanema ..." and she added, "and never realizing I couldn't be that" (Lomnicki, Interview 2). Thus, she provided insights into both her character and her personal and psychological development.

These examples only scratch the surface of the rich and detailed additions to my analysis and the interplay between different elements of the research. Thus, Interview 2 turned out to be exciting because it opened up the discussions, or the interplay, between the artists, their performance work and me. New themes emerged and others were deepened. The data sets were becoming richer and more nuanced through this conversation.

4) **Interview 3 questions**

The third interviews presented each artist with a letter that outlined some of the major findings from both sets of the research data. Each finding presented included my interpretations and quotes from the artist or from the performance that illustrated the finding. In this way, the research reflected back to each artist what we had learned together thus far. Following each listed finding and detailed description was a set of questions about this finding. Some of the questions asked the artist to expand on the finding, and some questions asked for clarification.

A letter went to each artist in advance of our scheduled third interview. Each artist was given several days, and up to a week, to review the letter in advance of our interview, and think about the questions. During the interview, the artist and I followed the letter as a guide for the discussion. In this way, the third interviews went as planned, and the conversations with each artist deepened, expanded, and clarified the findings beyond the previous interviews.

c. **Data set 2: Thematic analysis of performance texts**

This data set contained the performances texts and analysis of them. The term “performance texts” refers to the script and video of Wade’s *Sassy Girl*, and the script, DVD, and observations from live performances of Lomnicki’s *Blurred Vision*. I considered these texts to be additional qualitative documents because they are based on the personal experiences and autobiographical stories of each artist. To analyze these performance texts, I used my template for qualitative thematic analysis. The template provided initial codes for analyzing the texts. “Template analysis” is not a single, clearly defined method, but refers to a varied group of techniques “for thematically organizing and analyzing textual data” (King, 2004, p. 256). Template analysis and thematic approaches are flexible, allowing other themes, both inside and outside of the template categories, to emerge from the performance texts.

It was important to me that the participants had a prominent role in this research study. Each of them recommended performance pieces for me to analyze, providing a sense of what aspects of their work they felt were important. In addition, each artist was given opportunities to provide feedback and insights to my analysis of their performance work. The process of interviewing, analyzing performance texts and interviews, then presenting findings to each artist during the next round of interviews offered and incorporated participant input into the interpretive process. Again, this is the interplay between data sets: each interview and subsequent

analysis of the performance work incorporated the previous analysis, feedback, and interview data from the time before. The findings presented in this dissertation represent the final analysis of all of the combined data.

The autobiographical performance texts, *Sassy Girl* (Wade, 1995), and *Blurred Vision* (Lomnicki, 2005), were initially analyzed through the template, described and defined above. Once the categories from the template were “coded,” I accounted for additional themes and text not previously coded. Beyond patterns of themes and categories identified by codes, I also analyzed the performance texts looking for how the narrative of the performance was put together. My standpoint epistemology, which influenced my analysis of these performances, views the world from what Snyder and Mitchell call a “politically informed disability subculture perspective” (2006), which includes knowledge from disability culture and my own embodied experiences. As a result, I am sensitive to, and conscious of references to common disability narratives from the mainstream, stereotypes, and different forms of oppression found in social encounters, medical relationships, and cultural misconceptions. My analysis of these texts incorporated my awareness, consciousness, and experiences from this perspective.

In addition, questions were incorporated into the analysis of the performance texts, generated from my template. Many of these questions look at the disability portrayals and the artists’ perspective, which meant that the videos and observations were useful for my analysis. Questions were asked as I read through scripts, looking for explicit and implicit references to my template categories, as well as other themes that relate to these ideas.

Since I am visually impaired, I could not always see clearly what expressions were on the artists’ faces in their performance videos, but each of them used their voices and physical gestures to enhance, punctuate, demonstrate, or sarcastically contradict what they were saying in

their monologues. Analysis of the videos, and memories and notes from live showings of *Blurred Vision*, were used to corroborate, deepen, and enrich my analyses of these texts.

In the following section, I explain my process for analyzing all text (performance and interview texts) from this research project.

3. **Analysis: Qualitative thematic analysis and template analysis**

This research involves revealing and interpreting meanings of the social, cultural, and political phenomena of disability, its lived experiences and representations in solo autobiographical performances, and its powerfully transformative potential. Disability in solo autobiographical performance raises concerns about how disability is constructed in the dominant culture, how these constructions affect the lives of disabled people, and the ways that dominant cultural representations of disability play out in society. For me, these social and cultural concerns raise questions about how society could change if culture conceived of disability differently. In this way, this contemporary and historical account of solo autobiographical performance art/storytelling by disabled artists must consider the body of scholarship and theorization that exists in the interdisciplinary field of disability studies, placing the transformative aspects of this work into a cultural frame and social context as disability cultural practice. Sandahl and Auslander explain that disability studies and performance studies have similarities and differences that complement one another, particularly for a study that seeks to look closely at a few individual artists for a wider social and cultural commentary (2005). Thus, the analysis applied to the data sets in this study utilized my template, as outlined earlier in this chapter, which incorporates definitions and concepts derived from both disability studies and performance studies.

My approach to analysis is “thematic.” Braun and Clarke (2006) define this “theoretically-flexible” approach (p. 2) this way:

Thematic analysis is a method for identifying, analyzing, and reporting patterns (themes) within data. It minimally organizes and describes your data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic. (Braun & Clarke, 2006, p. 6)

“Going further” infers flexibility in this approach, enough to allow the researcher to interpret other “various aspects of the research topic” (Braun & Clarke, 2006, p. 6). Braun and Clarke’s article explains this “widely used” method and the steps involved, which I explain below. Similar forms of thematic analysis are used in other qualitative techniques, such as thematic discourse analysis, phenomenology, and grounded theory, and thematic analysis differs depending on the research goals.

Template analysis can be considered a subset of a qualitative thematic approach. I discuss how the template varies from thematic analysis below, which was used to initially guide and structure my research questions. My approach to analysis, both thematic and template techniques was to incorporate a balance between what the artists told me during their interviews, and my own interpretations as a research. In some cases, such as in the theme of “radical vulnerability” that is discussed in my findings on Wade, my interpretations were not congruent with what the artist remembered and said in her interviews. As a result, I listened carefully to what the artist was saying, but kept my initial interpretation of “vulnerability,” which she objected to. Accepting that she never felt vulnerable on the stage, but did perform her character as vulnerable during many scenes incorporated her objections. In this way, I do not feel that my interpretation was compromised, but that her objection clarified my interpretation, helping to define and refine it.

a. **Analyzing data with the template**

In his article, “Using Templates in the Thematic Analysis of Text” (2004), Nigel King argues for the benefits of this approach to analysis. He states that thematic analysis, using a template, is more flexible and less prescriptive than other qualitative approaches, such as grounded theory, which has extensive rules to follow. Since I adhere to the social constructivist and advocacy/participatory paradigms, King’s descriptions of this approach apply to this study.

He writes:

Template analysis can be used within...a ‘contextual constructivist’ position. Here, the researcher assumes that there are always multiple interpretations to be made of any phenomenon, which depend upon the position of the researcher and the context of the research. Concern with coding reliability is therefore irrelevant; instead issues such as the reflexivity of the researcher, the attempt to approach the topic from differing perspectives, and the richness of the description produced, are important requirements. (King, 2004, p. 256)

Template analysis guided my interpretations of both data sets and focused them on the artistic representations being expressed. Again, I set out to balance my interpretations of what the artists said with the context of my template categories. This allowed me to look at my own interpretations of the artists’ works reflexively with their interpretations and to follow my position as a researcher within the study’s context.

In addition, King sees template analysis as a process by which codes are defined. The process he outlines utilizes certain pre-defined codes as a template, but then he refines the template as he moves through different stages of analysis. King notes that “the initial template is applied in order to analyze the text for the process of coding,” but is revised in light of ongoing analysis (2004, p. 259). I started with a template in my research proposal using just the names and broad ideas of the categories listed. The template outlined above is the final template, which explains the initial codes in more detail.

b. **Analyzing data with thematic analysis**

I apply both disability studies and performance studies lenses to my analysis through my template, and also through thematic analysis. Braun and Clarke point out that thematic analysis requires reflexive decision making by the researcher. These decisions include: rich description of the data, or a detailed account of one particular aspect; inductive or theoretical thematic analysis; and either semantic or latent themes. The latter decision indicates the difference between semantic (or explicit) themes, which are at the surface level and, in this case are primarily expressed by the template, or latent (implicit, underlying) themes, which occur beneath the surface level. They explain:

A thematic analysis at the latent level goes beyond the semantic content of the data, and starts to identify or examine the *underlying* ideas, assumptions, and conceptualizations – and ideologies - that are theorized as shaping or informing the semantic content of the data. (Braun & Clarke, 2006, p. 13, emphasis original)

As a result, choosing the latent level also includes the semantic level of the data, or surface codes. Braun and Clarke continue, explaining my decision to look more closely at latent themes:

Thus for latent thematic analysis, the development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorized. Analysis within this latter tradition tends to come from a constructionist paradigm, and in this form, thematic analysis overlaps with some forms of discourse analysis” (which are sometimes specifically referred to as thematic discourse analysis), where broader assumptions, structures and/or meanings are theorized as underpinning what is actually articulated in the data. (2006, p. 13)

While I used my template and initial codes from the semantic level, my analysis and interpretations proceeded toward the latent level described above.

The steps Braun and Clarke outline in the process of analyzing data thematically are discussed below. It is important to note that my process analyzed data sets of individual artists. Once the first interview and performance text were analyzed for Lomnicki, for example, the next layer of analysis, the second interview, would include the previous analysis. At each stage of the

research, analysis was completed beginning with Braun and Clarke's "phase 3, searching for themes." Thus, the first interview and performance analysis set the stage for the remaining interview and performance analyses in the research process.

The first step is "familiarizing yourself with the data"—including transcribing recorded interviews (Braun & Clarke, 2006, p. 14). In this project, interviews were recorded digitally, and I listened to the first interviews several times before transcribing them, familiarizing myself with the data. I transcribed all three interviews with each artist, and during transcription would include my interpretations and bracketed thoughts and responses as a researcher. "Writing is an integral *part* of analysis," explain Braun and Clarke (2006, p. 15, emphasis original). Since the performance texts were already "transcribed" by the artists as scripts, I watched and re-watched the performance videos several times before going back to the transcripts to write interpretative notes and thoughts.

The second phase of thematic analysis, according to Braun and Clarke, is generating codes. As I explained above, my initial codes were established as the categories of my template, so these specific codes were pre-set. But, as I went through transcripts of interviews and scripts, other codes emerged and were applied to the data. This process was accomplished by marking off segments of text in these transcripts that were inclusive of a pre-set code, or given a new code when initial codes from the template did not apply.

The third phase, according to Braun and Clarke is called "searching for themes" (2006, p. 19). In this phase, all the data are coded, but the codes are re-focused, moving analysis to "the broader level of themes, rather than codes," which "involves sorting the different codes into potential themes, and collating all the relevant coded data extracts within the identified themes" (Braun & Clarke, 2006, p. 18). Braun and Clarke explain that this search for themes is across

data sets, but to clarify this process in my research, all analysis was completed across data sets for individual artists, but not across artists. Analysis across artists occurred at the final writing stage of this process. Here, during the third phase of thematically analyzing my data, themes can be understood more broadly, with main or overarching themes and sub-themes.

Phase four, “reviewing themes” was my opportunity to re-assess themes, making sure that the data within themes “cohere together meaningfully” (Braun & Clarke, 2006, p. 20). Phase four required looking at the coded segments within themes, as well as looking at the themes across the data sets for each artist.

The next phase, “defining and naming themes” (Braun & Clarke, 2006, p. 22), begins once phase four is completed. Phases four and five went in tandem in my analysis of each artist’s data sets, because it made sense to me to interpret and review themes while also trying to define and name them. For me, this process involved interpreting and analyzing the data, organizing and collating themes at the “latent” level, “where broader assumptions, structures and/or meanings are theorized as underpinning what is actually articulated in the data” (Braun & Clarke, 2006, p. 13). Therefore, it was helpful for me to name and define themes as I reviewed them using a “contextual constructivist position” (King, 2004, p. 256). In this phase, I was able to “define and refine” the themes, which meant, “identifying the ‘essence’ of what each theme is about” (Braun & Clarke, 2006, p. 22), including the overall themes, and explaining what is captured in the data of each theme. In this part of the analysis process, Braun and Clarke suggest that researchers take extracts from the data and organize them into a coherent narrative. These extracts should demonstrate the data, and “identify what is interesting about them and why” (Braun & Clarke, 2006, p. 22).

Braun and Clarke's final phase, "producing the report," involves the final step of analysis and the "write-up of the report" (2006, p. 23). Writing is thought to be a critical, integral part of the process of analysis in qualitative thematic research. "I firmly believe that writing-up should not be seen as a separate stage from analysis and interpretation, but rather as a continuation of it," says King (2004, p. 267). As such, Braun and Clarke agree, stating, "writing should begin in phase one, with the jotting down of ideas and potential coding schemes, and continue right through the entire coding/analysis process" (2006, p. 15). The chapters that follow present the entirety of this process, where writing was integrated throughout all aspects of the analyses of data sets.

V. FINDINGS

A. **Introduction**

In the chapters that follow, I present findings from this research project uncovering a rich relationship between lived experiences of disability and their representations by two disabled artists. The study revealed themes from two data sets: the interview data and thematic analysis of solo autobiographical works. The artists' perspectives, which are illuminated through the findings, exposed aspects of lived experiences and represented experiences that deepen and expand knowledge about disability in social and cultural contexts. The artists' re-imaginings of disability from a creative, disability-centric and culturally significant perspective have profound potential to transform mainstream culture, and to therefore narrow the gap between art and life, representation and reality.

B. **A Note About Reading "Wade" and "Lomnicki" Chapters**

The findings that follow are divided into four chapters: Cheryl Marie Wade, Tekki Lomnicki, Discussion, and Conclusion. Because the findings use two data sets, I found a way to help the reader distinguish between interview quotes, and text/quotes from the performance pieces using different typefaces. For Wade and Lomnicki's interviews, the data will be in regular type, as written here. In addition, I use "Wade" or "Lomnicki" when speaking about each as an artist, research subject, or speaker in the interview data. For quotes from the performance pieces, *Sassy Girl* or *Blurred Vision*, I use *italics*. The character in *Sassy Girl* is referred to as "Cheryl," and the main character in *Blurred Vision* is referred to as "Tekki." The differences in typeface and names are intended to clarify the data set being used, and assist readers to follow the story of each artist's data and analysis.

In addition, the findings were written for both artists before Cheryl Wade's passing in 2013. Her findings are written in present tense, however, in keeping with her ongoing presence as a research subject and artist. However, whenever speaking about Cheryl Wade outside of the findings, I have changed those references to reflect that she is no longer with us.

VI. CHERYL MARIE WADE

A. Introduction

In this chapter I present evidence and analysis that elucidate the relationship between disability experiences and artistic representation in *Sassy Girl: Memoirs of a Poster Child Gone Awry* (Wade, 1995). Cheryl Marie Wade re-articulates her disability experiences in new, resistant, and transformative ways that deepen and redefine meanings of disability for the artist and her audiences. Illuminating disabled artists' voices and perspectives are critically important for disability studies. This is particularly true for Wade, arguably an important and pioneering figure in disability arts and culture. This chapter is an effort to reveal and understand Wade's perspective as a disabled artist. For this purpose, I formalized conversations with Cheryl Wade about her performance work and the experiences she used to construct it. Wade's work frames our conversations and focuses the data – our interviews, the performance text, and video – to reveal a rich and complex portrait of this artist.

I argue that Wade practices “radical vulnerability,” a performance strategy that expresses experiences from her life in which she has been vulnerable, and transforms them into powerful messages that disrupt expected narratives and assumptions about disability, and expose their ableist origins. This strategy helps Wade construct “complicated reality” in her performance piece, which refuses any single simplistic moment for herself or for disabled people, adds paradox and unexpected shifts to the narrative, and further excavates and expands her radically vulnerable approach.

This chapter begins with brief overviews of Cheryl Wade and *Sassy Girl*, followed by a comprehensive definition of radical vulnerability. The bulk of the chapter is a series of sections that discuss significant themes from the data. These themes, which include complex

embodiment, disability consciousness, objectification/violation, grief, and disability culture, convey distinctive concepts that define and characterize Wade's performance of *Sassy Girl*. The chapter concludes with a discussion of how these themes, via radical vulnerability, create Wade's re-imagined disability paradigm.

1. **A brief history of Cheryl Wade**

Cheryl Marie Wade was a pioneer and leader of the disability arts and culture movement, and one of the first physically disabled performance artists to gain critical acclaim. Wade used her "crippled" body on stage, along with raw, vibrant poetry, autobiographical experiences, and "in your face" storytelling (McRuer, 2006, p. 40) to carve out her particular style as a solo performance artist.

Cheryl Wade was born in Vallejo, California to working-class parents. From there she eventually moved to Berkeley, California where she became a student, earning her Bachelor's and Master's degrees in psychology from the University of California, Berkeley. Wade was also an activist, leading the school's Disabled Students Union during her time as a student. She developed her skills as a writer and performer in Berkeley as well.

In 1985, Wade joined Wry Crips, a disabled women's readers theater group, founded that same year by Laura Rifkin, Judith Smith, and Patty Overland (Walker, 2005, p. 101). Wry Crips featured artistic writings and poetry by disabled women. Wade was originally hired as their coordinator, but eventually moved into the spotlight and shared her own work, which included her feelings and perspectives about being disabled.

While with Wry Crips, Wade honed her writing and performance skills until she moved into a solo career in 1989. During her career, she performed her one-woman show *Sassy Girl*:

Memoirs of a Poster Child Gone Awry (1995). She also made the performance videos, *Here* (1990), *Disability Culture Rap* (2000), and *Body Talk* (2001).

Wade put her insights from experiences with childhood rheumatoid arthritis, diagnosed at age 10, into her work. However, she never divulged her diagnosis. “The minute I give them the name to [my diagnosis] I’m dismissed: [they] can dismiss it as *not them*,” she explained during our second interview (emphasis mine). Wade also experienced childhood sexual abuse, and talks about that in our interviews. She had a profound capacity to address the complicated and difficult history she had as a disabled woman. Poet and Performance and disability studies scholar Jim Ferris states that Wade “claims a kinship with disabled people through history, including those hidden away, left to die, even executed for their disabilities” (2007). He marks this kinship as emblematic of disability poetry. Speaking from her own experiences, Wade galvanized other disabled people through her performance work, poetry, and essays. She felt a deep connection with other disabled people, which was evident in her work. Creating connections with her audiences seemed to drive her creative endeavors.

Wade was considered the “Queen Mother Of Gnarly” (Walker, 2005, p. 64). She had stopped performing because it became too physically difficult. She explained:

I loved [performing] while I had it. It was exhausting, I tell you; it used to kill me. It was never easy. I never got to be a performer easily because I’d get off that stage after doing a full hour show and have to pop codeine so that my neck and head wouldn’t feel like somebody hit me with a sledgehammer...then I’d have to stay in bed all day. Every time I performed. I’d have to stay in bed all day. (Wade, Interview 3)

Her chronic pain and medical conditions prevented her from continuing the work she loved.

Wade continued to write and thrive in Berkeley, California, until her untimely passing in August 2013, at age 65. Hers is a tremendous loss to the disability community, disability arts and culture, the world, and to me personally.

2. **Sassy Girl: A brief synopsis**

Sassy Girl: Memoirs of a Poster Child Gone Awry is Wade's chronological story of her experiences with disability. The piece is performed minimally in the video she provided, with only Wade and her wheelchair on a stage with a spotlight. Yet, without musical accompaniment, props, or even the necessity of a spotlight, Wade's play could be performed anywhere, including non-traditional theater spaces, outdoor spaces, in classrooms, or on the street. Additional footage from her performance at the University of Michigan in 1995, provided by *Vital Signs: Crip Culture Talks Back* (1996) filmmakers Mitchell and Snyder, demonstrates Wade needed no special lighting, stage, or assistance. The performance includes Wade's narrative interspersed with original songs and poetry, all adding to the story she is telling. Her story is primarily told linearly, reflecting on her life with disability and her experiences with family, men, strangers on the street, her environment, her community, doctors, governmental agencies, and college and activist life. Wade creates experiential vignettes, mostly synthesized from her life, but some are what she calls "creative fictions" (2006, Interview 1). The result is a 90-minute performance that is engaging, entertaining, and full of insights about living as a disabled person.

In *Sassy Girl*, Wade incorporates her love for strong, provocative language, vicious humor, and uncompromising authenticity to create a disabled woman character unlike any other. Her story explores her personal journey from newly diagnosed adolescent to empowered disabled woman without depending upon dominant cultural prescriptions to be "inspirational" or to "overcome" disability. Wade represents her life in a realistic way by constructing a complex character that inhabits a complicated world. As she moves her narrative through physical changes, social interactions, and political consciousness, she sprinkles each scene with both

positive and negative aspects, changes in perspective, and unexpected reactions that reflect the inconsistencies, paradoxes, and fluid shifts that occur in life.

Although positive and negative experiences lived at the same time also describe the human condition, this must be spelled out for disabled people. People with disabilities have been repeatedly represented as either tragic or inspirational with very little in between (see Longmore 2003a, “Screening Stereotypes”). Wade’s narrative, however, inhabits these in-between spaces, adding multiple dimensions that complicate her character’s experiences and reflect the rich, textured, and varied lives of people with disabilities.

Sassy Girl exposes Wade’s critical disability perspective, uncovering oppressive structures and illuminating deeply held cultural misconceptions. Wade’s performance sometimes elicits cheers, sometimes gasps, but she always provokes and challenges her viewers while they are being entertained. Wade takes her audience on a journey toward becoming the “*Sassy Girl*,” connecting with them on multiple levels, which eventually leads to both empowerment and pride, but completely on Wade’s complicated and radical terms.

3. **Wade’s creative process**

Like all good storytellers, Wade does not set out to hit her audiences over the head with a lesson; she is not trying to teach. “I’ve always tried to figure out ways to do that without pointing to it, you know, . . . I always find it gets in the way of the art when the education is on the front burner too much, because then it starts to feel like a lecture or an exposition, rather than a story being told. (Wade, Interview 2). Nevertheless, she does hope they learn something from her performances. In our first interview, Wade told me: “People have a lot of crap in their heads. . . I don’t have a lot of time to get that out. What I do is to try and grab their attention.” She does this through the language and narrative choices she makes, as well as with her gift for

performance. For example, Wade avoids telling an “inspirational cripple” story, focusing instead on developing a uniquely self-determined identity as a disabled woman who refuses to follow any scripted models, even those set by her own community. Her distinctive ideas get in with an approach that provokes audiences to suspend their “crap” for a moment and pay attention.

While everything Wade writes and performs comes from her experience, she admits, “it’s not the truth, the whole truth, and nothing but” (Wade, Interview 1). She says she is no documentarian, and for her performance work, documentary style would not have the same effect. Her autobiographical tale elicits closeness with her audience and makes her work seem very “truthful.” In this way, her work has authenticity without revealing too much to her audience. Performance, Wade says, is a way “to amplify, to edify experience, not necessarily to reveal myself” (Interview 1). Instead, Wade edits some experiences to enhance her work, and she will “find another way to get across the emotional aspect of me – you know, changes or whatever I am trying to express – but I may do it by coming up with a whole different experience, not something that’s happened to me” (Wade, Interview 1). In this performance, a condensed and fictional tale, which I discuss in “Grief,” helps move her audience forward in the story, and introduces the grieving process, without revealing everything she actually went through. Additionally, this “creative fiction” encompasses emotional and psychological processes that often take many years, with many stops and starts and repetition. “What gets you through in life is not necessarily a dramatic moment,” she explained (Wade, Interview 1).

Wade’s personal story – a political, social, and cultural artifact of disability culture – struck a powerful chord in her community. She told me: “I just knew I was on to something with this...stories about evolution of a life interest people. People like autobiography, they like

autobiographical fiction...we like to know, ‘How did you do that? How did you get there?’” (Wade, Interview 3).

Wade’s work still interests people. *Sassy Girl* has had a profound influence on how I think about disability as an artist, a scholar, and a disabled citizen. And it continues to be an important cultural artifact, which resonates with many people, disabled and nondisabled.

B. **Radical Vulnerability**

1. **Introduction to this section**

Radical vulnerability is the strategic approach to performance practice that Wade utilizes in *Sassy Girl*. It explores the depth and complexity of disability by transforming Wade’s lived experiences on multiple levels. Her emotional, psychological, physical, social, political, and cultural reflections are converted into powerful messages that complicate, interrogate, and resist the dominant cultural heritage and social structures of disability.

This section defines radical vulnerability, explaining it as the thesis and strategy of Wade’s findings. Radical vulnerability includes Wade’s concept of creating a “complicated reality,” and this strategy and practice is described here as well.

2. **Explaining radical vulnerability**

Explaining my theory of radical vulnerability to Wade, she agreed that her work is radical. But, she insisted during our interviews that she never felt vulnerable while performing. She felt powerful and in control on stage or behind a microphone. Yet, as I pointed out to the artist, Wade performed vulnerability from her experiences. My point is that being vulnerable, or showing that one has been vulnerable, demonstrates great strength, courage, and willingness to engage with others rather than weakness. It takes courage and self-awareness to perform one’s vulnerability. According to Brené Brown, a qualitative researcher of vulnerability, shame, and

shame resilience, being vulnerable is about courage: “Our willingness to own and engage with our vulnerability determines the depth of our courage and the clarity of our purpose” (2012, p. 2). This kind of courage allows one to be truly seen by the world, and in turn creates connection to it. Brown explains:

Vulnerability is not weakness, and the uncertainty, risk, and emotional exposure we face everyday are not optional. Our only choice is a question of engagement... the level to which we protect ourselves from being vulnerable is a measure of our fear and disconnection. (2012, p. 2)

Brown emphasizes that vulnerability and connection are linked, and therefore, vulnerability requires the willingness to engage with the world, put oneself out there, and enter the “arena” (Brown, 2012, p. 2). I would also argue that solo performance work, or being alone on the stage with one’s personal story, evokes an even greater level of risk, uncertainty, and engagement. Brown is speaking of vulnerability as part of daily life, and Wade is exposing and expressing vulnerability from her past experience. Wade’s performance of vulnerability from lived experiences requires her to fully engage with her own material and with her audiences, which cultivates and deepens connection.

Sassy Girl creates connection on Wade’s terms. She avoids typical disability narratives. She complicates her storytelling with contradictory concepts and messages. And she constructs disability in her own distinctive way. Telling her story, being imperfect, owning those imperfections, and being “truly seen” require Wade to dig deep; excavating psychological, emotional, and physical episodes from her life. This in itself is a radical act because being deformed and “crippled” usually means hiding and trying not to be seen. This radical act is also a political, social, and cultural act of tearing down oppressive structures that contribute to vulnerable experiences from her life. The strong empowered sassy girl results from Wade’s practice of radical vulnerability in her performances both on and off the stage.

Wade recognized early in her career how most people perceive her, react to her presence, or respond to her physicality. As a performer she is able to confront such responses and social perceptions. During our first interview, and prior to my viewing of *Sassy Girl* in its entirety, she told me about “I See You Staring” as a means to confront and express her anger at others’ reactions. She says:

I don’t make people comfortable when they look at me. As an artist, right away they’re not comfortable. Right away I’m in the spotlight waving my hands saying, “look at me, look at me”... There are individual poems that I’ve written that were definitely supposed to offend. They were written to express my unmitigated anger. [“I See You Staring” is] a really vulgar, very brazen piece, but I’ve always tried to use it in context... and I thought it was the perfect poem to amplify depression and the anger that I felt at a time in my life, and it’s really powerful.... It’s a really small, ugly piece, but I would never be that cruel; there would be no point. (Wade, Interview 1)

Wade exploits the discomfort she generates because of her body and magnifies it on the stage. She notes how she used that discomfort to her advantage. Expressing her “unmitigated anger,” and wanting to offend people, comes across as a means of retaliation for the oppression she faced. Yet she admits that she would “never be that cruel.” Instead, “I See You Staring” is a performative attack for the audience. Thus, Wade uses her status as an artist, as well as her experience of feeling vulnerable, to perform an extreme and radical response to rude, dehumanizing behavior.

Taking advantage of the discomfort her presence generates, the vulnerability she felt, and the opportunity to talk back from the stage, Wade’s performance of this poem reflects her level of engagement. “It’s being all in” (Brown, 2012, p. 2), and connecting with her audience allows Wade to tell a deeper story about disability, challenging expectations. She told me, “able-bodied people expect us to educate them, make them feel comfortable and all that. So that’s where [‘I See You Staring’] came from” (Wade, Interview 2). Wade does not want to educate able-bodied

people, or make them comfortable. She would rather tell a provocative and compelling story, and use the audience's attention to make them think.

Beyond thinking, however, Wade wants to incite people to make changes. She remembers a response she received after performing "I See You Staring," during her Wry Crips days. She explains what one audience member said during a talk back session:

I love how vicious that piece is, and in some ways how vulgar it is. I've been called on that. I remember performing that piece at a Wry Crips performance, and it had come from many years of trying to deepen and expand that piece... I remember a woman asked a question, and I remember her courage. Sometimes people get very afraid to address you, they patronize you that way, and I hate that. But she says, 'I don't understand that piece, what am I supposed to learn? What am I supposed to think about that?' I want you to think about what it feels like for me to experience what gets me to the point of saying that back to you... I'm trying to get you to notice... (Wade, interview 2)

In other words, Wade wants to provoke a response from her able-bodied audience. She wants to make them aware of her experience, and while they feel unsteady, they may gain deeper understanding from the performance. The poem references painful events that insulted, dehumanized, and angered her, and Wade wants her audience to feel with her, and think about their behavior. This approach engages emotionally with her audience and with the experience. In this way, her audience may notice future staring encounters, and feel uncomfortable enough to intervene.

As Wade *performs* vulnerability, she also elicits vulnerability in her audience.

Encountering "I See You Staring" or "I Am Not One of The" and much of *Sassy Girl's* content, shakes up her spectators, pushing them out of their comfort zones and agitating them in order to disrupt their preconceptions. Wade hopes for this from her work. She says:

I think it opens a door to something... I want to shake them up. If they feel humiliated, just a little bit in the moment, like when I'm doing "I see you staring", if they see themselves in that, if they've treated someone that way, then I want them to feel embarrassed or hurt or bothered. It's not to hurt them; I'm giving them an opportunity to do better. (Wade, Interview 2)

Thus, she wants her audience to feel something from her work that carries over into their lives—to bother them enough to “open a door” or “to do better.” Wade’s intention is to create fundamental change in the way people perceive disability, treat disabled people, or think about disability issues. It is a radical goal that requires a radical approach. And *Sassy Girl* achieves its radical-ness because it is tinged with vulnerability. That is, the work is emotionally charged and sensitive enough to involve and sway her spectators. Wade’s strategic approach to performance and disability is “radical vulnerability.”

3. **Defining radical vulnerability**

To clarify radical vulnerability, I include some definitions. The word *radical* comes from the Latin word “radix” meaning root (www.oxforddictionaries.com/us, 2014). From Merriam Webster Online, radical can mean: “going to the root or origin;” “very different from the usual or traditional;” and “favoring extreme changes in existing views, habits, conditions, or institutions” (www.merriam-webster.com, 2013). These definitions further reveal the variety of meanings and approaches that I see in Wade’s performance work: finding the root, favoring change, and transforming traditional views. The Oxford English Dictionary states *radical* can also mean “far-reaching, thorough.” *Sassy Girl* is radical because it is a thorough, nontraditional examination of disability that gets to the root of the matter, promoting fundamental changes in existing views and conditions for disabled people. Wade uses a radical approach – extreme, militant, uncompromising – within her performance. And *Sassy Girl* is “cool;” another definition for radical (www.urbandictionary.com, 2014).

Vulnerability is not as easily defined when it comes to Wade or *Sassy Girl*. Typical dictionary definitions of *vulnerability* include “susceptible to physical or emotional attack or harm,” “in need of special care, support, or protection because of age, disability, or risk of abuse

or neglect” (www.oxforddictionaries.com/us, 2014), and “exposure” or “weakness” (www.thefreedictionary.com, 2014). Yet Wade is *not* vulnerable on the stage; she never felt more powerful or in control than when she was in a spotlight. However, Wade communicates and performs layers of vulnerability *previously experienced*, which she re-creates on the stage. These previously experiences events, transformed for the performance, now reflect the Brown (2012) definitions of vulnerability I spelled out above. I am making the distinction that Wade is not experiencing a “state of being vulnerable” while performing, but that she portrays a past state of vulnerability while maintaining complete control, which now equates to courage, strength, and engagement with her audience.

The Oxford English Dictionary further defines vulnerability as: “the sensitivity, resilience, and capacity of a system to adapt to stress or perturbation” (www.oed.com, 2013). This definition is fitting because Wade – her performance and her words acting as the system – effectively express sensitivity, resilience, and capacity to adapt. Her performance, while referencing vulnerability from her lived experiences, is also sensitive to stressors from an ableist society and at the same time, resilient and adaptable to them. She displays both responsiveness and flexibility in her work by directly addressing the many causes of the pressures on her: a society unwilling to accept her as she is, a culture that devalues and misrepresents her, a community that reifies ableist values, a body that struggles with pain, and medical institutions that objectify her.

4. **“Complicated reality”: Expressing contradictory concepts simultaneously**

Through the process of reformulating and re-structuring her past experiences, Cheryl Wade exposes the emotional, psychological and physical fragilities created by an ableist society and exacerbated by mainstream culture. At the same time, Wade expresses disability in a

radically vulnerable and complex way. Radical vulnerability includes “complicated reality,” contradictory concepts within the same scene, poem, or song in the performance that expound upon the reality Wade is representing, giving her work a comprehensive, nuanced depiction of being disabled. She exposes the ableist roots of expected disability images and narratives, which often leave out the intricate, realistic fullness of disabled people’s lives. In this way, Wade’s approach includes “complicated reality.”

Complicated reality is one of the first things I noticed about Wade’s work. I immediately saw that she was portraying both positive and negative aspects of disability at the same time and avoiding binaries. “Exactly,” Wade agreed in our first interview. “What I’ve always tried to do [is] try to say there’s pain and struggle and joy all mixed up in one. Unfortunately we live in an era of either/or, black and white. It isn’t very realistic” (Interview 1). Mixing up contradictory ideas is her way of crafting a realistic version of her disability experience. As a part of, and in concert with, radical vulnerability, complicated reality frames Wade’s work in terms of the content of her performance, how it contributes to transforming disability metaphors and narratives, and why it is powerful.

Wade delivers spectrums of possibilities for being disabled in *Sassy Girl*, painting textured, multi-layered scenes that resemble reality for disabled people. However, if reality appears too simplistic, Wade will complicate it. She diligently tries to make her work a vibrant and comprehensive expression:

I have worked very hard to create powerful metaphors, to create images that haunt you and live with you beyond the moment that you’re being entertained...I do work hard at that, I did work hard at that. (Wade, Interview 2)

The images “haunt” and the metaphors are powerful because they are complex, paradoxical, and unexpected.

Sassy Girl is characterized by Wade's unexpected and complicated style as a way to furnish her version of reality. This often includes multiple and contradictory concepts performed within the same scene or poem. For instance, she opens the play with "Cripple Lullaby," a poem that seems to expand on what she is "not" with a key phrase: "*I am not a reason to die.*" Similarly, she ends the play with "I am Not One of The," a poem that also counters what she is "not" with haunting imagery and unexpected metaphors. Each of these poems offers startling, evocative imaginings to describe disability experiences, disability culture, her identity, connection to her audience, and Wade's particular brand of pride.

Sassy Girl is a work that embraces complexity. Yet even this idea – that the world Wade creates in *Sassy Girl* is a complicated reality – is complicated. She never claimed to be a documentarian, and her work is what she calls a "fictional autobiography... If it doesn't work, I don't use it" (Wade, Interview 1). She crafts the performance through edited and synthesized experiences, which she transforms; sometimes substituting actual events with imagined ones. Thus, the sassy girl is more of an illusion—a representation that seems to ring "bone true" to her audiences—but does not always include "the whole truth and nothing but" (Wade, Interview 1). Nevertheless, Wade's personal story retains its air of authenticity, and represents her experiences, and those of many disabled people, in an honest, compelling, and entertaining way.

Radical vulnerability and complicated reality express how Wade excavates the deeper meanings of disability, reveals the origins of disability oppression, promotes change and social justice for disabled people, and transforms cultural messages and traditional views of disability. By opening herself up, Wade breaks ableism down. By strategically and intentionally re-articulating her experiences, she complicates disability, including its psychological effects, and constructs fresh representational. Wade's performance strategies provide her with resilience and

empowerment, and provide her audience with an adaptive and thorough understanding of disability.

C. **Constructing “Complex Embodiment”**

1. **Introduction**

Sassy Girl illuminates the complexities and obscurities of living with impairment, pain, and disability. Portraying struggle and pain is not something that Wade views as negative representation of disability, but rather a realistic viewpoint. Tobin Siebers cites Wade as an example of what he calls “a new realism of the body” (2008, p. 65). He contends that: “Her account of complex embodiment ruptures the dominant model of pain found in body theory today, projects a highly individual dimension of feeling, and yet speaks in the political first-person plural” (Siebers, 2008, p. 65). In other words, pain is neither merely subjective nor an unshareable state in Wade’s performance, but realistic expression, cultivated from her lived experiences, and representative of other disabled people. In this section, I will discuss the ways in which Wade infuses her “complex embodiment” into her work to expand the notion of radical vulnerability, project a complicated reality, and build connections to community.

2. **Making the body central**

Wade makes her disabled body central in *Sassy Girl*, with body and impairment issues prevalent throughout the play. She does this, in part, as a political statement. Wade explained that the disability rights movement, in the 1980s and early 1990s, wanted to focus its message on access and convey a positive image of disability. This strategy was meant to contrast tragic disability images that were prevalent in popular culture and attempt to sever disability from medical discourse. “It wasn’t all just about access,” Wade said in our first interview, “it’s about a lot more than that. And I really felt when I began in the movement that’s all that we were

allowed to talk about,” (Interview 1). Of course, Wade insisted on talking about more than access. Snyder and Mitchell reflect, “disability studies has strategically neglected the question of the experience of disabled embodiment in order to disassociate disability from its moorings in medical cultures and institutions” (2001, p. 368). This trend in both the disability rights movement and disability studies had a strategic and political goal, but it left bodies out of the discourse. Moreover, these strategies, which neglected bodily experiences, worked to maintain medical power over disabled bodies. Focusing on access did little to change public perceptions. Meanwhile, Wade could not neglect her bodily experiences, and leaving her body out of her work was not an option.

Wade deals directly with body issues in reaction to these trends. The pain, deformity, and limitations she experiences, along with the way society perceives and treats her, dually create and inform her daily life. She recalls the strong discord and disconnection she felt with the movement at the time:

I felt there was a lack of body in it. The reality was my body called the shots always; I didn't get to leave my body behind. My body didn't suddenly become the social issue. I needed help getting on and off the crapper, you know? I couldn't get out of bed without help. I couldn't get dressed without help; I couldn't get my ass into the chair and into the world without help. That was always the reality. (Wade, Interview 1)

Her “reality,” which is dominated by the access needs of her body, defines her artistic and political issues. Wade’s statement emphasizes the centrality of her body: always significant in her life, including her political views and activism. The above quote helps clarify why complex embodiment is a focal point of *Sassy Girl*.

Wade explores the moorings between impairment and medical institutions in *Sassy Girl*. This means that she also uncovers the power struggles between the individual (Cheryl) and medical professionals over her body. The narrative uses the personal aspects of this struggle to

Small for her

Stop stop

Shine Time SED rate clean catch scoop your shit Dear blood

Just a little pin prick

to the bone marrow

to the ear drum

Cut off the nodule

realign the hip joint

scrape cut saw

Stop stop

Rebuild the classic deformities of the

small for her age

classic deformities of the

small for her

classic deformities of

deformities

small

NOOOOOOOO! (Wade, *Sassy Girl*)

Wade's attention to the details of hospital experiences – painful procedures, particularities of body parts, and judgments about her body – demonstrate a complete capitulation to the demands of the medical staff. “Small for her age” is repeated nine times, and “classic deformities” repeats four times, having the effect of both emphasizing and subverting the negative evaluations about her. These definitions are passed along with blatant disregard for the person. Wade performs the voices of the medical staff with controlled sarcasm and sickly sweetness, possibly to mimic a sense of false caring she felt at the time. As the piece progresses, she speaks faster, simulating swirling, confusing, and overwhelming control over her body. Scattered inside the poem are her own words: short questions and protests. Her final “No!” is delivered with a desperate scream-like cry. Our heroine is not totally assimilated here, but damage is done.

a. **Exposing medical power over disabled bodies**

The poem also highlights an often hidden but common experience about what happens in the hospital: loss of control, vulnerability to medical power, and a focus on the body without the person. Thus, “Hospital Litany” is radical and complex. Wade depicts radical vulnerability by revealing how medical institutions had power over her by: performing the confusion and distress of what was happening around her and to her; and reenacting how medical professionals constructed her body parts separately from her – the fragile girl they belonged to. She performs her vulnerability to medical power here, demonstrating the effect it can have on one’s psyche through her words, the speed of her performance, and the emotion she expresses.

Exposing messy bodily and psychological details risks criticism and rejection by disability activists of the time. She presents “negative” experiences focused on the body, but she doesn’t stay there. This poem is like a rollercoaster, taking the audience down then back up, because Wade complicates her character’s vulnerable, overpowered position in the hospital. She questions medical power within the poem, asking “what” and yelling “stop, stop” to the voices around her. She seems determined to take back the body that medical professionals usurped. In this way, Wade’s narrative defines and constructs her embodiment while it resists and refuses medical definitions. At the same time, the story she tells in this poem speaks to the first person plural, claiming the history and frequency of scenes like this.

Reclaiming power by constructing complex embodiment appears again in *Sassy Girl* when the teenaged Cheryl, working hard to fit in, takes her mother’s advice to put on a little makeup. Yet instead of focusing on her, all anyone can focus on are her deformed hands. Rather than asking her opinions, they ask if her hands hurt. Cheryl exclaims:

*All these little special quirky things I've been pulling together forever into this one-of-a-kind package—nothing but a pair of hands. Damn. But I figure, there has gotta be a way around this. So...I come up with what I think is a tres clever plan. I carry a shawl in my lap. Lace, delicate. Ultra feminine. And then every time someone comes along and tries to engage me in conversation, I simply slip the offending creatures [GESTURE OF PUTTING HANDS UNDER SHAWL], under the shawl, and then I can go about my business of being an ordinary girl. It works like a charm. For years. Then one day I notice: I'm not talking very much. And when I say something, I don't really say anything. (Wade, *Sassy Girl*)*

Wade's narrative points out the holistic nature between body and person. Her use of "offending creatures" supports a clear separation between her body and self, likely created by medical power. This disconnection from her body also separates her from the world. This scene depicts her character's discovery that her disabled body is integral and inseparable from who she is. Hiding her hands turns out to be a form of silencing, and reclaiming her disabled body is not only empowering, but also absolutely necessary.

b. **Re-integrating the disabled body**

At this point in *Sassy Girl*, Cheryl starts to see her body differently. She remarks to the audience, "*I look at my foot and my hand in the mirror as if they are objects in space. Ah, the line, the form, texture and tone – interesting*" (Wade, *Sassy Girl*, emphasis in original). It is as if she is beginning to accept the changes impairment has made, seeing them as a work of art. Re-articulating her interpretation of her body in this way is powerfully resistant to any psychological fragmentation, and is a fierce counter-narrative to the medical, social and cultural perceptions inscribed onto disabled bodies.

For example, Cheryl's embodiment becomes more empowered in the play once she comes "out" as a disabled woman. Wade said, "I did not come easily into empowerment" during our second interview. Expressing empowered embodiment was a process that involved performing *Sassy Girl*. "The more I performed the sassy girl, the more I became her," she said in

our second interview. A humorous example of “coming out” with reclaimed embodiment is available in this scene from *Sassy Girl*:

“Cheryl, isn’t it wonderful news? They’ve finally nominated Jerry Lewis for a Nobel Peace Prize.”
[HANDS STRUGGLE FIERCELY AND BREAK FREE, BEGIN FLYING AROUND WILDLY] ‘Jerry Fucking Lewis?’
[INCREDULOUS] No fucking way! Jerry Lewis? That piece of...Not Jerry Fucking Lewis. [HANDS IN AIR, UTTER DISBELIEF] Jerry Fucking Lewis?” (Wade, *Sassy Girl*)

Waving her hands around wildly, raising her voice with incredulity, Wade performs this scene with abandon. The extreme difference of her crippled hands as they flap and float in the air while she shakes them is obvious and possibly uncomfortable for some viewers. Meanwhile, her face registers utter disbelief. Cheryl is less fragmented here, refusing to hide or to protect others from the “offending creatures” and refusing to silence her opinions. This scene reconnects body and mind through political consciousness. Tying her body (coming out) with her sociopolitical opinions complicates the reclamation of her body with political perspective while also excavating another oppressive root of disability in social and cultural contexts.

Both “Hospital Litany” and the scene about Jerry Lewis speak directly to disabled members of Wade’s audience and community. She is relating *with* them about experiences in the hospital, which may also be familiar to a general audience. And her incredulity about Jerry Lewis for his work as Muscular Dystrophy Association (MDA) telethon host speaks directly to astute disabled spectators: she connects to her audience through a common, well-known, pity-mongering enemy.

3. **Representing complex embodiment**

Complex embodiment not only describes the way that Wade represents her disabled body, but also how her performed embodiment affects her lived experiences. During our first interview, Wade talked about her personal journey with her body as she evolved as a

performer. When she first began with Wry Crips, and speaking about performing “My Hands,” she told me, “I was still on the stage wearing skirts down to my ankles, shirts down to, you know, practically covering my hands, and I sat with a script in my hand. You know, that was the way I performed that [poem] in those performances” (Wade, Interview 1). In other words, she was still hiding her different body. But when she was performing *Sassy Girl*, the process transformed her confidence and how she felt about her body. She recalls:

I waved my hands in people’s faces. And I wore shirts that showed my deformed hands and my deformed elbows and I had a skirt that I could pull up and show my scars on my knee if I wanted to pull home the point. That is not my identity in the world; that was my identity on stage. And if I had ever been able to feel as comfortable in the world as I did on that stage, I would be a happy camper my dear! And that’s the truth. (Wade, Interview 1)

She is telling me that her performed identity matched her everyday identity when she first began on stage. Along the way, however, her performed identity grew confident while her “identity in the world” did not change or grow very much. Instead, the relationship between her performed embodiments differ from what happens in the world. The social and cultural baggage of disability complicates her embodiment in the world. In some ways, however, the empowered identity can translate into everyday interactions, but it is fragile. “There [are] always still moments in the world where you can be taken down very quickly by somebody diminishing you,” she explains. “Nobody takes me down when I’m on stage” (Wade, Interview 2). Wade often embodies an empowered disabled woman, but this identity is vulnerable to clashes with the social and cultural realities of disability in the world.

The paradox between what happens in life and what happens on the stage is important because it reveals more complexity and vulnerability within Wade’s lived experiences. Notice how Wade’s body is the focus of the above quote, representing her lived and performance experiences. Meanwhile, her body, which causes reaction, distraction, and disruption in the

world, becomes a source of power for *Sassy Girl*, transforming the performer from powerless to powerful. "...It's my show...No one can present the disabled body like I can" (Wade, Interview 1). Indeed.

Wade's powerful representation of the disabled body first occurred with "My Hands" during a solo performance with Wry Crips. This poem was "the genesis of my disability work," she said in our first interview. It is a piece in which she worked hard to express complex ideas about her disabled body, and where she claimed the defects and deformities of her hands in order to reframe the idea of beauty and sexuality. In *Sassy Girl*, Cheryl wistfully recalls what she wanted from this poem. She states:

I so wanted my first poem to be a masterpiece, to say everything I have ever wanted to say about disability, and then some. But all it's willing to be is this tiny little booga booga poem. (Wade, Sassy Girl)

Yet, this "tiny little booga booga poem" marks a pivotal moment in the artist's coming out as a performer. She explains:

There was quite a bit of coming out as a performer, as somebody who was really willing to deal with my disability and look at my body and try to figure out a way to express the things I go through and have been through -- artistically. Because I'm not somebody who just wants to vomit out stuff to people. (Wade, Interview 2)

Thus, Wade puts a lot of herself into "My Hands," pulling from her experiences in the world to represent them fully as an artist. She mixes cultural references with representations of her hands as a woman who is fully cognizant and accepting of the body she has. "My Hands" goes:

*Mine are the hands of your bad dreams
Booga Booga from behind the black curtain
Claw hands
The ivory girl's hands
after a decade of roughing it
crinkled puckerred
sweaty and scarred
A young woman's dwarfed knobby hands
that ache for moonlight*

*that tremble
 and struggle
 Hands that make your eyes tear
 My hands
 My hands
 My hands that grace
 your brow
 your thigh*

*My hands.
 (Wade, Sassy Girl)*

“*Behind the black curtain*” gestures to the title character in the film *The Wizard of Oz* (1939), who transformed lives from his hidden position. “*The Ivory girl’s hands*” references a popular TV commercial from the 1970s. These references, and her performance of the piece, are skillful. When she says the lines “*booga, booga*” she is waving her hands in the air, shaking them like objects toward the audience. Wade highlights words with her hands and her voice, using tenderness at times, sarcasm and fierce conviction at others. Her conviction is particularly evident on the final repetition of “*My hands*” where in some of her performances of this poem, she adds “yeah” (see Mitchell and Snyder 1996, *Vital Signs: Crip Culture Talks Back*) to punctuate her value. This radically vulnerable poem speaks volumes; claiming her body, beauty, sexuality, and power in just a few lines.

4. **Claiming the body: Disability, gender, sexuality, and power**

While “My Hands” comes from acceptance of her disabled body, Wade also transforms perceptions about her hands in particular. As Garland-Thomson notes: “From her wheelchair, she brandishes the hands that are usually hidden in polite society, their shape and function a bold affront to the delicate hands femininity fetishizes” (2005, p. 35). Thus, her hands symbolize the impossibility of feminine perfection, while simultaneously claiming their imperfect beauty, sensuality, and her own identity.

Although not the disability masterpiece Wade wanted to write, this “booga booga poem” became a crowd-pleasing feminist anthem, and spawned the creation of her first full-length show, *Sassy Girl*. She remembers:

The first time I ever performed the “booga booga” poem, the roar that went up from an all female audience, a lot of them not disabled, that was back in the Wry Crips days...It spoke to something about the way women feel they are devalued because of their bodies, and the contradictions we all feel because of our own bodies...literally the audiences would roar when I went, “mine are the hands of your bad dreams booga booga!” And it just was like immediate, it was visceral, it spoke and that’s when I knew I was on to something, because I had no idea before that. And that’s why that poem particularly is featured in *Sassy Girl* the way it is, as the most important poem I ever wrote, and as a general disability poem. (Wade, Interview 2)

Wade clearly understands the impact of her work, which inspired her to write more about her disabled body. The work confronts a myth of perfection and beauty that women of all abilities fail to meet. It “speaks” to the ways in which women feel devalued by cultural expectations, or as Wade puts it, “the contradiction we all feel because of our bodies.” Thus, her “little poem” launched something larger: it is meaningful to disabled and nondisabled women, raising feminist issues and connecting disability and the body for all women.

With “My Hands,” Wade is able to reach both feminist and disability communities, giving her license to claim both a woman and disability identity. Proclaiming her gender emphasizes her body and complicates her disabled embodiment even further. According to Garland-Thomson, Wade’s assertion of gender and sexuality in her performance suggests “a feminist disability politics [that] would uphold the right for women to define their physical differences and their femininity for themselves rather than conforming to received interpretations of their bodies” (1997, p. 25). Wade’s feminine proclamations permit women to freely accept and flaunt their own imperfect bodies.

Wade's feminist ideas seem to be influenced by her mother. When she became disabled, her mother encouraged her to get an education and to take care of herself because "a man ain't gonna do it" (Wade, Interview 3). "Females have a prescription to fill. Things like reproduction and beauty... and disabled women are not a catch. I mean come on, we're a devalued commodity," Wade explains. Yet her work pushes against that evaluation by claiming who she is: a sexual, desirable disabled woman. For Wade, feminist disability politics are simple: "Yes we're sexual. Cripples are sexual. We have bodies; we have feelings" (Wade, Interview 2).

Part of Wade's complex embodiment includes openness about sexuality. Performing sexuality and disability was radically vulnerable when Wade was doing *Sassy Girl*. Her character points out an acutely sexist and ableist attitude about sex for disabled people. "*The only Crips who have sex are paraplegic and quadriplegic men and the only people they have sex with—able-bodied women who are both attractive and active*" (Wade, *Sassy Girl*). In the play, she wonders aloud if she will be able to enjoy a sex life, but she is not willing to give up finding creative, accessible ways to do it. She asks the audience, "*don't all great discoveries happen because someone is willing to go exploring?*" This leads to what I call her *When Harry Met Sally* (1989) moment when she performs an orgasm on stage. Here is a snippet of that scene:

There. Yes, definitely there.
That tickles there.
It tickles, yeah, there.
A little softer there
Softer there.
Really, there?
Oh really there.
So that's what it's like there
Wow.
Yes there. Yes there.
there there there there there
Yes, oh my god YES
THEEEEEEEERE
 (Wade, *Sassy Girl*)

Wade's willingness to perform, or "fake," an orgasm in her show demonstrates an incredible vulnerability on stage because she directs the audience to focus on her body, its limitations and sensations. Not only is she making viewers think about her in a sexual way, she is pushing their comfort level with sex and sexuality. Yet, Wade never felt vulnerable doing this scene. "I had a blast doing that," she told me during our second interview. "How much fun was that! I mean just imagine, being on the stage and you get to do a funny orgasm in front of people. I mean every exhibitionist cell in my body was satisfied" (Wade, Interview 2). Rather than feeling vulnerable, she was having fun and totally in control. "You know, it's so safe," she told me. "I wasn't having a real orgasm, I was never comfortable being an exhibitionist in that way." Her orgasm scene exposes oppressive attitudes about sex generally, and sex for disabled people particularly, while claiming sexual agency and identity for herself and disabled people.

Wade's disruptive exposure of her body's differences, limits, and sensations – her complex embodiment – reveals how "complicated reality" manifests on the stage. Garland - Thomson expresses Wade's embodiment strategy this way:

Capturing the cultural assumption that impairment is an inappropriate aesthetic sight, Wade enlists the power of the unexpected, the transgressive, by demanding that her audience look at what they have been taught is not to be seen outside the clinic. (2005, p. 34)

Thus, Wade's complex embodiment boldly disrupts a cultural mandate that prefers bodies like hers to remain unseen. She refuses such mandates, and the reality they perpetuate, and demands to be fully seen. Through her performance of complex embodiment, Wade redraws the boundary lines between any appropriate aesthetic and what is unexpectedly, and distinctly, beautiful.

These unexpected, disruptive, and inappropriate changes that Wade illuminates in her work help to define and mirror her body's history with impairment and disability. Complex and

radical changes to her impaired body required her to tread through her experiences with emotional fluidity and psychological flexibility. Over the course of her life with chronic illness, her body constantly changed with often more pain, deformity, and loss. This constantly shifting landscape of her body is reflected in who she sees herself to be, and in this performance. I asked her about the impact of disability on her life. She explains:

You know, I think like everything else, there's not a constant. And the way that I feel about that is not a constant either. I've had long periods where I've thought there was nothing to be gained for any of this, where [disability is] just a hideous, monstrous, debilitating, unfair thing, and that shit happens and that's what it is. My job as far as being a human being is to try to not be a hideous one on this planet, not stink it up worse than it already is, and try to figure out a way to use whatever amazing things I have about me, for which I think there are many, to act upon those around you, your surroundings, in a way that is deepened. (Wade, Interview 3)

She appears to argue how disability and chronic illness have taught her what is truly valuable and “amazing” about her. Her experiences with disability and impairment have taught her about “her job as a human being.” But most importantly is her philosophy that “there is not a constant,” which she has used to adapt and flourish with this “hideous...debilitating, unfair thing.” This philosophy has given her fluidity and flexibility to move with her constantly changing body, in turn allowing her consciousness and identity to shift and adapt her place in the world.

D. **Disability Consciousness**

1. **Introduction**

In this section, I discuss the theme of disability consciousness, a term Wade used during our interviews to describe her process of integrating disability, political activism, and cultural criticism into her identity. I see her disability consciousness as a process through which she becomes resilient to shame, and forges her own constantly shifting and complex identity that includes her distinct brand of disability pride. Internal influences, like emotions, thoughts, and pain, interact with external forces such as social situations and the politics of her community to

influence and drive this process. This section will explore the process of Wade's disability consciousness through her depiction of it in *Sassy Girl* and through our conversations.

2. Reconstructing identity

In the previous section, "complex embodiment" I demonstrate how Wade's disability consciousness encompasses her disabled body. In the performance, Cheryl takes notice of her physical changes objectively, seeing them as a work of art: "*as if they are objects in space ... – interesting*" (Wade, *Sassy Girl*). In that moment, picks up the fragments of her identity that were broken by medical professionals. Additionally, she comprehends her physical changes as irrefutable and irreversible. As part of her process of taking back her body and identity, our heroine expresses an apparent identity crisis when she considers how deformities and physical limitations have taken an emotional toll. Cheryl remarks to the audience:

Something changed in me when I got rid of that shawl. It's like I poked a hole in this cozy web of depression I'd managed to wrap myself up in to keep from feeling so trapped and hopeless. I'm edgy, restless. [MOVING TO EDGES OF LIGHT AS IF COMING UP AGAINST WALLS] I can't bear to sit still. It's like if I sit still too long I'm gonna just disappear all together. (Wade, Sassy Girl)

The narrative reflects a growing disability consciousness, making visible her sense of despair at being "trapped", which separate her from the rest of the world. Cheryl also mentions the "cozy web of depression," or grief, which led to this point. She depicts internal and external factors colliding in this scene, and then erupting into a core issue: feeling invisible. Cheryl appears uneasy with this knowledge, delivering her lines with edginess in her voice, and nervous, sharp movements. It comes across as if she does not feel comfortable in her skin. Wade also experienced a similar kind of identity crisis in her life. In our first interview, she explains that it took her many years to get to a point that she could accept her body. "I hated my body. I hated the deformities. I was embarrassed. I was humiliated. I did not come easily into disability at all"

(Wade, Interview 1). Coming “easily into disability” refers to both a bodily category and an identity, and she gestures to the complicated relationship between what impairment has done to her body and how that makes her feel. She is expressing shame, awareness of shame, and the uneasy concurrent process of accepting one’s body and social status as a disabled person.

During this isolated and “homebound” period of the play, Cheryl’s monologue portrays her longing for social connection, which seems enmeshed with her consciousness. Her narrative mixes this desire with political and cultural sophistication. In this bit from *Sassy Girl*, Cheryl tells the audience how she keeps herself amused by singing, watching movies, and acting out scenes like this one from *Whatever Happened to Baby Jane (1962)*:

And I play these scenes. ‘What’s the matter Blanche, aren’t you hungry? You wouldn’t treat me like this, Jane, if I wasn’t in this wheelchair. Butcha are, Blanche, ya are in that wheelchair...I am an island.’ Anything to hear a human voice that isn’t coming at me from some damn box or through a haze of alcohol. Nothing works. Nothing I do stops me from longing to get out. (Wade, Sassy Girl).

Her budding disability consciousness is apparent here, as she humorously links her own forced isolation at home with the way Jane confines Blanche in the film. Performed with exaggerated impersonations of each character, this scene addresses segregation, social isolation, and neglect. She shows that such treatment is oppressive, regardless of intention (*Baby Jane*) or ignorance (her parents inaccessible home). Furthermore, I think Wade is speaking to her community through the shared experience of oppression. She seems to be calling out to other disability-conscious audience members, as well as educating those who may not get it, about a bigger picture. In this way, Wade illuminates oppressive treatment of disabled people and the cultural practices of Hollywood that support it.

When Cheryl deals with her parents’ unintentional confinement of their daughter in *Sassy Girl*, Wade’s awareness of more structural disability issues becomes evident. Cheryl tells the

story of how her parents purchased a new one-story house while she is in the hospital, now permanently in a wheelchair. She tells the audience how excited she is to finally have freedom to come and go, but when she approaches the new house for the first time, she sees “*three goddam stairs*” (Wade, *Sassy Girl*). Wade gets to the root of this situation as her character states:

If my own parents can't bear to look at me, if I'm invisible even to these people who've known me always, I haven't got a prayer. I haven't got a prayer. And I think this is just the way they want it. Me, dependent. Them with all the power. And then it can go on forever: How wonderful you are the way you care for your poor crippled girl.

*I'm not being fair. These are my parents; I love Mother and Daddy. Haven't they sacrificed so much for me? They take good care of me. I have nice clothes, plenty of food. I love my mother and father. And besides, they're so cool, everyone says I have the coolest parents—they let me smoke and drink when I was sixteen. I love my parents. It's a lot easier to hate a house. (Wade, *Sassy Girl*)*

This depiction of her growing disability consciousness, tinged with despair, allows her to uncover the root of the problem: invisibility. If she is invisible to her parents, then she is invisible to the world. If they do not or cannot really see her, then “*I haven't got a prayer.*” She says this with heartache in her voice. But Cheryl is also angry at this situation, and struggling aloud not to be angry with her parents. Conflicting emotions, and giving her parents the benefit of the doubt, complicates the reality for her character. Then, using radical vulnerability, she reveals the oppressive origins and larger picture involved here. That is, being invisible is painful and pervasive, and keeping disabled people dependent is systemic and far-reaching in our ableist society.

a. **Becoming “handicapped”**

The disability consciousness process depicted in *Sassy Girl* includes the awareness that Cheryl is part of a larger group. She realizes that she is “handicapped,” and muses aloud to her audience that there must be a government program for people like her. In her life, however, Wade remembers it never happened quite that way. She explains:

Nobody had ever used that word. That's the truth. It didn't happen [how it does in the play], but nobody ever, ever, ever said that I was disabled or handicapped. Ever. Even though I was crippled and in a wheelchair and my body was deformed in almost every joint. Nobody in the medical profession used that word with me, which is a word that implies a status that I could have learned to work with. (Wade, Interview 3)

Pointing to a systemic problem within society, Wade indicates they could only see her as an individual problem to be fixed, but not as a member of society. The failure to identify or connect her with social programs or services that could help her live with disability is indicative of systemic oppression and pervasive invisibility. In *Sassy Girl*, Cheryl tells the audience that she “learned to work with” her status as disabled. “*The State Department of Vocational Rehabilitation . . . That's the place through which all Cripples get funneled on our way to the real world,*” she says (Wade, *Sassy Girl*). But this does not mean she adopts a disability identity. Rather, she is willing to use the label of “handicapped” to achieve some of her goals. Wade and her character take advantage of this status for financial benefit, without a clear shift in consciousness.

With her status and social programs in place, Cheryl can afford college, transportation, and the means to develop an independent identity. In her story this begins to happen as a Berkeley student when she clicks with the important history of the place: 1960's anti-war protests, “*People's Park: THE symbol of the struggle for freedom and individual choice*” (Wade, *Sassy Girl*). More importantly, the narrative describes Berkeley's disability history - the Center for Independent Living, where disability rights and the independent living movement started – and Cheryl gushes, “*My god, C.I.L. Talk about freedom and choice*” (Wade, *Sassy Girl*). Freedom and choice begin to merge with independence and disability within her consciousness.

While at Berkeley, Wade's disability consciousness matures and expands. She comes out to the world as a disabled woman who claims her body, her identity and identification with other

“cripples” and other marginalized groups. Meanwhile, Cheryl is featured in a local news story that she describes as “one of these “*Super Crip Girl: Cheryl, the disabled hero we all aspire to be*”” (Wade, *Sassy Girl*). This overt acknowledgement of the overcoming narrative ascribed to disabled people is sarcastic since she intends to overturn it here. She tells her audience that, because of the news story, she has received monetary offers for her accessible van fund, and gets invited to speak at an upcoming Elks luncheon.

b. **Refusing the “social contract”**

The Elks luncheon is apparently an opportunity that Cheryl cannot refuse, since they offer her \$150 to give a talk. *Sassy Girl* reflects that she could not pass up such a profitable educational opportunity. Cheryl says:

I've worked up this talk I think covers the basics – all the things I think they ought to know, the Independent Living Speech, emphasizing how without access and services like attendant assistance, you don't even have a chance for a life. And, of course, I use my own story – the personal angle – to drive it home. And it's working. I'm going over big-time. They're about ready to make me an honorary Elkette, when I just can't resist:

*Cripple jokes; Dial –A –Comic, and the “I ain't a number” blues
Speedballin' through my brain.*

In nightmares

cold white hands

Rip feathers from my wings,

Crack fragile bones;

Thin pale lips smile and suck.

How do I roll into a Star-spangled-warm-summer-night?

Soft-cool-breezes dream--

The kind guaranteed in the Constitution,

The Bill of Rights

and on baseball cards in the back pockets

of young boys everywhere.

I want my All-American-Born-In-The-U.S.A. dream

and I want it fat and sassy,

Not battered and abused by the latest Dr. Fix-it

Who cops a cheap feel every chance he gets

So I'm forced to edge backwards down the alley,

Clutching my skirt to my knees.

Where's that “The Doors Are Wide Open, Go For It” dream?

*Where's my American dream?
The able-bodied white men's chorus sings:
It's in committee.
It's in committee.
It's in committee.*

*There's some part of me that always knows exactly what I'm doing, I know what was expected: a nice "how I triumph over my disability" story, I know it's perfectly acceptable to include some pain and struggle as long as I'm willing to put a positive spin on it. I understand the social contract, trust me on this, I do. And I would've been very willing to live up to my side of the bargain; I really would've, if they just hadn't patted me on the head.
(Wade, Sassy Girl)*

This is a long quote, but it conveys the complexity of Cheryl's consciousness, and demonstrates radical vulnerability. The speaker's "cripple jokes" ask poignant questions of her audience and, in this case, direct these questions to white male power. The poem displays a sophisticated disability consciousness, developed as a disabled woman activist who comprehends her situation beyond disability issues. She opens with scathing descriptions of her "nightmares," using disturbing imagery like "rip[ping] feathers from my wings" and "crack[ing] fragile bones," which indicate her own susceptible body and spirit. She describes her dream as "battered and abused by the latest Dr. Fix-It," whose "cold white hands" cop "a cheap feel" and implicate white, medical power as her abusers. This imagery is meant to provoke, incite, and tell brutal truths to power by getting to the radical core of medical and other forms of dominance. Where is her American dream? Where is it for women, disabled people, or any disempowered and marginalized group? This poem, however, exposes her, and she risks losing this opportunity for funding from the Elks. In this way, this passage expresses "radical vulnerability" as an approach she uses throughout the work, but also as a depiction of the complicated reality created by her blossoming disability consciousness.

Instead of simply abiding by “*the social contract*” where she plays the overcoming supercrip that the Elks expect, she complicates and dismantles it. Wade’s words integrate her disability consciousness with the courage to speak her truth. She remarks that the reason she refuses her compliant role is because of being “*patted on the head*” – shorthand for infantilization, objectification, and deep paternalism that was used to greet Cheryl at the beginning of the meeting. Wade’s poem gestures toward sexual abuse and the violation caused by being objectified in any way, including medical objectification. She refuses all expectations, and will not be objectified because of her disabled body or her gender. Indeed, she rejects violations of any kind, no matter the oppressive cause or false assumptions. She insists on her own “*American dream*” (Wade, *Sassy Girl*).

This phrase, “*American dream*,” signals that Wade is not just speaking up for herself. Again, her consciousness enters this discussion because it includes disability consciousness and identity that encompass the first person plural; other disabled women, disabled people, or anyone whose American dream has been battered by what she calls “*the able-bodied white men’s chorus*.” In fact, with this passage Wade’s disability consciousness reaches a critical point: it is deep, broad, radical, vulnerable, complicated, and powerfully resistant to dominant ableist structures.

E. **Objectification and Violation**

1. **Introduction to this section**

Dealing with the medical profession, as discussed earlier in this chapter, can have the effect of separating the person from her or his body. Medical practices often impose authority over diseased or disordered body parts, and patients receive messages that they are property of medical institutions rather than maintaining an individual identity. Susan Wendell (1996), in *The*

Rejected Body, contends that, “Western medicine has both the cognitive and the social authority to describe our bodies to ourselves and to others” (p. 117). This authority, she continues, “contributes to our alienation from our bodies and our bodily experiences” (Wendell, 1996, p. 119). Medical authority lays claim to disabled bodies, and in turn, we become cut off from our bodies. This authority can extend beyond clinical contexts into “the world,” as Wade might say. As a result, strangers may assert the right of unwanted and unwelcome authority over disabled bodies in the form of staring, questioning, or touching. In this way, the objectifying nature of medical authority can become intrusive, violating individual autonomy in the world. *Sassy Girl* depicts examples of objectification and violation from Wade’s experiences, while Wade’s commentary emphasizes these themes. In this section, I am interested in the ways that Wade’s work portrays this sense of alienation from her body, alienation from society, and how these feelings objectify and violate the complexity and distinctiveness of her identity.

2. **Objectification**

Wade’s initial indoctrination into “medical authority” began when she was first diagnosed at around age ten. The interactions she had with doctors shaped her self-perception and the relationship she had with her own body. In *Sassy Girl*, she artistically reproduces hospital stays with her poem “Hospital Litany,” where every aspect of her life was measured, scheduled, and controlled. The poem shows how Cheryl is reduced to an object of medical power, and depicts her lack of privacy, control, and autonomy. The poem shows how easily medical authority can usurp the body and self; Cheryl expresses signs of alienation from hers (see my discussion of “Hospital Litany” in the section: “Complex Embodiment”). “Hospital Litany” demonstrates how easily Cheryl is reduced to a simple, voiceless object – a “patient” –

and then “split” (Gill, 1994) into various body parts, rather than being a complex, multifaceted individual.

Wade sheds light on how “Hospital Litany” portrays the feeling of getting lost in the confusion of objectification, while also showing a typical flurry of questions and commands that seem to condense her to a “small entity.” Wade explains:

I took all the language from things that have been said to me, and I didn’t have to make much up. I just tried to put it into a chant and a rant and a rhythm...and when I performed it I felt like [these] million voices coming at me and I was a very small entity trying to fight [off] those voices. And it’s a very powerful piece. (Interview 2)

The power of the poem is in how skillfully Wade portrays a larger process. She refers to being small here not only as a physical state but also small against medical power: her insignificance as a child is magnified by her small size. In addition, the “million voices” she speaks of points to the many pieces of her identity being fragmented in the process. As the poem nears its conclusion, the pace quickens as words become scrambled and fractured to represent a longer process of alienation and “disintegration” (Gill, 1994) of the self – one that can rupture a still forming personality. This piece demonstrates how individual personality, emotion, and identity can be ignored and devalued, leading to alienation from her self, or turning away from the “problem” of her body as a way to protect what’s left of identity.

Medical interventions caused Wade to feel like “a thing,” and had a profound impact on her self-concept when she was a teen: “I was this thing that needed to be fixed, that could never be fixed. That’s the lie they tell you” (Wade, Interview 3). Expressing the “objectifying gaze” (Marks, 1999), she was not only an object filled with body parts, but also a hopeless one. And being an object that could not be “fixed” felt like personal failure. She remembers:

I knew I could never be fixed. So, I, as this crippled kid, I get to feel like a failure. Every time I went to the doctor and I was worse, I apologized. I felt demoralized that I had let them down. They were doing all these things to help me, and I can’t wear the brace on

my hand because it hurts too badly, so it's my fault my hands got worse. The doctors tell you that. (Wade, Interview 3)

Thus, the “lie” of medical authority creates an aura of benevolence; they are trying to help her. But, if she cannot follow their advice because of pain, she is the failure, not them. At least, that is the lie she is told. Furthermore, their push to “fix” her only adds to her objectification because it makes her a “thing to be fixed.” Focusing on her body, or body parts, ignores the complex needs of “a crippled kid.” This memory of her experiences shows how she had been vulnerable to medical power, internalizing their objectification and taking on their “failure” as hers. Society expects disabled people to either get better or act as normal as possible, but not to insist on being a complex, whole human being. Though Wade refuses these expectations, including the imperative to “overcome” in *Sassy Girl*, she admits that for a time she had been “*living outside my body*” and coming to a place where she could “*move back in*” (Wade, *Sassy Girl*). Thus, her story acknowledges a time of estrangement, or fragmentation, from her body without relinquishing any complexity of the experience.

Estrangement from one's own body can occur during a humiliating practice known as “public stripping.” The concept of public stripping, coined in Lisa Blumberg's 1994 essay of the same name, is a familiar practice to disabled people, reproduced at times in disability culture (see Kabillio & Walloch, 2001). It is understood as displaying disabled bodies, usually wearing underwear, at the whim of a doctor and a few (or a few dozen) of his or her colleagues. “The individual is almost always examined without a hospital gown. Other procedures vary: she may be told to undress in the examining area; or he may be forced to disrobe with others in a hall,” Blumberg writes (1994, p. 74). It happens to both disabled children and adults. Blumberg notes that disabled children are unable to give or refuse consent for these examinations, which are often performed in a medical amphitheater in front of a medical audience. Many disabled people

understand that public stripping happened to them because she or he was “significantly deformed and handicapped” (Blumberg, 1994, p. 74). In other words, public stripping is a kind of medically legitimized freak show, objectifying the disabled person’s body and often violating consent and dignity.

Wade represents public stripping in *Sassy Girl* in a segment I call “Zeus.” Instead of agreeing to be her doctor’s “*show and tell*,” Wade reinvents a humiliating situation with humor.

Cheryl tells her audience:

*I remember the first time I learned to put on “the face” in the face of humiliation. I’m fourteen, doing time in a teaching hospital when the head Honcho of orthopedics, Zeus I believe he was called, drags me in front of an in-service to be his “show and tell”. The in-service: that’s where all the residents and interns gather to hear the great oracle speak. Without ever introducing me by name, Zeus grabs my leg and begins putting it through its paces and talks about it as if it’s not even attached to a body much less a teenage girl. “Notice how the ankle is partially fused and sublaxed, the tibia, fibia nibia is showing signs of early decalcification with muscle weakness of the...” (Wade, *Sassy Girl*)*

I interrupt this brilliant monologue to direct your attention to the way Wade defines public stripping in this scene. She mentions “all the residents and interns” who come to hear this orthopedic “god.” She implicates him in cold, impersonal objectification, where he never mentions her name or asks permission to touch or manipulate her body. She never gives consent to this as he plows ahead for his own agenda. Cheryl continues:

*I start my internal mantra: ‘Don’t you dare cry, Don’t you dare cry.’ All of a sudden I get this picture in my head: a really lousy ventriloquist and his dummy in a very bad act on Ed Sullivan. I start mimicking the doctor. [EXAGGERATED ARM AND HEAD MOVEMENTS] ‘Subluxed, Subluxed. Tibia, Fibia, nibia. It starts with a few [CHOKED SNICKERS] here and there, but in no time at all, spreads to the entire assembly. The entire assembly, laughing. One hundred and fifty worshippers laughing out loud. Everybody’s laughing. Everybody. (BEAT). Except Zeus. (Wade, *Sassy Girl*)*

In this scene, Cheryl reveals her first reaction to public stripping, and tells herself not to cry. Exposing her “internal mantra,” she also exposes her emotional response to humiliation. But then, she suddenly sees the humor in the situation, and quickly turns her shame and humiliation around. What makes it funny in performance is the way she transforms her hands and her face into believable shapes and movements like those of a ventriloquist’s dummy. Is this the face of humiliation she puts on? Plus, the whole concept is funny because of its audacity. In one quick shift, the fourteen-year-old character takes charge of this situation, recovers her power, and transforms shame into comedy.

“Zeus” is an important scene in *Sassy Girl* as Cheryl subverts the medical authority that has objectified her. First, when explaining that she was “*doing time in a teaching hospital*,” she equates and exposes the institutional, prison-like effects of being in a hospital. By calling the head doctor “Zeus,” the most powerful of the mythical Greek gods, Cheryl evokes both medical and god-like power while simultaneously overthrowing it. As she mimics Zeus’s words, she parodies the doctor, satirizes the authority of this public stripping moment, and makes obvious the objectification of her body (her leg), subtly reclaiming it as the “dummy.” She redefines “public stripping,” too, converting its destructive potential into subversive energy, even while still incarcerated in the hospital.

Wade’s ability to resist the oppression of medical authority and to challenge her own objectification appears effortless while in character. However, she admits it can be difficult to deal with in her daily life. She explains:

I don’t feel vulnerable [on stage] as I do when I go into a doctor’s office because I have the flu and all they want to do is look at my hands and talk about my deformities. It’s hard to feel empowered in those moments and sometimes I’m not. Sometimes I go right back to being that 10-year-old kid, put in a diaper and asked to parade around and have them take pictures of me, you know. (Wade, Interview 1)

Once again, she references public stripping, or being “taken down.” In this quote, Wade emphasizes the difficulty of fighting medical authority and objectification in the moment when it happens. She admits that she is sometimes vulnerable with doctors, but empowered on the stage. Her self-awareness and critical reflection allow her to express radical vulnerability in her performance piece. Yet she describes her own experience of public stripping here to offer a vivid image of when she felt extremely vulnerable in her life. As the quintessential humiliating or shame-filled moment, she sometimes relives that particular moment when similar traumas occur.

Objectification in medical settings often extends into the public sphere. Wade is acutely aware of the way people view her disabled body, objectify her, and create distance from what they see. She has learned how to use this to her advantage in her work. She explains:

I can't cozy people into who I am. I come out on stage, and you know if I'd go into a room people would sometimes gasp, because people are so uncomfortable with deformity. I had to figure out that I had to work with that or I was never going to have a way to do what I did. So I just toughed it up, and pushed it out there like I wasn't embarrassed by it. And when I was in the spotlight, I wasn't embarrassed by it. No one humiliates you when you're in the spotlight. (Wade, Interview 3)

Thus, being “in the spotlight” was a way for Wade to have power over the inevitable objectification by people who encounter her. Understanding how others see her, she is able to direct their gaze on stage. Without embarrassment, flaunting and exaggerating her differences, works as an intentional means to play on people's discomfort. She uses it to make *them* feel vulnerable. The radical tactic of “pushing it out there” purposefully works with objectification of her body. It also grabs their attention, controls how they interpret what they see, and encourages thinking about what she has to say while “in the spotlight.”

In “Hospital Litany” and “Zeus” Wade deals with early assaults to her identity by medical authorities and the institutionalized nature of hospitals. These assaults objectified her, and left her feeling devalued, humiliated, and alienated from her body. Although she had

difficulty with being diminished by such assaults in her daily life, she was able to use objectification to fight back in *Sassy Girl*. In addition, *Sassy Girl* shows how objectification can also violate wholeness, autonomy, and spirit, which she refuses to relinquish.

3. Violations

The term “violation” is Wade’s word to describe the disruption, infringement, and defilement she frequently experiences while out in the world. Objectification and violation seem to work together to keep disabled people distant and devalued. Unlike objectification, which can have a lasting influence, violations disrupt daily life. They often occur without warning: a rude stare, averted eyes, a random and obtrusive question, or a cruel laugh. Violations infringe upon personal space and break the rules of polite society. Wade is often powerless against violations in public, but controls them in *Sassy Girl*, refusing to accept anything less than full, complex humanity from her powerful position on the stage.

In her poem “I See You Staring,” Wade expresses the rage she often feels at being violated in the public sphere. She explains:

How many times have I been out in the world and people violate my privacy, violate my space by intruding upon me with ridiculous comments you know, like asking a question about my hands, or asking a question about my body that is obtrusive and violates my spirit, my soul, you know? (Wade, Interview 2)

Wade defines her concept of “violations,” calling these public acts intrusive, “ridiculous,” “obtrusive,” and violating to her “privacy,” “space,” “spirit,” and “soul.” She refers to comments that people make about her body, turning her body into an object of public curiosity. With violation, she is no longer an independent subject simply living her life, but made into a spectacle: a hypervisible and unwilling public marvel. In this way, the public sphere frequently becomes an impromptu “freak show” for Wade.

Like many visibly disabled people who spend any time being in the public, I know what she is talking about. I frequently receive blatant stares, because as a legally blind person using a guide dog, the assumption is that I cannot see them staring. I often hear rude, inappropriate remarks about my dog, my scars, and my ability to see. And I am often asked irrelevant questions related to my dog: her age, her name, or her training. All of these intrusions leave me feeling objectified and violated by people who would seemingly rather ignore me than intervene on my behalf. I am usually trying to ignore it all or let it slide – neither is easily done.

With “I See You Staring,” Cheryl fights back against the public wonder that society makes of her. Yet, before she launches into the poem, she invokes the “freak shows” of an earlier era. This scene in *Sassy Girl* follows a long period of restlessness and isolation, and her character is contemplating leaving her home to head “*out there*” for the first time. Cheryl says:

And I don't know which is worse, sitting here alone, listening to my brain rattle it's cage or going out there. Out there, the flipside of the nightmare, where I get to be the object of ardent curiosity. "Ooh, ah, lookie Mama." Smack. "How many times have I told you, don't point at Cripples, it's not polite."

'Step right up, folks; it's Cheryl the Cripple, the carnival geek. If you're really lucky, maybe she'll bite the head off of a live chicken for ya.' (Wade, *Sassy Girl*)

The scene demonstrates her awareness of being a curiosity. Cheryl momentarily personifies a curious child and her/his mother, who admonishes the child with a “smack” for pointing and looking at her. Then she becomes a carnival barker, inviting people to gawk at her, the “*carnival geek*,” intentionally taking on freak show history and practice. Wade performs this part of the scene with sarcastic anger. Her voice, face, and movements convey that she knows this “*flipside of the nightmare*,” or at least, she depicts her character as being familiar with it. But in this case, both the artist and the character are speaking together to tell an authentic story about anger, unwanted objectification, and the violation of staring.

In the next breath, Cheryl chides those who stare. Using vivid imagery to describe the objectification that coincides with the violation, Wade performs her biting poem about staring encounters, “I See You Staring.”

*I see you staring.
 Would you like to pluck my nubby fingers?
 Would you like to pluck them,
 tie them with velvet,
 place them in a vase with fresh water and aspirin,
 then watch to see if they bloom?*

I see you staring.

*I see you cringing.
 Would you like to stick your finger in my twisted spine?
 Would you like to stick your finger in,
 lift it out,
 then check to see if you can tell
 which way the wind blows?*

I see you cringing.

*I hear you laughing.
 Would you like to trace my scars?
 Would you like to trace them?
 Connecting all the lines and bumps and blotches
 to see if you can decipher the code
 and reveal their hidden message?*

I hear you laughing.

*I heard what you called me.
 Would you like to kiss my pain?
 Would you like to kiss it, lick it, suck it, hump it?
 Maybe you'd like to see if you can make it come.*

*I heard what you said.
 What can I say? (Wade, Sassy Girl)*

Images of her objectification like “my nubby fingers,” “my twisted spine,” “my scars,” and “my pain” are used to inflict verbal harm on the listener. She makes these body parts/objects extreme and perverse in order to express the violation she feels. Intensifying her emotional defilement

with words, she accuses “you” of being abusive, sexually aberrant, and of fetishizing her body. Thus, she indicts “you” of grotesque acts perpetrated on a body that is not supposed to talk back. But she does talk back as a way to angrily claim her subjectivity, reverse the objectification of the encounter, and resist the violations to her spirit and soul. This powerfully raw poem is delivered with Wade’s quivering voice, full of fierce but controlled emotional intensity. The poem speaks back for Cheryl, but also for disabled people who have experienced similar reactions.

Wade refuses to be a victim in *Sassy Girl*. With this poem, she can tell her audience that she is unwilling to participate in her own abuse. “I’m not gonna get you off by being your little cripple whore here,” is how she puts it (Wade, Interview 2). The performance stage gives her the space to express her rage at the onslaught of such violations from her daily life. Wade explains:

It’s like what I call my vent poem, my rant poem about [violations]...And I’m supposed to politely explain things to them when I want to spit in their face, or kick them in the ass, or get a gun and blow their bloody heads off. (Interview 2)

Although Wade would never actually use a gun, her poem is like a gunshot with a silencer, annihilating its target yet protecting the shooter from her own implosion. The performance allows her to “vent” about these violations. Disabled people are expected to “politely explain,” as she points out, but Wade uses the poem to “spit in their face” in a figurative way. The poem and performance stage provide her vicious and vulgar sense of humor a means to “blow their bloody heads off” with raging words.

Yet, using rage in this poem delivers a particular idea from Wade’s life. She positions “I See You Staring” intentionally within the narrative of *Sassy Girl*. She explains:

In order to move on from being incredibly oppressed by your body, hating your body, hating what it represents in the world, feeling like a freak, an isolated freak monster, you have to deal with the rage you feel about that. And so I thought I found a really good

nasty piece that spits out the rage that is under depression. It is the underbelly of depression. (Wade, Interview 2)

Playing the “underbelly of depression” moves Wade’s character from isolated and depressed to empowered, and eventually able to accept her body. And this allows her audience to move with her character along this emotional spectrum. Furthermore, this quote speaks to the cause of her rage. “Hating her body” refers to her own feelings, but also to the ways that dominant culture and society construct and preserve this hatred. She is saying that if society can label you as a “freak monster,” or imply it with cultural imagery and objectifying stares, then you can also surmise this label as your own. In this way, her rage connects self-perceptions with social perceptions, and both are socially and culturally constructed, and often internalized.

Nevertheless, Wade refuses to accept her objectification and the violation that comes with it. She recognizes the complexity, absurdity, and vulgarity of “you“ staring, and she wants you to understand the damage “you” inflict.

Violations take an emotional toll. Wade reflects on the challenge of maintaining a sense of worthiness in the face of violation. I asked her during our second interview to talk about how staring and obtrusive questions affect her.

There’s definitely the aspect of, you know, the way that we survive the violation or the injury they inflict upon us. If we were to feel it completely (she says this slowly) in the moment and allow ourselves to sense that in the moment, we would be dead in our tracks. We would not move. (Wade, Interview 2)

Wade thoughtfully considers her response here, and comes up with a provocative answer. Fully experiencing violation at the moment it occurs would cause her (and us, since she is referring to disabled people) to be “dead in our tracks.” She seems to understand the psychological and emotional damage, and how distancing oneself from these feelings is a way to cope. Surviving

violations means retreating from the powerful emotions they cause in the moment. For Wade, this means fighting back.

[You do] whatever you need to do to turn the injury into a place of some sense of pulling your spine back up into your body...So instead we make the joke...flip the bird...you stick out your tongue, you tell them to fuck off. (Wade, Interview 2)

“Pulling your spine back up” with strategies that fight against the full blow of the violation is not going to alleviate the damage, but might help. Feeling the full impact of devaluation, discrimination, and social isolation could stop us “dead in our tracks” unless we deploy quick anger and retaliation. Such strategies are better than accepting the violation, and allowing it sink in. Maintaining dignity, however necessary, only delays the pain of the violation in the moment. Wade calls this a “dual existence” for disabled people.

It takes its toll, I mean I do think it eats your bones; you know it impacts very negatively on your body to have to play some kind of false reality. It adds to your own oppression to some extent at the same time it allows you to survive. It’s a very dual existence for disabled people, very complicated. The very things you have to do to survive help harm you at the same time: psychologically, physically, spiritually, and yet you have to do it to survive otherwise you would just be a puddle. (Wade, Interview 2)

Playing a “false reality” is about denying your emotional hurt in favor of anger or something else, as a way to fight back. And the toll refers to how the hurt comes out in other ways, such as pain in your body. This is the damage she is talking about: damage that comes from denying all of one’s emotions because of the complex social environment disabled people inhabit.

Sometimes we disengage from certain moments in order to survive them, which further separates us from society and our own bodies. Thus, disengaging adds to our oppression, like delayed damage to our bodies does.

By bringing out objectification and violation, Wade illuminates the complex reality disabled people experience. She complicates these forms of oppression by demonstrating their multifaceted effects. Objectification, often caused by medical authority, can create a sense of

alienation and estrangement from body and self. Violations devalue us, and can cause anger and harm us in the moment. Surviving both objectification and violation often comes with a price – they cause further separation, further distance, and disconnection from the rest of society. *Sassy Girl* depicts how Wade’s character addresses these injustices, and reveals how Wade deals with them in her daily life.

F. **Grief, Loss, and Disconnection**

1. **Introduction to this section**

In this section, I discuss an important theme in Wade’s performance and in our interviews, which encompasses two aspects. First, Wade explores the painful process of bodily changes and losses along with the lengthy process of coming to terms with those losses. In *Sassy Girl*, Wade places this process into an eight-minute portion of the play that she calls the “depression sequence.” Second, a theme emerges from the data that goes beyond the emotional and psychological pain of physical losses: the grief of disconnection. This kind of grief is also caused by disability, or rather, society’s unwillingness to accept disability as a fundamental part of human experience. Wade touches on society’s fear and refusal to create meaningful connections between disabled and nondisabled people. All of the losses she describes are profound. Her willingness to openly grieve these losses is an act of resistance towards the dominant culture’s mandate that disabled people express cheerful adjustment to their physical, emotional, and social situations.

2. **“The depression sequence”: grieving the body**

As an artist, Wade tells a complicated story that includes her body and all of its inherent contradictions. She constructs an empowered disabled woman character who grieves for

her physical and other losses, and incorporates grief, loss, and depression in a significant way in *Sassy Girl*. She says:

The grief thing – I guess that there was obviously a point when I understood that, when I wrote *Sassy Girl*; that’s what that whole thing with the little girl across the street is all about. I never had that in an epiphany moment like that, which is why I felt the need to create it. (Wade, Interview 3)

The story of the little girl in the sprinkler is key to her depression sequence, and according to Wade, one of the best “created fictions” she ever wrote or performed. In *Sassy Girl*, this piece follows the angry poem “I See You Staring,” which opens the depression sequence. Wade describes the sequence this way:

It became a very powerful, and for me one of my favorite moments in the show is the depression sequence that moves from rage to depression and she is able to release the sorrow of what she’s lost, and [move] to the joy, the childish joy of being in the world. (Wade, Interview 2)

Wade’s definition for the “depression sequence” begins with “I See You Staring,” then moves into the scene about the little girl in the sprinkler. While Wade never explicitly defined the sequence to include anger, denial, bargaining, depression, and acceptance, these five stages of grief (see Kubler-Ross, 1969) seem to coincide with what is happening during the depression sequence. The scene about the little girl hints at that “childish joy” that was lost, and a sense of denial that it will not return in the same way. With a breath and a beat following “I See You Staring,” Cheryl watches a little girl playing in a sprinkler across the street from her. Her anger subsides, and the performance softens as she says:

*One day I'm sitting on the front porch. I'm watching the little girl across the street. She's running through the sprinklers. I love watching her. She's delightful, the way she dances with the spray. I can't take my eyes off of her. Her legs. The way they move. Her legs. They're my legs. They're my legs. But I can't remember having legs like that. I know I did. We have a whole album full of pictures. There's me in my black patent leather tap shoes "Tea for Twoing" in the third grade talent show. Me, high-kicking in the chorus line of "Jack and the Beanstalk". Me, in the double Dutch tournament—I came in third. I can't remember those legs. I can't remember. Legs. Remember? Legs. Remember. Legs. (Wade, *Sassy Girl*)*

As a performer, the transition from rage to sadness is effortless. Her grief at losing her ability to use her legs in the same way as this little girl deepens to become a mournful, bittersweet nostalgia for the abilities she used to have. To me, this nostalgia reflects a type of denial – a wistful longing for abilities lost, but also imploring her legs to “remember” and to regain that ability. Cheryl touches and talks to her legs, moving her audience with her into her desire to restore them.

Although many of the scenes in the play are based on Wade's experiences, this one is completely made up. It did not happen. Wade crafted this scene to explore her process of grief as an important aspect of her personal journey to empowerment. She explains:

To get across that you have to mourn the loss of being able-bodied, and you can't really go on as a disabled person, living in that body and embracing any kind of experience that you have, if you can't truly mourn the loss of what you left behind...And so I created in *Sassy Girl*, where I am sitting at home very isolated, watching a little girl running through sprinklers across the street and [my character] suddenly sees the joy of life that she could not have at present...it's a very very powerful, very emotional, and probably for me...the best thing I ever wrote. For a theatrical piece, [it is] the thing I'm most proud of...a really, really a created fiction that told something I felt was essential and that I had to go through. But I did it in a way that made the audience kind of weep, and kind of go through it and be able to go to the next level of the story with me. (Wade, Interview 2)

Most people understand the sorrow and regret expressed in that scene. While not every disabled person would agree with Wade about the need to grieve physical and functional losses, it is how she wanted to convey her journey from able to disabled. Here again, Wade risks alienating her community by discussing physical loss and the negative emotions around bodily changes and

functional losses. This was radical for the time she wrote and performed it because it shows a “negative” side to disability. This portrayal decidedly moves away from the political goals of the disability rights movement of framing disability in a positive light.

Additionally, Wade chooses to privilege the messier emotional and psychological aspects of impairment and disability alongside the social and cultural aspects. With this scene about denial and wistful desire she is able to touch her audience in a deep way. While most of her audience may not be able to relate to her character directly, some of them will, and others will recognize the pain of loss and the very human longing to get back what is lost.

Following the little girl in the sprinkler, Cheryl asks her audience not to take their own bodies and abilities for granted. In her next poem, she asks, “*Do you walk?*” Here’s a slice of that poem:

*Do you walk?
 ‘til the balls of your feet blister
 Do you walk
 Do you dance
 Do you dance on tabletops
 Do you dance on tabletops in spike heeled-boots till dawn
 Do you dance till dawn?
 When you limp home
 your heel cords on blissful fire
 Do you walk (Wade, Sassy Girl)*

“*Do you walk?*” mourns not only the phenomenological experience of walking and moving on two legs, but also freedom of movement in an able-bodied environment. It relies on free-spirited images, like “*dancing on tabletops*” as well as pictures of the built environment such as “*as you step lightly on grass cement/run upstairs downstairs jump over curbs/Do you walk?*” (Wade, *Sassy Girl*). She spends much of the poem asking the listener to consider the sensations in their legs as they walk, run, jump, and dance: sensations that she will no longer experience. I see this poem as a kind of bargaining cry. In some ways, the speaker is asking herself to remember the

sensations that she no longer has, but I think primarily she is asking them to be grateful for what they have. It is a poem along the continuum of the five stages of grief because it signals that the speaker may have taken her body for granted, remembering aloud so that if and when her abilities return, she will not squander them. It also reads like a warning to others not to do what she did, and to enjoy the sensations and delights of walking, dancing, running, and jumping. This poem fits inside Wade's depression sequence and indicates the depth of her sorrows, her thoughts, and her anguish for her loss.

Recalling and mourning these things are part of her longer process that ends in reclaiming movement and freedom in a different yet "interesting" way. The depression sequence concludes with acceptance, when Cheryl describes her experience of coming back into her body and enjoying how it feels.

Sorrow fills up this space inside me that's been occupied for far too long by, "Don't worry, everything's gonna be just fine". I begin to feel this relaxation, this ease in my body I have not felt in years. It's like I've been living outside my body and finally, finally I get to move back in. And I notice my body in the chair. It's not all bad. And I notice my feet on the metal of the pedals. And that's not all bad. And I notice my butt on the cushion of the chair. Not bad. And I can feel the rhythm of the tires, the rhythm, the rhythm. Not bad. And, no it's not like walking. But it is...interesting. (Wade, *Sassy Girl*, emphasis original)

As this sequence closes, Cheryl mirrors and reformulates common assumptions about disability – we are sad but act cheerful, or life is not enjoyable in a wheelchair—and argues for a new way of being. She gestures back to the fragmented identity caused by medical authority: "*I've been living outside my body and finally, finally I get to move back in.*" and with this simple statement, she picks up the pieces of her disintegrated identity, reconstructing them to accept and embrace the body and identity she now has.

To be clear, Wade is not sad that she is disabled. By lamenting her physical losses through her autobiographical character, she can take her audience through a very real and time-

consuming process from her experience, in a few short minutes, without revealing everything about her life. She does this with the fiction of the little girl in the sprinkler, which helps Wade to move her audience forward in the story. Along the way, she grieves lost abilities and the joy of movement, finally reclaiming them and redefining them for herself and her audience. Each step appears to represent a Wade-esque version of the five stages of grief.

Unlike typical loss narratives, Wade complicates her grief story, deepening and expanding it with radical vulnerability. She expresses rage and despair for the loss of connection with the dominant world, which complicates her loss while also excavating its roots. *Sassy Girl* reveals that cultural and societal barriers are just as pervasive and limiting as physical or environmental ones, and that loss is multi-layered rather than simply emotional. Wade's work focuses on the multiple layers of grief that permeate all of these losses, including the profound loss and disconnection between disabled people and the able-bodied majority.

3. **Grieving disconnection**

Sassy Girl reveals a profound loss beyond the body. Our conversations indicated how the loss of function in Wade's body was equally as painful and emotionally difficult as the socially and culturally constructed impact of disability to her life. Violations, objectification, and grief along with emotional consequences, are not simply for the individual to bear. Loss can also be placed on the shoulders of a society that refuses to accept disability as human experience. Wade describes both the terror of experiencing this combination of losses, and the strong desire not to feel it at all.

I think I've always been very conscious of how frightening it is to feel fully the loss of what happened – of all of this—and why there is such a strong drive to numb it and deaden it. Because if you live it – and I'll be very honest with you, Terri – there's a part of me that I wish I could just numb the shit out of myself with opiates, to just not have to feel it. (Wade, Interview 3)

“All of this” that she wants to “numb the shit out of” are losses in physical function, loss of power, dignity, social status, and the emotional tolls of failure, abuse, and oppression. So many losses, even if they occurred over a long period of time, create excruciating pain. Not only does she feel all of this, she was told she needed to “stuff it.”

My mother, who when I would cry would say, “Why dwell on it. Crying won’t help.” But it does... Screaming sometimes helps... whatever the hell you have to do to let it out of your body so it doesn’t eat your goddam bones and your guts, and eventually destroys you... Internalized rage eventually becomes internalized hatred and then you want to kill yourself... So yeah, it can have enormously serious consequences to constantly stuff it. And that is of course the message; we’re supposed to stuff it because if we express it, it makes somebody aware that they are part of the problem. People don’t want to think of themselves that way. It’s like, how dare you make it harder for me. You don’t think I know how hard it is already? (Wade, Interview 3)

Wade explains how important it is to express grief. Yet, disabled people are told, either directly, in social relations, or indirectly, by cultural mandates, to stuff it. By expressing our pain, it becomes a form of resistance. And at the same time, expressing grief has a detrimental effect on others in our lives, reminding them of their role in our pain, and exacerbating the loss of connection with the world. Thus, she is attaching grief not only to physical losses, but also to interpersonal and social losses: our exclusion and disconnection from the dominant society and culture.

In *Sassy Girl*, Wade touches on her grief over disconnection when Cheryl tells the audience about her parents’ new house. I talk about this scene in “Disability Consciousness” because it relates the character’s recognition of her invisibility to her parents, and to the world. Her awareness of the invisibility she experiences also recognizes invisibility of disabled people, and the enforced invisibility and isolation brought on by an inaccessible house. Her awareness also suggests a profound sense of loss: her disconnection from people in her life and from the world, and the disconnection of disabled people from everyone else. Cheryl begins to understand

how her disabled body, her social status, and her life is now shaped by disability. In the scene, she refrains from blaming her parents for the pain this realization causes, even though they “*can’t bear to look at me*” (Wade, *Sassy Girl*). In a sense, this is a choice to hold in her grief, illustrating her point above that blaming them would only make her parents feel bad. She chooses instead to hate the house. I emphasize this scene to demonstrate the depth of her grief and how she generalizes it beyond her parents. This is a fundamental and pervasive loss, a radical loss, which may require sweeping social and cultural change.

Sassy Girl is Wade’s attempt to intensely connect with the world by fully expressing herself. Yet, throughout the play, Wade’s self-expression is more complex and multifaceted than simple self-interest. Her willingness to speak in such a radically vulnerable way through her autobiographical character also speaks to and for disabled people who engage with her work. Even the act of expressing grief onstage is an act of empowerment and resistance. Wade says:

Allowing myself to just wade deeply, which I don’t get to do because of my disability because of the treatment in the world. And they’re connected; they’re not removed from each other. There were lots of little moments of understanding, then of pushing it away... So I think I took that license and that feeling that I couldn’t express the grief, that I couldn’t express the terror at times, and then that I couldn’t include vicious humor, which is one of the things that I love to do. When I did that piece “I See You Staring” that’s a piece about grief. (Interview 3)

Wade ties it all together, here: the rage, sadness, grief, and fear. She is saying that not expressing her grief is part of the mandate of being disabled, but she gave herself permission, or “license,” and then it became an act of resistance, particularly the rage and “vicious humor” of “I See You Staring.” It is an act of reclaiming full humanity – body, emotions, dignity, and value. At the time, her community and culture argued that admitting the pain of loss to nondisabled society assumes the desire to be able-bodied. Wade admits: “I’m not going to say better; in some ways it’s an easier life to not have to suffer...it’s an easier life to not have pain. It’s an easier way to

[be in] the world in a body that does not have to suffer,” she said in our third interview. Yet, the desire not to suffer is not the same as the desire for an able-body. *Sassy Girl* absolutely claims disability for its main character, albeit a complex and distinctive identity. Expressing grief, or even wanting an easier life, complicates this identity further, and neither Wade nor her character claims disability identity without complicating it.

Wade’s attention to grief offers a new dimension to a typically neglected aspect of disability experience. Although not all disabled people grieve their lost abilities, Wade’s illumination of disconnection with the world provides an important yet under-examined barrier to our struggle for empowerment, equality, and opportunities. Complex social, cultural, and physical barriers have been set up by dominant society to keep disabled people distant from their broader human family. This could be what Wade calls “internalized rage” that turns into “internalized hatred” and separates disabled people from humanity writ large. These barriers, or social forces of exclusion and separation, must be examined, even grieved, if disabled and nondisabled people are to move our collective story forward.

G. **“Structure”: Transforming Experiences Into Art**

1. **Introduction to this section**

Sassy Girl potentially constructs powerful new meanings of disability for those who encounter it, while Wade reconstructs disability for herself. This section focuses on how she first constructs her story by writing and editing her experiences in order to obtain her artistic goals. Wade’s term for this process is “structure,” which for her means to give form to something that previously had no form. Wade explains:

It’s like giving structure to something that had no structure in my life. The same with disability – I had no control, I had no power: I had no structure. So when I write a poem, I get to give it its structure, I get to give its boundaries. I get to give it its limits and that’s

in my power, so that gives me so much more than someone who can't do that. (Interview 3)

Giving her experiences “structure,” she uses the term “disability” to include impairment and to claim control over how to remember the story of her life and body. Wade admits that writing and poetry are in her power, giving shape and structure, boundaries and limits to the unstructured experiences and events of her life. In this section, I am interested in this power, her choice to wield it, and the way that she shapes her story.

Controlling the shape and borders of her autobiographical story allows Wade to gain perspective and leads to transformation. This power to structure her personal story with disability calls up the first line of *Sassy Girl*: “I’m trickster coyote in a gnarly bone suit.” She is “trickster,” a mischievous boundary crosser and cultural creator, which I discuss in “Disability Culture.” But her trickster wears a “gnarly bone suit” and the story she tells is about that – her deformed and disabled body. Looking closely at the meanings of “gnarly” reveals more about the story: dangerous, challenging, and according to the Urban Dictionary online, “beyond radical” (www.urbandictionary.com, 2013). In this way, she clues her audience in from the beginning that this work will be unlike anything they might expect.

Even the title of her work, *Sassy Girl: Memoirs of a Poster Child Gone Awry*, is indicative of an unexpected and resistant disability narrative. Creating the “sassy” girl allows her character to speak her mind and talk back to social and cultural directives about disability. “This is a piece [about] a little crippled girl with a gimpy leg, that she can wear her red shoes, and that’s what that was about for me” (Wade, Interview 3). The “red shoes” represent showing off, being visible instead of in the background. Wade’s story is complex, often difficult, and radically resistant to expected narratives available to disabled people.

2. **Re-structuring shame**

Giving structure to something “changes...how you relate to your own experiences,” Wade said. For her, the first step in providing structure is writing, but Wade was not able to write about disability at first. Instead, her writing begins with the shame and pain of sexual abuse, which opens her up to writing about disability. Wade remembers that when she began writing about the abuse, she barely had the words for it. All she had was excruciating pain.

I just thought there was something in me that was so dirty and so shameful that of course it pushed my father to do those things to me. After all, he’s my father. So there was always something hideous about me sexually. (Wade, Interview 3)

The “something in me” is at the very core of shame, and she felt it happened to her because something was inherently “dirty or shameful” in her. These feelings are extremely painful, and according to Brené Brown, shame can hurt – and be as difficult to describe – as physical pain (2012).

Brené Brown has written extensively about shame, which she defines as “an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging” (Brown, 2012, p. 69). This definition comes from Brown’s qualitative research conducted about shame and shame resilience. Brown’s concept of shame extends beyond individual psychology as a “psycho-social-cultural construct” (2007, p. 45). Shame includes an individual emotional component, and is experienced interpersonally in social contexts. Culturally, shame also involves our relationship to “the very prevalent role of cultural expectations” and our own and others’ perceptions of how we are meeting them (Brown, 2007, p. 45). Brown’s work on shame offers an explanation that encompasses Wade’s experiences with both sexual abuse and disability. Disability often creates feelings of being unworthy of acceptance and belonging, particularly in social and cultural contexts. As a disabled woman, I

am frequently confronted by the cultural expectations of beauty, health, and ability that I cannot meet. My interviews with Wade often brought similar experiences to the fore from her life, and discussions of how she translates them to her work.

Writing her experiences of sexual abuse was a creative seed, which “helped me come to terms with a lot of things in my life and to catch the pits that I fall into faster” (Wade, Interview 3). Such “pits” can be the result of unexamined and unspoken shame. “Anything you do that counteracts [shame] can transform you in ways that you don’t even notice,” she said during our second interview. Writing was a way to understand and express shame, counter it and transform its power. And it changed her relationship to her experiences of sexual abuse.

The connection of emotional pain with physical pain must have clicked in Wade’s mind, because those feelings are what began to change when she started to write her story of sexual abuse. Additionally, the emotional pain of abuse is intricately tied with the onset of her physical pain from juvenile arthritis. Many posit that autoimmune diseases like juvenile rheumatoid arthritis may lie dormant in the body as a genetic marker until a stressful event triggers it. Wade explains:

The terror of [sexual abuse], in my belief, was what destroyed my immune system. You know, it was the fear of being exposed, and the internal mantra that I would say all the time was that it didn’t really happen. I would be crazy [if] this [abuse] was the truth. (Interview 3)

To be clear, Wade believes she would have had rheumatoid arthritis regardless, but in her mind, the stress of the abuse was a possible trigger that accelerated her illness. “About the time I began to really get ill from it was when I began to have an awareness of what was going on and how wrong it was” she said in our final interview. Her awareness of what was happening to her triggered even more stress and even more pain.

Wade's experiences of sexual abuse influence how she writes and understands her disability experiences, helping her become a deeper writer. She explains:

What I began to notice when I would write a poem...something changed in me about the way I felt about not telling what [my father] did...I think I really had a breakthrough where I started to become a really, really deep writer when I wrote about the sexual abuse because that is what opened me up to disability...I had to write about the sexual abuse first because it happened before the disability...And the power of letting go and starting to work with that shame and being abused, and owning that back and telling the story the way I felt it should be told, those were, quite frankly, some of my best poems ever.
(Wade, Interview 3)

Wade was able to understand disability shame as she began to "own" her story about sexual abuse. Brown notes that understanding shame, and having critical awareness about it, are two of the four elements of shame resilience. These elements are important in attaining the final two elements: "owning and sharing your story" and "speaking shame" (Brown, 2012, p. 71). These last two shame resilient elements are abundant in *Sassy Girl* with regard to disability, while sexual abuse functions beneath the surface of the narrative as subtext. In my discussion of "*Cripple jokes; Dial -A -Comic, and the 'I ain't a number' blues*" in the section on "Disability Consciousness," Wade mixes the fear and shame of sexual abuse at the hands of a doctor within a feminist disability rant. I am repeating this excerpt from that poem here:

*I want my All-American-Born-In-The-U.S.A. dream
And I want it fat and sassy,
Not battered and abused by the latest Dr. Fix-it
Who cops a cheap feel every chance he gets
So I'm forced to edge backwards down the alley,
Clutching my skirt to my knees. (Wade, Sassy Girl)*

This excerpt demonstrates her resilience. With the onset of chronic illness and disability following and intensifying the trauma of sexual abuse, Wade intensifies the emotional and physical pain she creates in this poem – "*In nightmares/cold white hands/Rip feathers from my wings, Crack fragile bones*" (*Sassy Girl*). Wade is able to approach disability and reconfigure it

as part of an integrated experience that emerges after expressing the shame of sexual abuse. In this case, she is able to neatly tie both together, owning her whole story and speaking her shame. The more she talks about shame, the less power it has, and the more she gains power over it.

Shame resilience is about connection. Brown's work teaches how to deal with shame as it happens in the moment in order to maintain our connections with others. Yet what Wade does with her piece is to portray shame resilience over past experiences that she performs in the moment. Like vulnerability, Wade is not experiencing shame in the moment of her performance. Rather, she is demonstrating her resilience over past painful times through compassion towards her character, critical awareness of her experiences, sharing her story, and wrapping her shame up in clever language to disempower it. Wade restructures those experiences for herself and her audience, allowing them to see her strength, through past vulnerability, and her resilience in the performative present. In this way, she is able to connect to her audience on a deep level.

3. **Re-purposing language**

One of the ways Wade restructures her experiences is by transforming the language she uses in *Sassy Girl*. She understood the power that vibrant language could have during her years as an activist with the disability rights movement. At that time, Wade avoided political language. If she could get to a microphone and recite "*I'm trickster coyote in a gnarly-bone suit*," she could get people's attention: she had a hook. She explains:

I've always felt that poetic language and literary language has an incredible ability to cut through the crap that people carry with them, because it's such a vibrant language, and political language is such a dead language. So I think it's where the art can really empower the movement. (Wade, Interview 1)

Thus, the artistry of the language she chooses gives her the ability to connect with audiences.

This kind of language had power to influence the movement, but the work she did as an activist

may have also empowered her as an artist. Wade is able to practice her attention grabbing poetic language and hone its effect, whether as an activist or an artist.

Wade's vibrant language choices can be provocative and disruptive. For example, while performing *Sassy Girl* in San Francisco in the 1990's, Wade remembers that an audience member sought her out after the show. The wheelchair-using patron probably wanted to congratulate her and gush about how much she liked the performance, or so Wade imagined. Instead, this woman could not get over her use of the word "cripple." "All she hooked on was that word 'cripple' and I'm like, because that word has been used like 'nigger' for so many people...It's not a word like nigger to me" (Wade, Interview 3). As such, Wade reclaims the word "cripple" for herself and for her community, and gives it a new empowered connotation.

I guess I just thought people understood the way I was playing with language, and I guess people didn't. I like strong words, I like words that tell you what it is; gimp, cripple; those are real words to me. (Wade, Interview 3)

Thus, Wade reclaims and repurposes the hurtful language that has been used to keep disabled people down. She changes the shape and meanings of these words, challenging her audiences to reinterpret the old, harsh words in new, descriptive ways.

Along with her provocative language choices, Wade is also fearless in making her body and her emotions fundamental to *Sassy Girl*. She puts it this way:

There is something about being able to use something you've always loved most in the world, which was language, in a way that allows you to tell the things that are most shamed – your body, the body of experience – in a way that has nothing to do with you. You cannot not be transformed by that in some way. That's what I mean by structure: the process of daily work, which I did as a writer. (Wade, Interview 3)

Writing her story "in a way that has nothing to do with you" reveals the perspective that Wade was able to gain while putting structure to her life. She created a character based on her, but that was not exactly Wade. Getting distance from her experiences in this way is transformative. It

transforms “what is most shamed” into a powerful story, which transforms how she sees herself.

She explains:

I think it’s like, for me, I think it’s a great gift that I can write, because at least psychologically, I get to give it a shape that’s of my doing, not it; not this random assault... Doing autobiographical art is always a very interesting experience for the person doing it. I always figured if I played the sassy girl and the woman with juice, the more I played her the more I would become her and that was true. (Wade, Interview 3)

Creating the character “Cheryl,” the sassy girl or the woman with juice, transformed the woman Cheryl Wade. Thus, giving her autobiography a shape, other than what she calls a “random assault,” gives her power and control over her experiences that ultimately converts her into the sassy girl. Plus, this power changes how she represents her body and experiences, which challenges and re-shapes disability beyond the subject of the story, and which re-imagines how disability is represented.

4. **Re-shaping narrative**

Sassy Girl not only re-interprets hurtful words and employs challenging language, it also refuses typical narratives about disability. It is a chronological story, but Wade’s narrative resists a linear or “normal” trajectory that takes the protagonist from tragic heroine to supercrip. Instead, she constructs her narrative in a way that shows the constant shifting between empowerment and diminishment, struggle and success, or shame and pride. Emotional, physical, and psychological struggles are continuously intermixed with empowerment, pride, or other positives. Often these contradictory feelings are experienced at the same time within a single poem or scene. This approach fits with her philosophy of life: “Like everything else, there’s not a constant” (Wade, Interview 3). Her state of being is constantly shifting: there is nothing that remains constant or stationary. And this attitude offers unique and complex perspectives about

disability. Writing *Sassy Girl* allowed Wade to bring her complicated reality to life, while also giving it shape.

Wade finds most disability stories unrealistic and unacceptable. “I think what has disempowered me is, and continues to do so, is the apology that some disabled people make for being in the spotlight, when they feel the need to tell an inspirational cripple story” she said (Wade, Interview 3). Telling an inspirational tale seems to stem from the pervasive cultural and social expectations placed upon disabled people to conform to media stereotypes of disability. Avoiding the “inspirational cripple story” requires resistance to expectations to conform, as well as critical thought about how to re-construct disability narratives. For Wade, this means transforming ongoing stories about her disabled body like “freak” and “monster.” *Sassy Girl* reflects how she challenges such ideas and does not feel the need to apologize nor conform.

Wade refuses to conform to social conventions like staring. According to Garland - Thomson, Wade invokes “freak” and “monster” purposefully in her performance to “fuse the cultural authority wielded by the high art of poetry with the extravagance of freak show display” (2009, p. 136). Garland-Thomson is specifically interested in Wade’s performance of “My Hands” because it invites audiences to stare at her deformed hands, and Wade wields the authority of artistic control over how they stare. Through this poem and staring interaction, Wade “has guided her audience to see her hands as she experiences them” (Garland-Thomson, 2009, p. 137). Additionally, Wade challenges how the staring encounter plays out in *Sassy Girl* with the poem “I See You Staring.” In this piece, Wade confronts those who stare at her and the violation of that encounter. Staring “make[s] them feel humiliated by what their body is doing. That’s what happens when you violate those norms of staring and questioning,” Wade said of this poem in our third interview. The violation of staring causes self-consciousness and humiliation, and

confronting this encounter allows Wade to defy a socially prescribed boundary that usually must be silently accepted. Yet in both “My Hands” and “I See You Staring” she refuses to acknowledge or submit to the so-called legitimate power of able-bodiedness. In the process, she claims power and dignity typically disavowed by dominant cultural values. Taking her power back onstage allows her audience, her community and her culture to follow her lead.

Along with defying culturally and socially prescribed roles, Wade shapes the narrative of *Sassy Girl* with how she represents the disabled body. “How do you write if you can’t write the most important thing in your life: your body and the story that your body forces you to live?” she asked in our third interview. Writing was essential for telling her body’s story and its many confusing elements.

Well, the writing is key always. When I began to write about the experience of my body, I really started to feel a sense of, I don’t know how to say it, but I felt like if I could write it, I could write an amazing story that looked better than my life did, I could figure out a way to put some sense into this. (Wade, Interview 2)

Through writing *Sassy Girl*, Wade is able to not only make sense of what was going on with her body, but also to rearticulate it in her own words. She shaped her story with the particularities of her body.

Drawing on the story of her body, Wade conveys imaginative and disruptive disability paradigms. In the poem “I am Not One of The,” Wade represents disability with colorful, powerful, and complex imagery. She remembers that this poem came from a series of images she had collected in her notebooks.

I’m not this goddam euphemism. I’m this, I’m this, I’m this, I’m this, I’m this! You know, all these live, vibrant, deep, rich, ugly, beautiful things, but I am not this crappy little euphemism. I will not be euphemized into submission. That was always one of my favorite lines. I hate euphemisms! Hate them! I would rather be called a cripple than a goddam able-disabled person, whatever the hell that is... “Abled” is the worst... It’s crazy the way people want to denude the language with some idiotic idea that that’s going to change anything in the world. (Wade, Interview 2)

Again, Wade insists on self-definition. Her passionate unwillingness to accept the “crappy little euphemisms” placed onto her and onto other disabled people is palpable. To refuse euphemisms is to refuse ableism from a society and culture that wants to feel better about disability.

Reclaiming the descriptive language of disability reveals who she is. She creates new, meaningful, and more realistic paradigms of disability that follow her lead: rich, vibrant, deep, beautiful, and ugly.

These paradigms dismiss the euphemistic limitations placed onto disabled people: patronized, marginalized, and oppressed beneath a vaguely more positive label.

Differently abled; yeah, I’m differently abled [from] Kristi Yamaguchi! What does that mean? You know what I mean? It says nothing... We’re all differently abled. (Wade, Interview 3)

With the images she claims in “I am Not One of The,” Wade replaces euphemistic ideas with penetrating, jarring, and often dangerous re-imaginings. Here is her poem from *Sassy Girl*:

I am not one of the physically challenged—

*I’m a sock in the eye with gnarled fist
I’m a French kiss with a cleft tongue
I’m orthopedic shoes sewn on a last of your fears*

I am not one of the differently abled—

*I’m an epitaph for a million imperfect babies left untreated
I’m an ikon carved from bones in a mass grave at Tiergarten, Germany
I’m withered legs hidden with a blanket*

I am not one of the able disabled—

*I’m a black panther with green eyes and scars like a picket fence
I’m pink lace panties teasing a stub of milk white thigh
I’m the Evil Eye*

*I’m the first cell divided
I’m mud that talks
I’m Eve I’m Kali*

I'm the Mountain That Never Moves
I've been forever I'll be here forever
I'm the Gimp
I'm the Cripple
I'm the Crazy Lady

I'm the Woman with Juice! (Wade, Sassy Girl)

Using images derived from her embodied experience, Wade claims her identity with disabled people in this poem. In the first several lines, Wade “draws on the archetypes of transgressive, powerful, and threatening quasi-female forms,” according to Garland-Thomson in her 2007 essay “Shape Structures Story: Fresh and Feisty Stories about Disability” (p. 117). This powerful imagery, “interlaced with stereotypical disability images” (Garland-Thomson, 2007, p. 117), evokes both specific “crip” and universal themes. Each line challenges euphemisms with an unusual, dangerous, but familiar disabled, feminine version of her character. Wade sets up contrast and interconnection between what has been projected onto disabled bodies as familiar stereotypes and repurposes these stereotypes as more realistic and complex icons of disability identity.

The poem is thus a character study and a strong assertion of lyric emotion, both of which depend upon speaker and audience sharing some understanding of the large narratives alluded to by ‘a sock in the eye with gnarled fist’ and the other ‘I am’ statements. (Garland-Thomson, 2007, p. 117)

In other words, Wade creates a hybrid of broader disabled and feminine narratives with descriptive identity assertions that are meaningful to the performer and the community of disabled people in her audience.

The identity claimed in the poem is plural, connecting the speaker to her community, and multi-layered. For example, in the second verse, she is not one of “the differently abled” yet she connects with and claims painful disability history. “*I'm an ikon carved from bones in a mass grave at Tiergarten, Germany*” connects her to eugenics history and victims from that period

killed for being disabled. This reference to Nazi Germany is “the broadest allusion to communal identity” (Garland-Thomson (2007, p. 118). But in the next line, she becomes “*withered legs hidden with a blanket,*” a common, nameless, and invisible disability image. By taking on common and distinctive imagery in the same space, she creates a complex communal identity that points out its own radical and vulnerable roots.

As Garland-Thomson asserts, the self-portrait Wade paints in this poem is also boldly feminine and sexual. Wade’s descriptions “structure a female subjectivity that decidedly departs from convention,” argues Garland-Thomson (2007, p. 116). “*The Woman with Juice*” wields the power of a “*French kiss,*” “*pink lace panties,*” and “*milk white thigh,*” which she cripps by mixing these “archetypal female allusions” with “*cleft tongue*” and a “*stub.*” Rather than simply claim her gender and sexuality, she embodies ugly, biting, disturbing, and ever-present images of disability. Wade includes “real words” like “*cripple,*” “*gimp,*” and “*crazy lady.*” By intermixing her particular variety of disability identity with femininity and sexuality, Wade’s poem disrupts all of these broader narratives.

Garland-Thomson argues that the piece makes “a series of identity claims that allude to broader narratives” (2007, p. 117). This poem does more than claim “communal identity” and sexuality while it reclaims the negative language ascribed to disabled bodies. More than these important assertions, this poem transforms narrative itself (Garland-Thomson, 2007). Garland-Thomson argues that narratives generally tend to structure the shapes of our identities – the person we see ourselves to be. It is based on a structure that views bodies as remaining stable through time, and thus shaping our bodies over time with the stories we tell about our lives. But Wade uses her ever-changing body, artistic language, and her declarations of identity in a “fresh and feisty” way that redefines narrative. The story contained in Wade’s poem utilizes the

disabled body to reinvent and reshape the structure of her story and her identity. “The poem’s assertion, then, of Wade’s fleshly being as a disabled woman is key to the poem’s identity politics...this ‘Woman with Juice’ tells a new story, a new disability narrative, in which shape structures story” (Garland-Thomson, 2007, p. 118). In other words, her body is the story, and the story she tells about her body and its connections to other bodies shapes (or reshapes) the configuration and reach of the narrative entirely.

Audiences, artists, and disability studies scholars have recognized Wade’s work and this poem for its significant contribution to disability culture. Jim Ferris cites it as an important piece of “crip poetry”(2007) with the potential to “transform consciousness” for disabled and nondisabled alike. “The poem situates people with disabilities not in the margins but in the center of human experience,” Ferris writes (2007). This is exactly where Wade sees herself and those she claims connection with, along with all the complexities such a position entails.

This incredibly complex poem is how Wade chooses to end *Sassy Girl*. It is the best example of how she creates structure from her experiences because it gives shape to parts of her life that had no shape. It extends the boundaries of her identity, her community, and her “reality” while also providing them with limits. She has power and control over her story, and in turn, shows her audiences how to take this power for themselves.

H. **Disability Culture, Community, Pride**

1. **Introduction to this section**

Wade envisions a new framework of possibilities for what it means to be disabled in *Sassy Girl*; a work that most clearly expresses the culture, community and connections she seeks to create. With *Sassy Girl*, Wade reinvents and expands disability culture, disability community, and disability pride in ways that are not exactly what her community or her

audiences might expect. During the course of the performance, many derogatory images or negative terms appear, but Wade skillfully disrupts their belittling power to allow for alternative meanings to present themselves. In addition, her performance enlarges the boundaries of disability community to incorporate a multiplicity of imperfect bodies and emotional responses, with the possibility of enrollment and contribution by many diversely identified members. She views common notions of “disability pride” – a community and political strategy designed to move the personal and public image of disability from negative to positive – as too simplistic. Through her re-imagination of culture, community, and pride, Wade puts forth her distinct and fluid framework for connection with the world: new definitions, new ways of being, and new possibilities for being disabled and being human.

This section examines the ways that Wade constructs disability culture in *Sassy Girl*, and how this culture connects to and expands her community. Using both *Sassy Girl* and data from Wade’s interviews, I will explore the following questions: How does *Sassy Girl* disrupt and redefine language, symbols, and other artifacts of disability culture? How does Wade’s construction of disability culture expose the structures of fear, invisibility, and separation that make up disability oppression? What does she have to say about disability pride? In what ways does Wade envision a framework of possibilities for being disabled and making human connections?

2. **Creating disability culture**

Sassy Girl is not just a performance; it is an artistic invention based on its creator’s experiences as a disabled woman. It is an expression of the artist’s version of experiences, landscapes, language, and symbols that resonate with other people who have had

similar experiences. In our second interview, I asked Wade to talk about her impact on the audience with this piece. She explains:

I think that [my] impact on the audience was that I think it opened them up to ideas about themselves and possibilities at their best. I have to think that it's something they just don't get to see or to hear from disabled people, particularly back when I was performing that show. It was pretty radical work: still is I guess. (Wade, Interview 2)

Thus, what resonated with her audiences, especially disabled audience members, opened them to new ideas and possibilities for themselves. What she shared with her story seemed to recount their experiences, possibly for the first time, in unexpected ways.

Sassy Girl reflects how she digs deeply into her history to excavate structures that oppress her and other disabled people. It is distinctive, stubbornly complex, and radically subversive, and it speaks to her community.

a. **“Cripple Lullaby”**

Wade starts creating disability culture and casting a wide net of inclusion for her community as soon as she opens the play. Her opening poem, “Cripple Lullaby,” delivers a key message about being disabled: “*I am not a reason to die.*” This message, and the way the poem argues for her value, foretells the final poem in her narrative, “I am Not One of The” (Wade, *Sassy Girl*). Each of these poems carries a similar thread and speaks to the core of her story: a refusal to accept social and cultural assumptions of disability. Wade confronts typical disability images that are placed onto disabled people by the nondisabled world and twists them in order to reclaim them for disability culture and community. In each of these bookended poems, the artist redefines disability in unexpected and intricate ways, which in turn recreate both the culture and community of disability.

In “Cripple Lullaby” she begins to furnish and construct a world of disability by artfully combining many reconstructed pieces from the dominant culture. The intricacy and refinement

of this new world is more meaningful, inclusive, and realistic. The opening poem begins with Cheryl on a dark stage, sounds of her power chair and her clear, unaccompanied voice. She says:

*I'm trickster coyote in a gnarly-bone suit
 I'm a fate worse than death in shit-kickin' boots
 I'm the nightmare booga you flirt with in dreams
 'Cause I emphatically demonstrate: It ain't what it seems
 I'm a whisper, I'm a heartbeat, I'm "that accident," and goodbye
 One thing I am not is a reason to die.
 I'm homeless in the driveway of your manicured street
 I'm Evening Magazine's SuperCrip of the Week
 I'm the girl in the doorway with no illusions to spare
 I'm a kid dosed on chemo, so who said life is fair
 I'm a whisper, I'm a heartbeat, I'm "let's call it suicide," and a sigh
 One thing I am not is a reason to die
 I'm the poster child with doom-dipped eyes
 I'm the ancient remnant set adrift on ice
 I'm that Valley girl, you know, dying of thin
 I'm all that is left of the Cheshire Cat's grin
 I'm the Wheelchair Athlete, I'm every dead Baby Doe
 I'm the Earth's last volcano, and I am ready to blow
 I'm a whisper, I'm a heartbeat, I'm a genocide survivor, and Why?
 One thing I am not is a reason to die.
 I am not a reason to die. (Wade, Sassy Girl)*

Wade remains in darkness, invisible during the first part of this poem. At about the midpoint, she enters the spotlight without missing a beat. Beneath the spotlight she sings the “chorus” of the poem, which begins “*I'm a whisper, I'm a heartbeat,*” and then ends in defiant tones: “*I am not a reason to die.*” Between each chorus, the poem refuses simplistic, positive, or politically correct images, preferring instead to distort negative, pejorative stereotypes in a way that they can be reclaimed. For example, in the second line she becomes a commonly held but negative notion of disability: a “*fate worse than death.*” But Wade complicates and contorts this with “*shit kickin' boots*” (*Sassy Girl*). She may appear to be a “fate worse than death” to some, but she will not accept her fate without kicking, or a fight.

Wade's use of "*trickster coyote*" to open *Sassy Girl* is interesting and meaningful, because it is a way of embodying a creative cultural figure to invent, or reinvent, disability culture. Tricksters, according to Hyde (1998), are mythical figures considered "lords of the in-between" (p. 6), which means that trickster shows up between worlds, but also between binary concepts. The trickster is also a mischievous boundary-crosser, according to Hyde, who is able to move across boundary lines, redraw them, or erase them entirely (1998, p. 7). In this case, the gnarly bone trickster shows up between able-bodied and disabled worlds. Coyote is another form of trickster, Hyde explains, from cultural folklores including Native American, where the coyote represents the "creator of culture" (1998, p. 8). Utilizing this information, it appears that Wade combines trickster with coyote to do two things: a) reveal "in-between" spaces; and b) to create culture. Her version of "trickster coyote" wears a "*gnarly-bone suit*," which reveals the in-between of disabled/nondisabled, and positions Wade as the creator of disability culture.

Reading the opening poem through this lens, with Wade as the creator of disability culture, Wade's words now bristle with powerful imagery that uses derogatory themes to argue for the value of life with disability. For example, she embodies "*the nightmare*" of disability, a frequent trope depicted in film and television to express the horror of deformity, disfigurement, or any bodily incapacity. Yet Wade reveals the nightmare's hidden truth. The next line, "*I emphatically demonstrate it ain't what it seems*," points out that nightmares, like dreams, are illusions (Wade, *Sassy Girl*). In other words, being a "*nightmare*" is just as constructed as being a dream. She is showing the in-between of nightmare and dream, and that one is as real as the other, depending on how it is defined. Wade disrupts the boundary of real/unreal, and demonstrates that disability depends on how you define it. Thus, she challenges the so-called

nightmare of her existence, asking the audience to reappraise based on the actual person before them.

Furthermore, the phrases she sings in the chorus of the poem – “*I’m a whisper, I’m a heartbeat, ‘I’m that accident,’ and goodbye*” – express meaningful metaphors about life as a disabled person. In this one line, she evokes what is unspeakable (a whisper) and unspoken (a heartbeat), and what is private but provokes us to stare or gawk (that accident). It implies pity, shame, repulsion, and brings up ideas of sadness, grief, and silence. Yet, with all of these negatively drawn images, taken from dominant culture’s persistent and limited representation of disability, Wade continues to claim her life and her value throughout this poem, and throughout the play.

Claiming her worth, Wade crosses boundaries of the living and dead, human and nonhuman, in the lines of “Cripple Lullaby:” “*I’m the Wheelchair Athlete, I’m every dead Baby Doe/ I’m the Earth’s last volcano, and I am ready to blow*” (*Sassy Girl*). By revealing former distinctions between living and dead, or between human and the Earth, she further demonstrates the invented nature of such boundaries. She opens these borders to revision and new possibilities so that new meanings and interpretations may emerge. Revealing what is hidden, invented, or typically unrelated allows Wade to push established categories in order to gain new potentialities. Human beings are part of Earth; death, disability, and aging are potentials in the spectrum of life. In this way, Wade “*emphatically demonstrates*” that the disability culture she is presenting here is open to different opportunities for language, landscapes, and the community of disabled people.

This renewed disability culture allows for its creator to cast her net widely for a more inclusive disability community. Positive sounding characters like “*Evening Magazine’s*

Supercrip of the Week” and the inspirational “*Wheelchair Athlete*” are positioned among negative ones (*Sassy Girl*). Yet, to Wade’s sophisticated audience, positive images can include harmful media figures that are used to keep most disabled people separate from dominant culture. The supercrip and the wheelchair athlete are permitted inside mainstream media because they behave in ways that “overcome” disability to appear as normal as their nondisabled counterparts. Their presence in Wade’s poem, however, is ironic. It signals broad inclusion for all disabled figures, even if they appeal to mainstream sensibilities.

Many of the characters Wade embodies in “Cripple Lullaby” show little resemblance to what we imagine disability culture and community to be. This is because Wade’s work expands the borders that regulate who is in and who is out. For example, Wade takes on “*the poster child with the doom dipped eyes*,” where fear and worldly knowledge are mixed with the eyes of the cheerful, compliant disabled innocent. It is as if “*the poster child*” or quintessential crippled kid, moves beyond her pedestal to perceive the complexity of her reality. Similarly, “*ancient remnant set adrift on Ice*” conjure images of older people cast aside by a social order that no longer values them. She is including the usual suspects of disability community, like the poster child or the aged, but she illuminates their typically unseen or discarded status. These characters exist invisibly in our world, and it takes the gnarly boned trickster coyote to show us what’s been hidden from view. What’s more, she opens the gates of disability to people who are aging, people “*dying of thin*,” kids “*dosed on chemo*,” the homeless, and the depressed. Her “cripples” are extremely comprehensive and diverse.

Wade’s argument in the poem is that she is “*not a reason to die*” no matter what character she claims (*Sassy Girl*). Yet exposing and embodying such figures seems counterintuitive since they emphasize what keeps disabled people at a distance. Her characters

scaffold the negativity of disability perpetuated by film, television, and other media from mainstream culture, while in the world, people with these characteristics remain at the margins, unseen and invisible. In order to argue for her value, and the value of disabled people, Wade could have employed cheerful, plucky or inspirational figures, and utilized the language of “disability pride.” Instead, she brings these figures into the forefront to make audiences look, to bother, and to place the marginalized into the center.

In addition, the poem’s conclusion, “*I’m a whisper, I’m a heartbeat, I’m a genocide survivor, and Why?*” (*Sassy Girl*), along with the lines I discussed above, not only widens the borders of her community, but also deepens emotional connections. It does this by first privileging disabled people, and then summoning certain mainstream narratives (i.e., “*Wheelchair Athlete*”) as a way to transform them. Then, she willfully connects disabled people, calling on “*genocide survivors*” to make her point about who is considered a “*reason to die.*” She channels the unruly, destructive energy of the volcano giving it generative power, which “blows” away old boundaries and reconstructs community and culture. In this way, Wade explodes the borders of inclusion in her tribe, and redefines the stories they tell.

This invented world, community, and culture are created to be a place where she can live and thrive. While familiar, it also values a variety of differences, all modes of being, and allows for endless possibilities to emerge. As a disabled woman, Wade seems to be calling all who identify, freeing them to be who they are, allowing for them to surface whole and welcome.

b. **Crip culture**

Throughout *Sassy Girl*, Wade constructs many relatable scenes – public stripping, public activism, and disdain for pity – as part of disability culture discourse. These scenes represent shared experiences within disability community that fortify and unify the

community. These experiences appear in the narrative in scenes I have previously discussed, such as public stripping in “Zeus,” and disdain for pity in Cheryl’s coming out scene with “Jerry Lewis.” I have not yet discussed public activism, or the disabled body as political object. All three of these particular crip culture scenes from the play also appear in *Vital Signs: Crip Culture Talks Back*, a documentary by David Mitchell and Sharon Snyder (1996). The film features many artists and scholars sharing their ideas about disability culture, referencing common social experiences and cultural criticism to shape how they view disability as culture. The scenes included in the film illustrate and explain “crip culture” with how these disabled artists, scholars, and activists broadly define it.

Mitchell and Snyder’s footage for the film comes from a 1995 conference about disability culture held at the University of Michigan (see Longmore, 2003b), where Wade performed *Sassy Girl* in its entirety, live in front of a mostly disabled audience. While Mitchell and Snyder’s film (*Vital Signs: Crip Culture Talks Back*, 1996) depicts clips of the three scenes from *Sassy Girl* I mentioned above, the clips actually “clip” the complexity and meaning that comes across in the full play. I think it is important to closely look at Wade’s scene about public activism in context to demonstrate how the design of her performance, in conjunction with common tenets of disability culture, construct it differently and more deeply than the clips in the film.

Wade portrays public activism in *Sassy Girl* through a scene where Cheryl ventures to the movies for the very first time. In this scene, Wade’s artistry brings together the common occurrences of being in the way or taking up too much space as a disabled person, and the will to stay put and make a political statement of the situation. The statement is about the inaccessible environment and her right to see the movie. Planting herself at the theater in her power

wheelchair, Cheryl remarks to her audience: *It's a balmy Friday night in June. And here I am, twenty-three years old; alone at the movies for the first time* (Wade, *Sassy Girl*).

Note the indication of time and place. If the story is truthful, and Wade has not disputed this, she would have been 23 years old in March of 1971. In 1971, there were no anti-discrimination laws that compelled movie theaters to create access to patrons in wheelchairs. Therefore, the theater was inaccessible and she had no recourse – yet. The story she tells next indicates that she was an early proponent of disability rights.

I am the woman in the wheelchair, who's always writing in her notebook. I know this is me because I can see my reflection in the eyes of the uniformed officer who is asking me to leave. "You're blocking entrance to this theater," he says. 'Entrance' – interesting word. "You are interfering with the rights of others," he says. I would hate to inconvenience anyone. The manager says I should come back tomorrow when there are fewer people and my aisle position won't be such a fire hazard. "Do you really think your cause will be helped by alienating people," he says. What cause? My cause is to see this movie. People are responsible for their own alienation. "I have to arrest you," he says. I have to sit here. I guess we both have jobs to do. (Wade, *Sassy Girl*)

Taking a philosophical tone, Cheryl is simply there to see the movie, and is arrested because she refuses to move out of the aisle – the only place for her to be at this theater with her wheelchair. It is a scene that many disabled people have lived: being asked to remove your service dog, or pushed out of the way while in your wheelchair, or bodily hoisted aside because you can't hear or see what is going on and because you are in the way somehow. She muses that she does not have a “cause” while the police officer blames her for “alienating” others. In this part of the scene, though, she states simply that this is her “job” to “sit here.” In the early 1970's, disabled people were still years away from the nondiscriminatory power of the Rehabilitation Act of 1973 or the Americans with Disabilities Act (1990). She did not have the right yet, but she did have the duty to sit there in quiet protest.

Cheryl's revolt transforms into a revelation of identity and independence. First, her father comes to take her home:

I wish I could say the story continues that I'm carted away in a paddy wagon, gnarled fist raised, 'Freedom, Freedom.' Not quite. The cop knows my father, they're old drinking buddies, and in no time at all, here comes Daddy, not in a good mood. Without saying a word, he pops back the clutches to my chair so I can't drive and starts hauling [MOVE CHAIR BACKWARD IN SUDDEN JERKING MOTIONS] me backwards down the sidewalk. Everyone in front of the theater is clapping. Now I know they're not applauding me because for the past half hour they've been yelling at me, "Go home. Stop making a fool of yourself." (JERK CHAIR BACKWARDS, BLOW KISSES TO CROWD) 'Why thank you all for coming, thank you so much. I have always relied on the kindness of strangers. Thank you all so very much.' (Wade, *Sassy Girl*)

I love how this scene shows Wade's critical reflection rather than simply documenting her past. In fact, telling her audience that she wishes she had been arrested or "*carted away in a paddy wagon, gnarled fist raised, 'Freedom, Freedom'*" illustrates one of the ways her performance works "to amplify, to edify experience" (Wade, Interview 1). The scene is all about freedom – a fact that may not have occurred to her during the time it was happening. Upon reflection, however, is the revelation that this could have been her first act of protest. She also recognizes the performative aspect of being visibly disabled – on display in public – as she acknowledges her movie-going spectators in a melodramatic way.

This revelation leads to another when her father starts to lecture her about appropriate behavior.

By the time my father gets me back to the house from the movie theater his head's spinning around like Linda Blair's in the Exorcist, smoke pouring out of his ears. My parents are of that generation raised on Dr. Spock so they don't believe in beating the crap out of their kids; they just talk you into submission. And Daddy's giving it to me with both barrels. "What in the hell is the matter with you? How could you? This is our home, these are our neighbors, this is your home, this is your home." No. This is your home. [HUSHED, RAPID SPEECH] The words are like ice water hitting me in the face. Until I hear them coming out of my mouth, I've never admitted I felt this way, but the minute I hear them, I know I'm telling the truth. It scares the hell out of me. (Wade, *Sassy Girl*)

In this scene, she understands how different and separate she is from her nondisabled family. She is individuating from her parents in more than one way. Beyond realizing that she is an adult and needs to be on her own, she realizes that as a disabled woman, she will live in a world that her able-bodied family will never be able to fully appreciate. Furthermore, she will never be able to fully take “entrance” into their world.

Within this revelatory space in *Sassy Girl*, Cheryl simultaneously feels afraid and deeply humiliated. She says: “*During that infinite three blocks back to the house what passes before my eyes is every humiliation I have ever experienced*” (Wade, *Sassy Girl*). Before getting back to her parents’ house as depicted in the scene above, Cheryl remembers “*the first time I learned to put on the ‘the face’ in the face of humiliation*” (Wade, *Sassy Girl*). This is when she recalls “Zeus.” Wade is writing and performing this as a reflection – a memory within a memory – that also works as a separate and relatable story in disability culture. As I pointed out earlier, *Vital Signs* (1996) treats these scenes separately, excluding the ideas of humiliation, the relationship between the two scenes, and the vulnerability her character experiences in both scenes. It removes the paradox in “Zeus” between humiliation and empowerment. The film’s edited versions of these scenes leave out Wade’s full expression and critically emotional interpretations. Wade’s play provokes thought and feeling, helping the audience connect with the psychological and deeply emotional aspects of these experiences. Without the full content and structure of these performed experiences, the audience is left with a more simplistic and uncritical version of these shared experiences. *Vital Signs*’ edited clips provide pleasurable and empowering vignettes that make us want to cheer, while Wade’s thoughtful reflection in her narrative allows her audience to grasp the character’s complex human vulnerabilities.

Wade seems to want her audience to feel the complex pain that accompanies joy and pride. When taken as a whole, the disability culture she creates is deeply thought provoking, emotional, and truthful. It continuously moves her audience inside the complicated “in-between” reality of empowerment and humiliation, sorrow and joy, good and bad, and between hope and despair.

Wade’s expression of disability culture is fluid, flexible, and continuously shifting. It is simultaneously recognizable and unsettling, open to rugged, uncharted terrain, as well as familiar landscapes. It allows for the expansion of borders and boundaries that permit entrance. It insists on complexity in language, critical reflection, radical insights, and emotional integrity. In *Sassy Girl*, Wade creates the world of disability culture, drawing from dominant perceptions that she has reshaped in her own image.

3. **Creating community and connection**

a. **Community**

In *Sassy Girl*, Wade speaks directly to her community. She speaks to disabled people who have experienced similar situations like being hospitalized, hiding differences, becoming limited, accepting limitations, and coming out as disabled. With her portrayals of these and many other common disability events, Wade lays a foundation of disability culture that is familiar, and strengthens and unifies disability community by relating directly to disabled people (see Gill, 1995).

In addition, *Sassy Girl* builds upon the foundations of disability culture and community by creating connections through empathy. Wade depicts many emotional and psychological consequences of shared oppression, which reveal her inner processes and feelings about realizing, for example, that the world sees her as an asexual, pitiable, devalued object, if it sees

her at all. The vulnerability and depth she expresses add dimension and authenticity to her narrative, which promotes empathy. Furthermore, she exposes the pervasive ableist structures beneath shared oppression in her community. The expanded community, as a result, is more knowledgeable about the conditions and structures affecting disabled people's lives.

Wade's definition of disability community seems paradoxical, however. On one hand, community includes those who understand disability history, past and present oppression, and know "disability" must be broadly defined. As I discussed earlier in "Disability Consciousness," *Sassy Girl* has moments, like when Cheryl acts out scenes from *Whatever Happened to Baby Jane* (1962) that speak directly to this community with such cultural references that uncover ableist structures, create complexity, and reinvent disability culture. Thus, this sophisticated community is narrowly defined. On the other hand, Wade casts a wide net for inclusion into disability community. She draws its boundaries expansively with her poetry, language, and landscapes from the play to include those who identify with the dominant culture. In other words, Wade defines community with both broad and narrow terms: broad to encompass all possibilities, but narrow to capture those who "get it."

There is a moment in *Sassy Girl* in which "getting it" seems to come together for Cheryl, though not without struggle. It happens when she is in Berkeley. While admiring the sites and recalling the powerful history of the place, she suddenly begins to panic.

Uh oh, maybe this isn't real. Maybe I'm not really here. Maybe I'm dreaming and any second I'm going to wake up and I won't be this woman in a big powerful wheelchair tooling down Telegraph Avenue, I'll be this girl in a rickety push chair [JERK CHAIR BACKWARD] stuck in a living room in an inaccessible house in Marin, no way out, [JERK CHAIR] stuck forever... What's the Dylan line, "when you ain't got nothin', you got nothin' to lose", but when you got freedom, you've got everything and there's everything to lose and it's so fragile, freedom. (Wade, Sassy Girl)

She has her independence and freedom, already connecting it with other socially and politically progressive movements, connecting her identity with a much broader community. But she panics as she realizes how fragile this is. She will need community to keep her here – free and self-sufficient. It is as frightening as it is exhilarating. While still “mid-panic,” Cheryl sees a striking woman with orange hair and a purple wheelchair. The woman notices her stress and acts to calm her fears. Cheryl describes the scene like this:

She pulls out a long, thin brown cigarette from the black leather pouch beside her in the chair. She lights it, takes a drag and passes it to me. “Girl, you have got to stress down.” I take a drag. And another. [LONG PAUSE, LAUGH] I look at her. She’s flashing me this smile, this “Welcome to the community” smile. Welcome to the community of Cripple Women with Attitude. (Wade, Sassy Girl)

I appreciate how Cheryl describes this woman in detail, as if she’s never seen anyone like her. The woman’s dress, hair, chair, and demeanor invite a sense of “disability cool” (Longmore, 2003b), and Cheryl starts to feel at ease. This woman invites her to belong and enjoy this new community of “*cripple women with attitude.*”

“Cripple women” becomes “sassy girls” in Wade’s eloquent hands. Both phrases create meaning about women with disabilities who refuse to be labeled, contained, or controlled by the mainstream society. “Cripple women” and “sassy girls” promote self-definition, ostentatious attitude, and feisty, impudent style. With so much style and attitude, “sassy girls” can use their assets to promote freedom and community for disabled people.

From here, Cheryl sings an original song about “sassy girls” that celebrates the disabled women from her community. They shake up “tired ideas” and shatter stereotypes “*like sassy girls.*”

*[SINGING, DANCING AROUND STAGE]
Like Clubfoot Annie wearin’ bright red shoes
Like Harriet the Hairlip deliverin’ the news
Like Spastic Jenny strokin’ the cat on her hat*

And One-Legged Ruthie, She teaches tap
Ya clap hands
Ya shimmy, ya shout
Ya rock ya tired ideas right out
Like sassy girls, sassy girls, sassy girls, unh huh
Like Old Blink Wilma readin' a novel a day
She's a doing it the fingertips way
Like Capucine the Deafie and Deaf Lily Rue
Betcha can't keep up with all the talkin' they do
Now who ya callin' crazy, Mary Louise?
Hey, she's the one knows how to talk to tress
Yeah
Ya clap hands
Ya shimmy, ya shout
Ya rock ya tired ideas right out
Like sassy girls, sassy girls, sassy girls, unh huh
Like Mumtaz, the Mute One, preachin' the word
And Diana, the Cripple: She flies like a bird
Like all us crips who sing a strugglin' tune
And at midnight
Together
HOWL at the moon
Ya clap hands
Ya shimmy, ya shake
Ain't nothing but worn out notions at stake
Skip-a-rope, hear the sound?
Just a bunch o' stereotypes hittin' the ground
Ya clap hands
Ya shimmy, ya shout
Ya rock those tired ideas right out
Like sassy girls, unh huh, sassy girls, yeah
Ssssassy! (Wade, Sassy Girl)

Wade sings this original song in full, joyful voice. The verses feature several examples of “crips” and how they function in the world their way. Each verse celebrates and showcases women with different impairments who “rock ya tired ideas right out” (*Sassy Girl*) with their own particular styles. These “girls” don’t follow any prescribed methods from the nondisabled world in order to be in the world. More importantly, however, the song brings these divergent styles together into the community of “sassy girls.” Every chorus brings this community together, reinforcing their power. Plus, she highlights the group with “at midnight/Together/HOWL at the moon,” which

she punctuates with a beat and loud singing on “*howl*.” Each chorus spells out what this community can do: shatter stereotypes, “*tired ideas*,” and “*worn out notions*” of what being part of disability community is all about.

One of the things I notice about the “*sassy girls*” song is how direct it appears. While the song is fun and playful and performed almost like a cheer, Wade’s message to the audience is clear. It is both fun and educational to those in her audience who have not been getting the through-line or thread of her performance. The song links back to the title – a mischievous, bold, defiant character that wants to uncover the roots and complexity of being disabled instead of remaining passive or compliant toward dominant notions. Yet Wade lets us in on her message in an entertaining way. She states:

My first job is to entertain, not convert you to anything. I am in essence the court jester or whatever. I come from that tradition. I would like the entertainment to have value, it doesn’t always have to have that, and it sometimes can just be fun. That’s not something in terms of disability. We’re not allowed to have that prospect. (Wade, Interview 3)

This quote is another example of Wade’s deep understanding of how the dominant society limits and separates from disabled community. For her, even being lively and having fun in the song is an act of resistance as much as it is a clear message. Although she may not be performing to “convert you” to her ideas, the playfulness in the song is contagious. Wade sings about “*sassy girls*” to claim her community, deliver her ideas about freedom for disabled people, and to make connections with her audience in a fun, feisty manner.

b. **Connections**

Wade uses the power of disability culture and community to make connections. As Brené Brown claims, we are all hard wired for connection (Brown, 2007, 2012), and people with disabilities are no different. Indeed, the disconnection that disabled people experience, and that Wade presents in *Sassy Girl*, is arguably more excruciating and profound

because the nondisabled world reminds disabled people of it frequently. As disabled people, we may see disconnection from the public in people's fearful reactions to our presence: a gasp, a scream, or complete stillness. We may understand it during our periods of isolation in our homes, in hospitals, in nursing homes, or in adult day care. We may recognize it in the ways we are ignored by taxis, forgotten by para-transit services, or by an inability to travel because we lack these services in our neighborhoods. We experience it during our attempts to interact with the world that are met with blank stares, being referred to in third person, or the inability or unwillingness of our communication partners to engage with us. It happens to me each time someone refuses to board an elevator, or moves to the back of the bus, or announces why she or he cannot be near me because I am a guide dog user. And these responses from others can create shame, as well as silence, greater distance, and isolation from society.

Yet Wade's work connects. It is about connection in interpersonal and public relationships. It connects us with our own diverse communities, and sometimes connects us to self by lifting us out of shame and isolation. *Sassy Girl* seeks connection through Wade's subtle education of the nondisabled and those who identify with mainstream culture. And it connects disabled people with their relationships to the mainstream frameworks that oppress them.

Wade especially points out these connections in her poem, "I am not One of The." This poem ends *Sassy Girl*, and is the bookend poem to "Cripple Lullaby," claiming identity and "pride" through her connections to others. The poem resists euphemisms and creates new, unique, and uneasy metaphors, in a similar way to "Cripple Lullaby," by pairing what dominant culture sees as ugly, unruly bodies with what Wade sees as uncommonly beautiful. In this poem, Wade claims power through language and imagery while also resisting oppression with what connects disabled people as culture and community. She sees these connections in this way:

We're connected to the things, where we come from. We're connected to the people still locked in the pits, in the closets. We're connected to those people who were, you know, gassed and injected and who still might as well be gassed and injected because that's the way they're treated because they're cripples. We're connected to all of that and that is in [I am Not One of the], and I hope, even if people are feeling uplifted, that that resonates with them somewhere on a deeper level; that it haunts them a little bit. (Wade, Interview 2)

Both opening (“Cripple Lullaby”) and ending (“I am Not One of The”) poems connect her – identity and community – with historical actors and living victims of oppressive structures within ableist society. And, at the same time, these poems also claim and celebrate the multiplicity of bodies and experiences that inhabit disabled lives. I understand this poetry to be Wade’s strategy for public resilience and complicated pride against the pain and grief of social and cultural exclusion. Therefore, she wants these poems to “haunt” and “resonate” beyond the end of the performance so that her complex and radical ideas about connection have the opportunity to sink in.

4. **Disability pride**

Wade resists disability euphemisms and dominant narratives by specifically saying what she is “not” in both “Cripple Lullaby” and “I am Not One of The.” She refuses the oblique labels established by the nondisabled, such as “physically challenged” or “able disabled” especially when such labels are forced onto the disability community. Many disabled people, who want to be seen as being like everybody else, happily accept these euphemisms without question, which is another aspect of cultural forces that Wade reacts to in these poems. What she manages to get across, however, is her complex and realistic version of what could be considered “disability pride.”

In Wade’s version of disability pride, she considers the narratives that society and culture perpetuate for disabled people. If you are disabled, you are expected to tell an “inspirational

cripple” story about “overcoming,” demonstrating that you are sufficiently “plucky” (Linton, 2006) to surmount obstacles in the way of being normal. She has noted that disabled people are discouraged from being angry, sad, or having fun, but are accepted for being cheerful, compliant, and striving to be like their nondisabled peers. This is the “crap,” as Wade calls it, that audiences have internalized and left unquestioned in varying degrees (Interview 1). Wade is willing to call everybody on his or her “crap” in order to gain attention to what she has to say.

Disability pride, in Wade’s view, can be another form of disability oppression. As she notes in the following quote from our third interview, disability pride follows a prescribed story instigated by a society that refuses to look at the complicated realities of being disabled.

I’ve never been able to hang with this simplistic crippled pride, you know, disability pride... It’s just as stupid as telethons to me, like it’s a great thing to be crippled. No it’s not. Give me a break. You’re telling me that when you need to take a shit and you need somebody to get you on the toilet, that’s a great thing? I’m not going to buy that lie; do you think anybody else is going to buy it? But I am no less human and no less worth everything because I need help getting to the shitter... (Wade, Interview 3)

Wade says disability pride is more complicated usually expressed. Once again, she includes the complexities of impairment in the discussion, and in the same breath, she claims that she is “no less worth everything.” Thus, she doesn’t disagree with the basic tenets of disability pride, which is about claiming disabled people’s value in a society that continually devalues us. She goes on:

That’s the difference with what I’m trying to say and what... story we’re asked to tell all the time, and what unfortunately some disabled people play into because they get accepted for that. And I don’t think a lot of people who do that are in tune with their oppression. Because, you know, you can’t live up to that. It’s going to hit the fan eventually, unless you’re just very good at living in denial. (Wade, Interview 3)

Here, she gestures to the cultural narratives that disabled people buy into because they are “accepted” for it. These narratives (“the story we’re asked to tell all the time”) come at us frequently, telling disabled people to be inspirational, overcome disability, be normal, be cheerful, and don’t complain. In other words, work your ass off trying to live up to what society

expects, but don't get upset, don't live the way that works for you, keep your oppression silent, and don't do anything about it. Realizing one's oppression, or not "living in denial" and then challenging disability oppression may disrupt prevailing power structures, and therefore, simplistic disability pride continues oppression. Wade sees it as another form of ableism.

Thus, disability pride lacks complexity and realism. In this assertion, Wade reduces "disability" to impairment by referring to "getting to the shitter," and attacks disability pride rhetoric without acknowledging any progress it has made toward resisting negative ideas about disability. For some disabled people and disability pride activists, such an assertion is akin to blasphemy. But that is her point. Sometimes disability is negative, positive, and everything in between. It is complicated, and taking on "simplistic crippled pride" does not go far enough. Simply smiling and saying one is "disabled and proud" potentially leaves the mainstream thinking we don't recognize our oppression or the need to overturn it. Disabled people who have "played into" the story society requires are not "in tune with their oppression." Instead, disability pride may be another form of objectification and violation.

Being worthy even though she needs help is an important statement, and one that disability pride supporters want to convey. Being unable to do something, or doing it in a different way, does not take away from Wade's humanity or anyone else's. In this way, Wade agrees with the motives behind disability pride. By claiming disability identity, community, and self-respect, disability pride is very important for disabled people. However, in terms of explaining the depth and complexity of disability oppression, "pride" fails to explain anything. Disability pride potentially reproduces binaries in order to reverse negative stereotypes. Thus, disability pride replaces an ability/inability binary with proud/not proud without spelling out the destructive forces and complex issues between these binaries.

What disability pride discourse fails to do is acknowledge any of the internalized oppression or shame associated with body image, pain, and other standards of ability, beauty, and productivity that pervade social interactions and cultural expectations. It maintains a comfortable storyline for disability, keeping disabled people in their proper place while simultaneously making nondisabled people feel good because we are proud (and hopefully cheerful). “Pride” fails to articulate ableism or disabled people’s limited public repertoire. A simple narrative of “pride” fails to make clear the complex issues of impairment, or of the oppressive structures that govern social services and health care systems. And disability pride fails to intervene on behalf of the representational gap: cultural and social forces that reproduce disability oppression.

Wade seems to seek to explain the complex relationship between being an empowered disabled person (pride) and the daily struggles of shame, oppression, and the body. Disability pride may be a way to reclaim the value of disabled lives, but does it continue to claim the need for access, equality, opportunity, and civil rights? Wade could be saying that disability pride, like the disability rights movement, does not attend to the very real needs and differences of our impaired bodies – a fortifying pride movement will make sure that everyone feels “no less worth everything” because he or she needs help.

I. **Conclusion**

1. **Introduction to this section**

In *Sassy Girl*, Wade uses her artistic talents to complicate reality and reveal radical and vulnerable representations of disability that are distinctive, provocative, and fresh. *Sassy Girl*, and the performance stage, was Wade’s opportunity to have a conversation about disability on her terms. With her love for language, and her skill for writing and turning phrases,

she produced a story that exposes ableist structures and practices, and presents human struggles and frailties. Through the complexity of her personal story, Wade represented “the first person plural” (Siebers, 2008), expressing and connecting with many disabled people’s experiences.

In this final section on Cheryl Marie Wade, I discuss how the themes found in Wade’s data create her re-imagined disability paradigm and her particular disability standpoint. I begin this discussion by deconstructing the title of Wade’s performance piece, then move into an examination of the themes via radical vulnerability, and conclude with Wade’s disability perspective and standpoint.

2. **Deconstructing the title, “*Sassy Girl*”**

Sassy Girl: Memoirs of a Poster Child Gone Awry positions the main character as someone who starts out in a certain way, then somehow “goes awry,” through the dramatic changes her body, mind, and spirit undergo with impairment and disability. While Wade does not claim any personal history of being a “poster child,” Cheryl uses the term in “Cripple Lullaby,” right after she tells her audience that she was born a “regular” girl, but “fate” makes her “special” (Wade, *Sassy Girl*). A “poster child” refers to the practice of placing an image on a poster, typically of a disabled or deformed child, to raise funds for charity. Disabled children were used to represent charitable organizations such as Easter Seals, Muscular Dystrophy Association, and the March of Dimes among others. These images, which morphed into deplorable telethon personas, relied on pity and fear to spark action. Yet, in more recent usage, the term has come to mean “example” or “perfect fit for a stereotype” (www.urbandictionary.com, 2014). Cheryl embodies the cheerful, brave and compliant poster child in *Sassy Girl*, but not for long. There is a point early in the story where Cheryl, the quintessential crippled girl, begins to “go awry” toward becoming the “*Sassy Girl*.”

To “go awry” means to go “away from the appropriate, planned, or expected course” and “out of the normal position; askew” (www.oxforddictionaries.com, 2014). In a disability story, the “expected course” or “normal position” is about becoming like everybody else—normal and able-bodied. Wade performs a character that drifts away from the “normal” and mainstream position, eventually losing her cheerful, compliant role. She is unable to achieve the mainstream’s social or cultural expectations. Once the character realizes that she does not fit within cultural expectations, she decides not to be an “inspiration.” Wade’s body, beliefs, and values go awry, too, especially when compared with what is normal and accepted. But Wade uses her differences as a means to construct her identity, her personal narrative, disability culture, and her standpoint as a disabled woman.

Unpacking the title further, “*Sassy Girl*” is defined in the play as “*crippled women with attitude*” (Wade, *Sassy Girl*). Cheryl is the “sassy girl,” and as a crippled woman with attitude she has political goals and an inclination toward social change. Traditional definitions of “sassy” indicate “bold,” “impudent,” “lively,” and “full of spirit” (www.oxforddictionaries.com, 2014). The UrbanDictionary.com, however, defines “sassy” with what I consider the best fitting definition for Wade and her character: “possessing the attitude of someone endowed with an ungodly amount of cool” (www.urbandictionary.com, 2014). “Sassy” describes her style for using language and creating imagery, as well as crafting a main character and identity that is impudent towards dominant culture, refuses to equate “ability” with humanity, and models a brash, confident, in-your-face attitude that privileges her disabled body and validates the lives of disabled people.

Having summarized the story through the title, the question arises: does Cheryl go from “poster-child” to “sassy girl” in her performance piece? Yes and no. Wade’s narrative resists its

apparent linearity because of its creator's refusal to submerge any aspect of the disability experience. She maintains her story's complexity, follows her path through her body's ups and downs, and avoids "overcoming" or trying to be like able-bodied people. In other words, she never follows the dominant culture's script.

Additionally, *Sassy Girl* presents a character that loses her self in the shuffle of medical power and treatments. Although she re-emerges with her wholeness and empowerment intact, there are various points in the narrative where Cheryl questions this. From the time she embraces her body different, moving into the world with disability identity, she shows her audience several times when this identity falters, or when she is less self-assured and confident. Such shifts in continuity and progress in the play reflect Wade's lived experiences. She explains:

Your journey takes so much longer and has so many false starts, and the reality is that you don't live one hundred percent in empowerment, ever. You know, you sometimes fall back and struggle to get back to that, and I think that is hard. (Wade, Interview 3)

Wade points out the difficulty of these uneven processes. Yet, she always regains her empowerment, usually with more determination and desire to make changes in the mainstream world. Thus, her refusal to follow her own apparently linear narrative, and the complexity it retains, gives the performance nuance, and a sense of honesty and realism, which typical disability stories lack.

3. **Radical vulnerability through the themes**

Sassy Girl is Wade's master treatise on disability, using radical vulnerability to connect deeply with her audiences while exposing deeply entrenched, ableist, social, and cultural structures and practices. Radical vulnerability, and its cohort, complicated reality, works at a Meta level to move around, between, and above *Sassy Girl's* content. In this way, Wade maintains an omniscient point of view, while her character, Cheryl, exists within the content.

However, Cheryl's also speaks from the omniscient viewpoint at times when she exposes radical vulnerability and complicated reality within the content. Both strategies work in tandem to frame the character's perceptions and perspectives, and support the artist's critical disability-cultural and disability-centric discourse.

Radical vulnerability and complicated reality also work at a Meta level supporting the themes and categories found in the data. First, "complex embodiment" makes the artist's visibly disabled body central to her personal story. Her body complicates experiences within the performance, while also making the oppressive elements of disabled embodiment explicit. In *Sassy Girl*, the centrality, prevalence, and politics of her character's embodiment mirror these effects from Wade's life to illuminate ableism, which undergirds how dominant culture and society deal with bodily differences. Additionally, Wade's embodiment challenges cultural representations of disability, making the disabled body a complex and dynamic participant in the story.

The artist's disabled body is integral to the performance, but also fundamental to the next theme: "disability consciousness." Wade depicts how her disability consciousness developed through bodily changes, new experiences, social interactions, and political awareness, and how these events are profoundly linked with her body. Disability consciousness, radical vulnerability and complicated reality are interconnected in the story by Wade's skill for exposing what constitutes ableism; all requiring critical reflection, political discernment, and the self-definition gained from these processes. In her lived experience, her consciousness also developed through her work as a disability rights activist. Wade explains:

I would always try to include the personal into the political story I was trying to tell, I knew that this was something the [disability rights] movement needed, and my stuff was always fueled by activism first. I mean I'd always dreamed of being a writer and a performer, but I never thought it was a possibility for me, because I never saw anyone

who looked like me doing it. But I found, in politics, a way to be a performer and writer, and it came out of my activism. I always felt like what I was doing in terms of disability was always part of fueling the movement. ...I always thought there was a political edge I could bring to the work that I could do, but it wasn't completely, overtly political. (Interview 3)

Wade's "political edge" shows up throughout *Sassy Girl*, particularly through radical vulnerability. Her work is entertaining, but more political than she may have thought. Fortunately for us—her audience and members of the disability community—she was able to become the performer and writer she dreamed of, fueled by her activism. Her disability consciousness is expressed as radical vulnerability, while at the same time; radical vulnerability demonstrates her politically and culturally sophisticated consciousness.

Each theme or category overlaps and connects with every other theme. This trend continues with the third theme: "objectification and violation," which is about how Wade's embodiment and consciousness create knowledge of the ways internal forces (emotional, physical, psychological) interact with external forces (social, cultural, political, environmental) to construct specific forms of "random assault" (Wade, Interview 2). Objectification is represented and resisted, for example, as part of the medical content in *Sassy Girl*. As a result of the "alienation" (Wendell, 1996) from her body caused by medical authority, she felt like "a thing to be fixed" (Wade, Interview 2). The story of *Sassy Girl* reveals how this internal sense of being an object is repeated in the social environment. *Sassy Girl* portrays how disabled people are treated sometimes—as objects—in Wade's "rant" poem, "I See You Staring." The events described in the poem establish a cycle of oppression: psychological and emotional assault linked with social attack (i.e., staring, laughing, cringing, or reacting to her physical form). Objectification and violation can stimulate shame, or "internalized hatred" (Interview 3) and the need to resist it in the moment. The self-objectification inflicted by doctors is reproduced in the

public sphere by the objectifying gaze of strangers. Thus, objectification is also a violation of the spirit, an assault to emotional equilibrium, and a verbal, visual attack of the person. Wade's poem is radically vulnerable in its honesty and emotion, taking public intrusiveness to task. In other words, the poem portrays, resists, and rebukes objectification and violation, exposing internal and external forces of ableism by representing both internal harm, and the need for social change.

In the fourth theme of "grief," Wade uses radical vulnerability to expose the complexities of loss. *Sassy Girl* not only chronicles how Cheryl deals with the loss of her able-body, it also exposes the disconnection and pain that Cheryl realizes as the consequence of disability. Her losses are profound, effectively distanced from the mainstream world of her family and friends. As Cheryl says, "*I haven't got a prayer*" (Wade, *Sassy Girl*). Wade uses the grieving processes she depicts to deepen the discourse around disability, and to expose the deep separation between disabled people and everyone else.

"Structure," the fifth theme, is about the act of writing and performing *Sassy Girl*. Wade points out that expressing honest emotions is also an act of resistance. She explains how she was often told to "stuff" her feelings: to silence them rather than express them. "If we express it, it makes somebody aware that they are part of the problem" (Wade, Interview 2). In other words, the nondisabled people in our lives are usually in denial about our oppression and their role in it. The "problem" of being disabled appeared nebulous, unruly, and ill defined to Wade, and putting a structure to her experiences helped her gain knowledge and control over them. The process of "structure" opened Wade to the radical roots of disability issues in personal, political, social and cultural ways, and confirmed her desire to be "truly seen" (Brown, 2012).

The final theme, disability culture, is Wade's artistic rendering of experiences, landscapes, language, and symbols in *Sassy Girl* that resonate with other people who have had similar experiences. Wade intertwines all the previous themes to construct a version of disability culture that is both familiar and fresh. The familiar images are treated with radical vulnerability, to divulge the more haunting meanings within. Fresh images are complicated so as not to suppress any aspect of disability. Two poems speak to Wade's construction of disability culture in particular. These poems, "Cripple Lullaby" and "I am Not One of The," also bookend the narrative. With these two poems, Wade delineates her distinctive disability culture, with expansive boundaries, inclusive definitions, and imagery that mixes mainstream representations with reclaimed and re-inscribed meanings. Her rendering of disability culture sets the stage for Wade's particular disability perspective: inclusive of a diverse disability community, and at the cutting edge of cultural and political critique. It is biting, crystalline, and once understood, also expansive and welcoming.

These themes not only expose the ableist origins of disability experiences, they also resist ableism. Radical vulnerability provides a complex and comprehensive examination of disability. It is evaluated on multiple levels, and Wade's treatment of disability experiences offers empowered, inventive ways to resist cultural inscriptions and assumptions, and to re-imagine a world inclusive of disability and all forms of human difference.

4. **Wade's disability standpoint**

New disability representations must overturn the socially and culturally entrenched "representational system" of disability (Dolmage, 2014) with familiar myths, stereotypes, and tropes of disability. And, they must reverse the "ideology of ability" (Siebers, 2008), which equates being human with being able-bodied. Wade's strategy of radical

vulnerability, not only interrupts underlying ableism within Wade's representations, it also resists the oppressive practices she represents, and transforms dominant disability tropes. To do this, to create a strategy that has the potential to transform dominant cultural assumptions, Wade needed to shift her own assumptions. Instead of viewing herself and her story from a mainstream lens or through an abled voice, she calls upon her distinctive disability perspective.

As part of the process of creating an autobiographical performance art piece, Wade reflected on her disability experiences and transformed them for the performance stage. She examined her lived disability experiences on multiple levels—emotional, psychological, physical, social, political, and cultural—and converted them into powerful messages that complicate, interrogate, and resist the dominant cultural heritage and social structures of disability. In order to re-formulate her experiences, and express the complexity and political agency of them, Wade needed an alternate paradigm. Thus, Wade's performance strategy expresses this paradigm shift and articulates her "standpoint." In the tradition of feminist standpoint theory, Wade's performance is constructed from her particular disability perspective and artistic position.

According to Wood (2009), "a standpoint arises when an individual recognizes and challenges cultural values and power relations that contribute to subordination or oppression" (p. 397). Writing on feminist standpoint theory, Wood notes that feminist standpoint "hinges on realizing that the conditions and experiences common to girls and women are not natural," but rather, they "result from social and political forces" (2009, p. 397). Similarly, Wade recognizes the dominant culture's values—ableism and compulsory able-bodiedness—are neither natural nor normal. She understands that the experiences common to disabled people are the result of social, cultural, and political forces.

Wade's ongoing and active interrogation of dominant cultural assumptions about being disabled were likely influenced by the "skewed view" (Wade, Interview 3) she felt from living in Berkeley. Combined with her political work and activism, Wade was perhaps able to have discussions with other disability activists and artists that influenced and challenged her views, and supported her standpoint on disability.

Wade's standpoint assumes a centralized disability position, with the presumption that being disabled is a valuable, natural part of life. Disabled people have much to offer the rest of society, and therefore transforming ideas about disability benefit everyone. Her standpoint offers the dominant culture and society an opportunity to "do better" and to change according to a more flexible, fluid idea of what being human entails. In other words, disabled people deserve the same respect, rights, opportunities, and value afforded nondisabled people. The knowledge gained from disability has the potential to improve society for all. Wade assumes a critical disability standpoint that takes the complexity, contradictions, good, bad, and everything in between into account.

Wood points out that, even though "girls' and women's circumstances and activities may shape their perspectives, they do not automatically confer a feminist standpoint" (2009, p. 397). Indeed, this is true for disabled people who may have perspectives shaped by their circumstances, but they may lack any "disability standpoint" because they have not yet engaged in an "intellectual struggle to recognize, analyze, and contest broad power relations that account for the subordinate status" of their existence (Wood, 2009, p. 397). In fact, many disabled people may have internalized ableist and oppressive cultural values from the dominant culture. They have not yet relinquished their desire for acceptance and legitimacy from the mainstream society or culture. Thus, it is this "intellectual struggle" to recognize ableist values and power dynamics

between disabled and nondisabled people that has informed Wade's standpoint as a disabled woman and artist.

Cheryl Marie Wade discloses her disability standpoint through the noted themes of this research. Wade's distinctive standpoint claims power and control over her own experiences and over the dominant perspective that ignores and dismisses her artistic productions, and fails to acknowledge or integrate the rich, complex, "interesting" experiences of disabled people.

Wade's disability standpoint exposes the neglect of disability by the mainstream and its awry representations, and resists disability oppression in all of its forms. Wade puts this into words, saying:

To be able to... take a story, a very hip story from our society, and to try and push it out there in a way that was a lot tougher than I thought was being done. I liked that, I liked that my work felt a little provocative to me; I liked the fact that I was entertaining people... who didn't get to see themselves represented very honestly very often... The minute I began to understand that I had an ability to do that, which was long before *Sassy Girl*, there was empathy and awareness in that. (Interview 3)

VII. TEKKI LOMNICKI

A. Introduction

In this chapter I present evidence and analysis that elucidates the relationship between Tekki Lomnicki's lived experiences and how she represents these experiences in her performance, *Blurred Vision: The Relapse* (2005). For this purpose, I formalized conversations with Lomnicki about her piece and the lived experiences she used to craft it. Lomnicki portrays her disability experiences in fresh, transformative, and relatable ways that connect with audiences and deepen understanding about disability. This solo autobiographical work frames my conversations with Lomnicki and focuses the data – our interviews, the performance text, video, and observations from live performances – to illustrate a multifaceted portrait of this artist.

This chapter seeks to illuminate Lomnicki's perspective as a disabled artist. I argue that Lomnicki practices “building bridges,” a performance strategy for stage and everyday, that expresses her disability experiences in common, universal, and humanizing ways. Lomnicki utilizes her specific lived experiences and transforms them into powerful, universal themes that disrupt expected narratives and assumptions about disability, exposing the human similarities between disabled and able-bodied communities. This strategy allows Lomnicki to construct representational bridges between presumably opposing viewpoints. Her work often situates disability out of its marginal position and into the center by depicting commonalities between her personal experiences and the average person's. Lomnicki's approach assumes a sophisticated disability attitude that touches on social and cultural issues relevant to disabled people, navigating disability culture for her able-bodied audience while narrating the dominant culture for her disabled cohort, even as she transforms familiar narratives. “Building bridges,” which

also functions socially and interpersonally for Lomnicki, allows her artistic work and daily experience to go beyond negative, limiting stories of disability toward more honest and relevant disability representations.

This chapter begins with a brief overview of Lomnicki, a brief synopsis of *Blurred Vision*, and a comprehensive analysis of Lomnicki's strategy of "building bridges." Additional sections discuss major themes from Lomnicki's data, including: subverting medical power, disability culture, and performing identity. Finally, the chapter concludes with a discussion on how these themes, via building bridges and Lomnicki's perspective, create Lomnicki's re-imagined disability paradigm.

1. **Brief history of Tekki Lomnicki**

Tekki Lomnicki is a little person who uses crutches, and intermittently a scooter, for mobility. The 3'5" tall actor, performer, director, and playwright has a striking face and luminous personality that fans find difficult to ignore or forget. Her accessible demeanor, in both her life and her performance work, draws audiences in and puts everyone at ease.

Lomnicki has lived in the Chicago area all of her life. Originally from Elmhurst, Illinois, she graduated from Dominican University. She has had a successful career in advertising as a copywriter and editor while also pursuing her passion and talents for theater and storytelling. In 1995 she co-founded Tellin' Tales Theatre in Chicago, a non-profit company committed to building community through storytelling (see www.tellintales.org for more information on her company's history, mission, and list of works).

Lomnicki is a significant artistic voice within the Chicago theater community. She is a prolific playwright and performer, with works that span two decades. Lomnicki creates solo autobiographical performance work, as well as writes, headlines, and produces full cast theater

shows as artistic director of Tellin' Tales Theater. Lomnicki is a leader among the Chicago storytelling community, using her company to mentor and produce work by and about disabled adults and children. Her solo work focuses on her personal experiences as a little and disabled woman.

Lomnicki and Tellin' Tales Theater have a large, faithful following of dedicated fans, friends, and colleagues in Chicago. Lomnicki's work first came to my attention in 2003 when she was suggested as a guest for "Crip Slam! Disability Takes on the Arts," a disability arts and culture festival that I produced under the mentorship of Dr. Sharon L. Snyder. The first solo autobiographical work of Lomnicki's that I saw was *Paper Doll* (1999, unpublished manuscript), a short performance piece that deals with her journey toward accepting herself in an able-bodied world. The story focuses on Lomnicki's dwarfism and how people react to her with thoughtless, patronizing, and often insulting remarks. Lomnicki utilizes voiceover in the piece to mimic the disparaging comments from her daily life, then uses her own voice to refute these reactions and claim agency as an adult woman with disabilities.

I have become better acquainted with Lomnicki's work since she appeared in "Crip Slam!" Much of it deals with her journey of self-acceptance and claiming her own voice within a nondisabled world. I have seen live performances of *Blurred Vision* (2004), *Blurred Vision: The Relapse* (2005 and 2006), *Clothing Optional* (2006, unpublished manuscript), *Striptease* (2007, unpublished manuscript), *Love in the Time of Facebook* (2009, unpublished manuscript), and *Thanksgiving* (1996, unpublished manuscript) which I saw in 2011 and 2013. For the sake of full disclosure, I also worked as a board member for Tellin' Tales Theater for five years, and most recently appeared as part of the ensemble in *Six Stories Up, Up and Away* (2013, unpublished manuscript), part of an annual project that pairs six adult mentors with six middle-school

“apprentices”; a mix of able and disabled performers, who co-write and perform alongside Lomnicki in a full-scale production based on a central theme.

2. **Blurred Vision: The Relapse – a brief synopsis**

In *Blurred Vision: The Relapse*, Tekki’s character is on a quest to figure out why she is experiencing blurred vision and headaches. She seeks out the expertise of many specialists hoping for a cure. Imagining the worst – multiple sclerosis, bird flu, or a brain tumor – she takes her audience on her quest for a “fix.” Along the way she remembers what it was like to be a “*little crippled girl*” growing up in a hospital, where the goal was to “fix” her twisted legs. As a child, she internalized others’ ideas about disability, believing that someday she would be “normal.”

Blurred Vision is an identity story that includes Tekki’s disability story from birth to the present day. It focuses on her experiences with medical systems, moving between two time periods – the present and past – including early childhood years in Chicago’s Resurrection Hospital. *Blurred Vision* showcases Lomnicki’s talents as a solo artist and performer. While she is not alone onstage, a detail of this performance that I discuss in the section called “Disability Culture,” focuses on Lomnicki’s personal stories: her experiences as a “*little crippled girl*” and as a disabled woman (Lomnicki, *Blurred Vision*). The play is sprinkled with many colorful characters from Tekki’s life that she portrays hilariously. It deals with her personal evolution, demonstrating how her identity shifts and reshapes, in the midst of powerful social and cultural forces, along her journey toward self-acceptance and self-definition.

3. **Lomnicki’s creative processes**

Lomnicki creates at least one new solo autobiographical performance piece and one full theater production (*Six Stories Up*) every year. She works year-round to ensure these

shows come to fruition. Lomnicki has many other duties and responsibilities in her role as artistic director, including teaching playwriting workshops and after-school programs.

Since her solo performance work is done regularly, she is constantly storing ideas away during the year. “I think, ‘what cool stories have been ruminating? What happened to me that will work in a story?’” (Lomnicki, Interview 1). In addition, Lomnicki admits that her work is often grant driven. As a not-for-profit theater company, she must think about themes and projects that will be funded by local and national funding organizations. She explains:

It’s the strangest thing – how my work happens – it’s really grant driven, which is really strange...I always have to state for the IAC [Illinois Arts Council] what my theme is for the next show...so it’s really driven by need. (Lomnicki, Interview 1)

What this means for her organization is that she usually receives the IAC grant, along with other forms of funding, and that Lomnicki must know what future productions will be about at least one year in advance.

“My work is all about real lived experiences, but sometimes I take an experience and I fictionalize it a bit, just to make it more interesting,” Lomnicki told me during our first interview. In *Blurred Vision*, she fictionalizes the visits she had with her doctors, synthesizing them to make them more succinct, and more appropriate for the play and audiences.

Lomnicki told me that *Blurred Vision* began as a commissioned work for Loyola Hospital about her childhood hospitalizations. The initial idea came about when Loyola asked her to write a piece for their Thanksgiving mass about how her childhood hospital experience affected her life in a positive way. For this piece, Lomnicki put in stories about her mentor, Sister Mary Thecla, her Dad, and other nurses. It originally only included her childhood story, but Lomnicki decided to expand it with more recent medical issues. She liked the contrasts between past and

present, being special as a disabled kid versus invisible as a disabled woman, and other themes that became apparent as the play took shape.

At the time she wrote *Blurred Vision*, Lomnicki was actually experiencing blurry vision, terrible headaches, and feared she had a brain tumor. She thought, “Oh my God, this has got to go in there [the performance piece]!” (Lomnicki, Interview 2). She remembers being struck by how she had been “treated, as a kid, like a little princess” and now with doctors telling her “hell, I don’t know what’s going on with you. You’re a hypochondriac” (Lomnicki, Interview 1). Utilizing these differences between her experiences, Lomnicki worked closely with her director, Ann Filmer, to focus the play on the present, but also to go back and forth between the two time periods.

In *Blurred Vision and Blurred Vision: The Relapse*, Lomnicki resists portraying a simple cheerful cripple or angry adult. Tekki’s quest for answers, told through disjointed trips in and out of the present, depicts identity development as simultaneously fragmented and fluid. The configuration of the play carries this fragmentation and fluidity through to an idealized childhood, then into the reality of adulthood and back again to childhood, with her memories of the past eventually becoming clear, more realistic, and more congruent with her present-day identity. In this way, the play seeks a balanced, mature, and attainable representation of her lived experiences.

B. **Building Bridges**

1. **Introduction to this section**

Tekki Lomnicki’s performance work seems to fulfill an inner drive she has to connect with her audiences.

The way that I feel that I connect the best is to find the places where we are similar. And maybe that would be with being angry, you know, or maybe that would be with being hurt; just some very true feelings. (Lomnicki, Interview 3)

This statement explains Lomnicki's artistic goals and approach to performance work. She wants to connect with audiences through similarities between all people, and she uses universal ideas, such as "very true feelings" to achieve this. Thus, linking disability and able-bodiedness, or "building bridges," is what I see as Lomnicki's strategy for connection, both on the stage and in her daily life.

In this section, I discuss the ways Lomnicki works with two frameworks in *Blurred Vision* to connect with audiences and build bridges between disability and able-bodiedness. With universal themes pulled from her experience, Lomnicki connects disability with the mainstream, helping her able-bodied audience understand their similarities. With her disability perspective, she uses these similarities to signal a typical disability narrative, at least at the beginning. To sketch out this theme, I will draw the reader's attention to specific aspects of the play, and to conversations I had with Lomnicki. The distinction between her uses of universal themes versus disability themes is clear, though most of these examples are complex, and deal with both general and particular aspects at the same time.

Additionally, this section will discuss how this artist's drive for connection builds bridges for community. Her theater company, Tellin' Tales Theatre, has a primary mission of, "building community through storytelling" (www.tellintalestheatre.org, 2013). Community, connection, and commonalities are at the heart of Lomnicki's performance work, and also her personal style.

2. **Connecting similarities and differences**

By tapping into the universality of her experiences, Lomnicki connects to the "places where we are similar" as people. She also likes to blur the fourth wall to personally relate

with individuals, making eye contact, drawing people in with her charisma and humor, and keeping them coming back with her relatable stories. Yet *Blurred Vision: The Relapse*, which is the focus of this chapter and my analyses, goes beyond just being universal and relatable. Lomnicki uses this work to build a bridge between the two worlds she inhabits: the dominant, able-bodied world and the disability community.

As a little, disabled woman, Lomnicki interacts with society on multiple realms. She was born into a family where everyone was able-bodied and regular-sized, and she experienced the able-bodied world as primary. The childhood story in *Blurred Vision* begins with making her “normal:” an obvious solution if she will ever fit in, and this is based on her lived experiences. Along the way, she develops a sense of herself as a disabled or “crippled” girl, which grew into disability identity and pride, associating with other disabled and little people. She learned to accept her differentness, and uses her crutches onstage to symbolize her disability identity. Thus, she accepts differences, but nevertheless, is sensitive to, and connects with, “very true feelings” that emphasize similarities. She emphasizes similarities in her performance work as well as her life.

Lomnicki relies on two frameworks to bridge her two worlds. First, she seeks common ground with people rather than focusing on her different body. Second, she uses her disability perspective to frame her performance work, using the particularities of her disability experiences to locate commonalities. She believes that people are more alike than different. “I kind of want people to know that I’m like them more than not like them... I focus on finding the connection between myself and the average person,” she told me during our first interview. Usually, the connections are found through shared humanity, and she uses universal ideas and emotional themes to create links. At the same time, she cannot deny her differences: her physical presence,

experiences, identity, culture, and perspective from being disabled and little. Using her disability and little person identities, her work is infused with personal experiences. “I think the big thing is that I really want to portray my experience in my work, and that disability is a part of that” (Lomnicki, Interview 1).

While Lomnicki’s two frameworks – one permeated with disability particularity, and the other permeated by common, human qualities – appear contradictory, together they become a strategy for her work. She utilizes her specific disability experiences to direct attention toward more universal human themes. In this way, her personal *is* political. While she chooses not to be overtly political in her work, Lomnicki nevertheless mixes disability messages with humanistic themes, demonstrating that disability experiences can also be converted into relatable, human stories. Using both frameworks in her work, she creates a metaphorical bridge between two worlds often separated by misperceptions and cultural representations. Building bridges increases awareness, understanding, and empathy about disability for her able-bodied audiences. It creates space for disability within the mainstream, and concurrently, creates and sustains connections with her disability community.

Lomnicki also bridges the gap between little people and disabled people. She does not distinguish between her experiences with mobility impairment and short stature, apparently combining her impairments without explanation or distinction. In this way, she presents her impairments as disability, focusing on the social model – environmental barriers, how others perceive her, and how she is treated – rather than conflating social model concepts with impairment issues such as pain or physical limitations.

3. Performing disability and common themes

Lomnicki begins immediately building a bridge between disability and her audience. The lights come up on the main character, Tekki, seated in a chair downstage right, crutches leaning on another chair next to her. This side of the stage is set with three chairs and a small table: a waiting room. Tekki is reading a magazine, and in a tiny voice, she looks over her magazine and says, “Hi.” She continues:

(Pause. Read magazine) have you ever had one before? (Pause) Me neither. I hear they're real claustrophobic. Well, I'm not usually claustrophobic, but I don't know, being shoved in a tube? I've seen people getting them on TV but you never see what it's like from the inside. I mean they probably can't fit a camera in there. Did you see that episode of NYPD Blue when Sipowitz had to have an MRI and he freaked out and they had to take him out? He was screaming and... I'm sure it can't be that bad. (Reads a little more). What part are you having it on? (Pause) Oh. Me? My brain. I'm having blurred vision and these headaches. I mean just terrible headaches. Sometimes at the top. Sometimes at the back. Sometimes at the temple. Do you think it could be a brain tumor? I looked up my symptoms on the Internet and I'm sure I have a brain tumor. Blurred vision. Headaches. It's gotta be a brain tumor right? You must think I'm a hypochondriac, don't you. My friends do too. Well, I gotta admit that even as a little kid I was a magician at pulling drama out of thin air – and my able-bodied assistants took many forms. (Lomnicki, Blurred Vision)

This opening monologue sets up the story: Tekki has been having headaches and blurred vision – symptoms she will continually attribute to one catastrophic illness or another – and she wants to know why. In this scene, she “casts” her audience in the role of fellow patients in a waiting room: waiting to be seen by the doctor, tested, or treated. Her character uses the cultural reference of an old TV series to relate her experience to her audience, which captures attention and possibly stirs imaginations. The audience can picture the scene in *NYPD Blue*, and imagine what an MRI is like. Then Tekki brings it back to her personal story, relating her symptoms and her fears with the audience.

Notice that Lomnicki does not mention disability here. Most of her solo performance work is about disability without necessarily being obvious about it. “I think the only time I refer

to it in [*Blurred Vision*] is when I say ‘my legs were like a twisted pretzel,’” she remembers in our second interview. Lomnicki does not need to blatantly discuss disability in her performances because she plays the main role. Creating and performing a character based on her experiences, she is able to perform disability as accepted fact. Her body and size often do all the necessary explaining about disability.

Yet, the use of “*able-bodied assistants*” is intentional. This line subtly introduces disability along with an actual “able-bodied assistant” played by an able-bodied actor and dancer. The script, from where we left off above, reads:

(TRACK 2: Magical sound)
And my hospital room was my stage.

(TRACK 3: Applause)
(Nurse twirls out and strikes a pose). (Lomnicki, *Blurred Vision*)

Tekki gestures to center stage, and lights come up on the set. This is where her “*hospital room*,” her childhood “*stage*” materializes. The nurse, who acts as a bridge for all the characters in the play, twirls out as her introduction. I will discuss the nurse in greater detail in the section on “Disability Culture.” In this section, however, I want to focus on how the nurse is a bridge for Tekki between different aspects of the play. First, after entering the stage on cue, she transitions Tekki to a new scene by physically picking her up and carrying her to it. Tekki says to the nurse:

Do you think I have a brain tumor? Because if it's a brain tumor, I don't know what I'm going to do. I don't know if I could go through it again. I mean the whole hospital thing. (Nurse swoops Tekki onto the fainting couch, puts a hospital gown on her pillow behind her. One under her knees). (Lomnicki, *Blurred Vision*)

The two actors move into the “hospital room” at center stage, where Tekki transforms from her adult self into her child self. Tekki maintains her adult character until the nurse “*swoops*” her onto the hospital bed, where she becomes childlike. In the center stage, set with a fainting couch and a window, young Tekki recounts her early years spent in Resurrection Hospital. Tekki will

tell her disability origin story from here, where most of her formative years took place while doctors “*fixed*” her. Transitioning Tekki between past and present, and from waiting room to doctor’s office (stage left), will be one of the nurse character’s main functions.

Being small enough to be carried is something Lomnicki took advantage of. She explains: In some ways I really use my impairment in creative ways. For example in *Blurred Vision* I use my being small to play myself as a child, and then have the nurse carry me. (Lomnicki, Interview 1)

Not every actor can get away with playing a child, but this works in Lomnicki’s case *because* the nurse can carry her. In this way, Lomnicki’s own body performs as a bridge between the two time periods she is depicting. As soon as she is “*swooped*” onto a set piece that represents her hospital bed, the audience can follow the story, recognizing what Tekki means in the line, “*the whole hospital thing.*”

Besides transitioning Tekki back and forth between present and past, the nurse also provides physical support for the story. The nurse acts as a bridge of ability, facilitating Tekki’s body in some scenes, and playing out Tekki’s childhood fantasies in others. When young Tekki describes her future “*normal*” self, the nurse acts this out. Thus, the nurse’s body will reflect young Tekki’s aspirations, acting as a bridge between ability and disability, as well as reality and fantasy. The addition of this silent but versatile character facilitates Lomnicki to tell a more comprehensive story.

a. **“Very true feelings”**

Blurred Vision utilizes the “true feelings” Lomnicki speaks about to connect with all members of her audience. For example, in the childhood scenes, Tekki deals with the loneliness and isolation of being in the hospital. After delivering Tekki to the memory-space on center stage, the nurse tries to leave. Tekki protests:

Mom. Where's my mom? Can you call her? I just want to talk to her. It's not too late. She's up.

(Nurse rubs her forehead to comfort her, puts her fingers to her lips as if to say to be quiet, gives her a pill and a little cup of water with a straw in it, gives her a stuffed animal and walks out.)

Nurse! Nurse! I don't want to be alone. I'm going to die. Mom! God? Are you there? Jesus? Holy spirit? (Hums Puff the Magic Dragon while rocking herself). (Lomnicki, Blurred Vision)

First, young Tekki pleads with the nurse for her mother. She needs to be comforted, and the nurse does so with touch. But when the adult figure leaves, Tekki seems to panic. She cries out to the nurse, and then calls on other beings as a way to feel less alone, including “Puff the Magic Dragon” (Lipton & Yarrow, 1963).

In the adult scenes, Tekki deals with fear. As we saw in her opening monologue, she fears the worst possible diagnosis, which for her is a brain tumor. But her feelings may be more about fear of the unknown. As the scene continues, Tekki walks upstage left where there is a rolling chair, a metal table with a drawer and clipboard, and other props indicating a doctor’s office. Tekki, an adult once more, begins telling the nurse about why she scheduled this appointment.

Blurred vision. Headaches. Real bad headaches. (Points on head) Here. Here. Here. And sometimes here. I'm looking at that headache chart up there and I have all of them. Did you write down blurred vision? Good. Because I want the doctor to know about the blurred vision. I'm here – well, specifically here because the neurologist at Northwestern couldn't get me in for six months! Six months! Do you believe it? I'm grateful that this doctor squeezed me in because I probably have MS. Well, the radiologist who read my MRI thinks I have MS. I mean he saw the lesions. (Lomnicki, Blurred Vision)

Lomnicki performs this interaction with intensity. Her voice, expressions, and manner indicate that she is afraid, anxious, and needs to get this across to the doctor. Her words also tell us that she is feeling out of control – she was not able to see her choice of a doctor for six months and it looks like she has MS. She is jumping to conclusions as she tries to pin down an answer to her symptoms, all as a way to feel more control over this situation.

After she concludes her visit with this neurologist, who has no diagnosis for her, he tells her to “lose weight” and come back in six months. This answer feels unsatisfying and dismissive.

She says:

(Tekki as self)

*But the headaches. The blurred vision. You gotta do something. What if I'm dying. What if I have early Alzheimers? This would never have happened when I was a kid. The doctors would've listened. My parents would have made them listen. They'd do surgery. They'd fix it. (Lomnicki, *Blurred Vision*)*

This visit does nothing to calm her fears. She is still afraid she could be dying, and without answers there is still no way for her to feel in control. Then, she remembers she would not have felt so out of control when she was a child in the hospital. Her doctors from that time would have “fixed” it, and she would have the support of her parents. At least, she says, “they would’ve listened.” These scenes launch this well-crafted story and the narrative tension between her medical experiences of the past and present, and the scene is moved forward by common themes of fear and lack of control – “very true feelings” that her audience can relate to.

b. **Storytelling**

Lomnicki began storytelling during her early years in the hospital. In my third interview with her, I asked her about the importance of storytelling. Now as an adult, storytelling is a large part of her life, but how did it begin in her childhood? Did it help her to deal with her physical pain, or was it more about the emotional difficulties? Lomnicki said:

I think it was more about the emotional stuff really. The physical pain was there, but it was more about, yeah, that wasn’t even as bad as I remember the emotional stuff being. Especially because they would give you drugs, you know? (Lomnicki, Interview 3)

The memory of physical pain fades as the body heals, while emotional scars take longer to fade.

For both the child character in *Blurred Vision*, and for Lomnicki, Sister Mary Thecla brought

storytelling to her and helped her cope with the fear, loneliness, and loss that can accompany disability, and a lengthy hospital stay.

Sister Mary Thecla figures prominently in Lomnicki's performed experiences. She speaks fondly of her mentor and namesake who cared for her while she was a child in the hospital. Sister Thecla appears in other works by Lomnicki, including *The Miracle* (2007), a film by Jeffrey Jon Smith based on Lomnicki's play, *Thanksgiving* (1996). Both *Thanksgiving* and *Blurred Vision* recall the miracle of Tekki's birth, where Tekki and her mentor's relationship began. Here is how it is told in *Blurred Vision*, with Lomnicki playing the role of Sister Thecla:

(Nurse hands Tekki the nun's habit)

*If you quiet down I'll tell you a story about a little girl who was born to be special. They called me into the delivery room, oh I gotta say 1, 2 in the morning. I was woozy I'll tell you. That poor woman was still in labor from late afternoon. Little skinny thing. In all my years as head OB nurse, I never saw anybody so brave. And oh, that husband, smoking like a chimney in the fathers' lounge. And the language. She had her hands full with him (crosses herself). Who am I to say though, God puts people together for a reason. It hadda be about 6:30 am and that baby finally jumped out feet first – breech. Breech baby. No wonder it took so long. I took one look at the little girl (crosses herself). Dead. And I say to myself, "Thec, it's up to you to baptize this poor kid. Too many babies in Limbo as it is. This one deserves to go to heaven." So I find a Dixie cup, fill it with water, dip my fingers in it... and place them on her little blue forehead. "In the name of the Father and the Son and the Holy Spirit I baptize you... I baptize you... What? What am I gonna baptize you?" The mother was out of it. The father... well let's just say I didn't have the guts to ask him. Well here goes... I baptize you Mary Thecla." (Lomnicki, *Blurred Vision*)*

This story of how Lomnicki came into the world is also featured in the film *The Miracle*: another story that, among other things, also portrays how Tekki gets her name. Her full name is Mary Thecla Lomnicki, but her parents shortened it to Tekki. As this quote demonstrates, Sister Thecla is a prominent figure in Lomnicki's life and in Tekki's story of childhood medical experiences. The nun not only brings Tekki back to life, she is also a bridge between Tekki and the doctors, Tekki and pain, Tekki and loneliness, and Tekki and her love of storytelling. In this story, she is the bridge between Tekki and all of her early experiences.

Introducing Tekki to storytelling is one of Sister Thecla's roles in *Blurred Vision*. The nun also alleviates the stresses of being in the hospital, and uses storytelling to teach young Tekki how to cope with the emotional and physical realities of that time. In this quote, Tekki remembers her mentor like a "guardian angel." Tekki says:

*When I was kid, Sister Thecla never left me alone. She was like one of those guardian angels we learned about in CCD. Always there, bringing you things, protecting you from falling rocks or a speeding car or the devil. So she didn't look like the angels in the pictures. She was chubby and her face was red most of the time. Big whoop! I figured it was because she ran to my room whenever the nurses told her I was acting up. You'd act up too if the reward was one of her stories, not to mention eat the little cardboard cup of vanilla ice cream she brought with her. When she started talking I was no longer in that hospital crib, with Sister Thecla, I traveled all over the world starting with...
(Tekki puts on habit)*

The Catskills. (Lomnicki, *Blurred Vision*)

At the end of this quote, Tekki transforms into Thecla, putting on the red scarf as a nun's habit and speaking in a voice that reminds me of Edith Bunker's. The habit and the voice cue the audience that Tekki is now Sister Thecla. We also see from this quote how much Tekki loved the nun, who always made Tekki feel protected and special while she was doing her job of "getting better."

After recounting several stories about Tekki and Sister Thecla, Tekki tells her audience how the nurse distracted her from the reality of her situation.

That was when I got my first taste of a new addictive substance – drama! Sister Thecla became my pusher, tempting me with a sparkly turban, a nurses' hat, fancy pillboxes with feathers, a pink boa! (Mindy slithers this out from under couch) If I became someone else, I didn't have to be me. I didn't have to be in pain. I didn't have to be a little crippled kid. (Lomnicki, *Blurred Vision*)

While this scene references her disability experiences, Lomnicki is also using the notion of becoming "someone else" to appeal to many in her audience. Specifically, many disabled people can understand what she means about being a "crippled kid," yet, she easily connects this message with one we can all relate to – not wanting to be in pain and not wanting "to be me."

Thus, her particular experience reveals the universality of the “very true feelings” that accompany experience. The particularities of her childhood disability experiences meet and reflect her mature and cultivated disability perspective in this scene, and both build a bridge between disability and human similarities.

Additionally, the scene shows how Thecla represents storytelling, which became an important part of Lomnicki’s adult life. As a child, storytelling is a way to cope with the loneliness, fear, and stress of going through a long hospital stay. In the following scene, Sister Thecla is more direct with Tekki about how she can cope.

(Tekki as Sister)

*(Singing) Puff the Magic Dragon, lived by the sea. (Speaking) Now Mary Thecla everything's gonna be OK. What did I tell you? When you get scared tell yourself a story or sing a song. You can make yourself feel better. You don't have to rely on anyone else. Dragons may live forever, but I'll tell right now—I won't. And neither will the doctors or your parents. You gotta be big and brave like Puff the Magic Dragon. Sure, he was sad when Little Jackie Paper didn't come around any more, but do you think he died? No siree, the song leads you to believe that maybe he did. But I met him once when I was a little girl and he was alive and kickin'. Now promise me to be brave. (Lomnicki, *Blurred Vision*)*

Tekki’s mentor teaches her how to make herself “*feel better*” and that she does not need “*anyone else*.” Reminding Tekki to tell herself “*a story or sing a song*” is one of the important things she learned from her mentor. Lomnicki said:

It’s important when you’re going through an illness to have something to occupy your thoughts; your mind and your spirit. For me it was storytelling. [It’s a way to] soothe yourself and get yourself out of this reality as a way to cope. And ... sister Thecla was that bridge. (Interview 2)

Lomnicki points out how Thecla was “that bridge” that helped to occupy her mind and spirit.

Thecla had been important in bringing these coping strategies to Lomnicki, and showed her how to buffer painful realities with the wonder and adventure of storytelling.

In many ways Lomnicki still uses the safety of the theater and warmth of an audience to help her cope. For example, she explains that while dealing with post traumatic stress disorder (PTSD) and panic attacks, the audiences at *Blurred Vision* propped her up in a way that, “I never had a panic attack while I was on the stage because I had the people there,” she said in our second interview. In this way, performing her own story became a way to buffer the painful anxiety she was going through with a temporary bout of PTSD.

In the play, young Tekki seems to make the connection about how she can feel better on her own. After Sister Thecla tells her to “*be brave*” and reminds her about Puff the Magic Dragon, Tekki links these two things. She says:

(Tekki takes off the habit)

Be brave. Be brave. Be brave. (Sings quietly) Puff the Magic Dragon lived by the sea ... (Speaks) Puff would never leave me. He never left Little Jackie Paper, Little Jackie Paper left him. I want to fly on his back away from here. Away from the parallel bars, and those stupid ice chips and the yucky green beans and these dippy stuffed animals and these heavy casts. Puff! Come to me, I promise I won't grow up and leave you. (Lomnicki, Blurred Vision)

Reciting the encouragement to “*be brave*” and singing the old folk song, Tekki connects the two. These two things become a mantra to help her cope with all the things she hates about being confined. Her mantra becomes part of the story of Puff, and Tekki imagines seeing the mythical dragon.

(Puff appears above the bed either in a lit up window in the form of lights or maybe a gobbo. We see Tekki notice Puff in amazement)
(TRACK 13: Magical noise)

Let's go.

(Tekki comes out of hospital space and speaks)
From that night on, when nobody else would pay attention to me, I'd hum that song and Puff would appear in the lights of the hospital parking lot outside of my window and I'd fly with him until I finally fell asleep clutching his tail. (Lomnicki, Blurred Vision)

Puff transforms into a strategy for coping that Tekki discovers in childhood. And Lomnicki relates that this part of the story is a “touchstone.” She said, along with storytelling, “having Puff the Magic Dragon as a kind of spirit animal” was also a way for her to cope (Lomnicki, Interview 3). Apparently, imagining adventures with Puff engaged her mind and spirit and kept her hopeful and optimistic about her confined state.

Performing the stories about her disability experiences is a way for Lomnicki to build a bridge between disability and the world, including the communities she lives in: disabled and nondisabled. *Blurred Vision* utilizes her disability experiences as a way to focus on “the places where we are similar” in order to connect with her audiences (Lomnicki, Interview 3). One of the places we are similar is our need to cope with despair, loneliness, and hopelessness. Lomnicki is adept at finding the emotional similarities underlying her experiences to connect with audiences. She expands what may seem specific to her – a little person with a disability – to demonstrate that what mark her experiences as universal are “very true feelings.” *Blurred Vision* connects what may seem foreign to nondisabled audience members by bringing out what is common to the human experience. In this way, Lomnicki is able to feature her particular disability experiences, helping those that are not disabled to better understand that experience without alienating anyone. Her ability to build a bridge with her experiences creates a performance event that appeals to disabled and nondisabled audience members alike.

4. **Building community**

While Lomnicki bridges her disabled and nondisabled audiences with her performance work, she is also “building community” between these groups. Using universal themes that appeal to general audiences and disability themes that appeal to disabled audiences, Lomnicki intentionally creates performance projects that seek community to unite both.

Tellin' Tales theater's project, *Six Stories Up*, builds connections by pairing six adult mentors with six middle-school-aged apprentices to create a show. Five such teams, plus Lomnicki and the able-bodied lead kid, comprised of a mixture of disabled and nondisabled pairs, work together to write a performance piece that will be integrated into the show. I was recently cast as a disabled mentor for "Six Stories Up, Up & Away about a circus filled with superheroes. My apprentice was a thirteen-year-old nondisabled girl. The theater company states that this project is specifically about building community:

Adults and children, with and without disabilities, of all races, and income levels, work together on equal terms. Both adults and children learn lifelong lessons, self-esteem blossoms, and community is built where none existed before.
(Tellin' Tales Theatre, www.tellintalestheatre.org, 2013)

Thus, building community is central. And Lomnicki attempts to pair disabled kids with a nondisabled mentor, and vice-versa. In this way, she is not only trying to build community; she is building a bridge between disabled and able-bodied people.

Observations of Lomnicki's audience revealed she has a core group of followers consisting of mostly nondisabled people with a small group of disabled fans that support shows. Additionally, *Six Stories Up* is typically the only project that includes a combination of disabled and nondisabled performers. Lomnicki's solo show usually features her performance piece plus several solo pieces by able-bodied artists. In order to develop both sides of the communities she seeks to build, I wonder: Does her company's work regularly attract a disability arts and culture audience? Are the productions appealing to disability-centered audiences? I think my analysis reveals that many of them do, particularly *Blurred Vision*.

Lomnicki seems to value connecting her two worlds in a way that brings nondisabled people greater understanding of disability. It appears important for Lomnicki to express and promote the similarities between disabled people and everyone else. She strives to eliminate the

disconnection between mainstream society and people with disabilities – a disconnection that is ingrained in people through social and cultural messages. Lomnicki seems to prefer inclusive practices, as she demonstrates with her company’s *Six Stories Up* project, over separation or segregation.

Lomnicki’s practice of building bridges is also largely part of her personal interactions. I will discuss this in more depth during the section called “Performing Identity.” Both personally and professionally, Lomnicki approaches her role between disability and able-bodiedness as an ambassador. She helps each side navigate terrain on the other side. For nondisabled people, she helps them realize what unifies people: the common, relatable, human aspects that we all share. In addition, she is able to show them around disability culture, making it accessible and entertaining through her work. For disabled people, she reminds them of how the mainstream perceives disability, showing them around common misperceptions and demonstrating the importance of maintaining connections with nondisabled allies. In this way, building bridges makes disability part of the mainstream and makes the mainstream more welcoming and accessible. Lomnicki’s practice creates space within the mainstream for disability, disability arts and culture, and performances that foreground disability experience, while also creating community for all kinds of people.

C. **Representing Doctors, Subverting Medical Power**

1. **Introduction to this section**

In *Blurred Vision*, doctors, hospitals, and other medical professionals fill the play and seem to impose their will on the main character, shaping her perceptions, identity, and future. Present day scenes include specialists of all kinds as Tekki seeks a diagnosis for her symptoms. Lomnicki, taking on the mannerisms, vocal style, and attitude of each doctor in a

comedic way, performs each specialist. Yet, in the hospital scenes from childhood, no doctors appear: they exist only in relation to Tekki's parents or her nurse, and only when these characters talk to doctors. Why, then, does Lomnicki choose to represent the doctors she visits currently but keep the doctors from her childhood out of the play? Clearly doctors from her past, while unavailable in the play, leave a lasting impression on Tekki in the performative present.

The stark contrast between the two time periods of the play create conflict and tension for the main character. This story reveals a power struggle between Tekki and her doctors (medical power), and in the main character. Portraying doctors in the present, but not the past, suggests that Lomnicki seeks critique and subversion of pervasive medical authority undergirding her disability experiences. In this section I examine how Lomnicki portrays adult and childhood medical experiences in *Blurred Vision*, focusing on the contrast she shows in her medical treatment, and how she portrays its effects on her, including what her interview data reveal about these depictions.

2. **Opening with an edge**

Blurred Vision opens with Lomnicki's portrayal of her first visit to a neurologist for her symptoms. After Tekki speaks to the nurse, and as the doctor "enters," the actor puts on oversized glasses, a white coat, and picks up a clipboard, becoming Dr. C. She delivers Dr. C's lines as if doing a Dr. Ruth Westheimer impersonation, saying:

So. (Looking at clipboard) You had an MRI and now you think you have MS. But what is MS? And do you have it? I don't know. Give me your foot. Do you feel this? This? How about this? Good. (Lomnicki, Blurred Vision)

Tekki has her foot in the air here, while the nurse moves it. The actor breaks out of Dr. C momentarily to make grimaces and sounds of pain. Dr. C continues:

Now let's get some history. (Pulls out Dictaphone) I don't write anymore, I talk here, my nurse types later. Name... Uh ha. The patient's name is Mary Thecla Lomnicki. Nickname

Tekki. Period. End of paragraph. Age... The patient is 49. Period. End of paragraph. Profession? The patient is an advertising copywriter. Period. What? You write plays too. Do you write comedy or tragedy? The patient writes comedy. Period. End of paragraph. Ahh! I would like to slap that radiologist across the face. (Lomnicki, Blurred Vision)

Lomnicki is hysterically funny as Dr. C, with an accent, rolling her R's, and emphasizing certain words. She takes on an abrupt manner during this doctor's lines, using exaggerated facial expressions to ask about the kind of plays Tekki writes, and then sounds critical about Tekki's self-diagnosis. Lomnicki transcends herself in this scene because she is so funny as Dr. C that you momentarily forget that it is Lomnicki behind the big glasses and strange accent.

As the scene with Dr. C continues, Lomnicki shows her audience how she is treated, how she feels invisible, and how disability seems to create a barrier with new doctors. This manifests in her performance of Dr. C this way:

(Slide of MRI up)

MS! You see these white spots on your brain? (Nurse points to them with a long pointer) Lesions. Could be from your high blood pressure. Could be MS, but you display no symptoms. Headaches? Stress! You write comedy, stressful. Blurred vision. You got bad eyes. MS! Why do you want MS? Look at yourself! Don't you think you have enough problems? Lose weight. Come back in 6 months. (Lomnicki, Blurred Vision)

Clearly, the doctor dismisses Tekki and her symptoms, alluding to the fact that Tekki's body is already a "problem." The doctor seems to use Tekki's dwarfism and disability as evidence that she does not have a neurological concern, but for good measure throws in Tekki's weight. While it is a riotously funny exchange, the doctor has not taken Tekki seriously. Of course, the audience's laughter demonstrates that Lomnicki has not taken this doctor too seriously either.

With her outrageous parody of this neurologist, Lomnicki pokes fun at her doctor, and the rest of the doctors in the play, and turns them into exaggerated representations of themselves. By performing caricatures of doctors, she is able to disarm their authority, largely bestowed by

society and culture. At the same time, Lomnicki admits she worried about what these doctors would think. She said:

Like for example in *Blurred Vision*, all of those doctors are real, but the conversations that I had with them may have taken place over a few different sessions, and then I put it into one session. And of course, I exaggerate all of them. I mean, I think they'd know who they were if they'd see the show, but I'm hoping they don't. (Lomnicki, Interview 1)

Here, Lomnicki admits how she synthesizes some medical experiences and fictionalizes them somewhat, while still sticking with her lived experiences. "Exaggerating them" is how she makes them funny, but in the same breath she is concerned about the doctors seeing themselves in the show. When I followed up on this in our third interview, she explained:

Well, actually I hoped that if the doctors, if they did recognize themselves, I hoped that they could laugh at themselves, and realize that, you know I was doing it in good fun. And especially with the neurologist [Dr. C], with the first neurologist who says, "look at yourself, don't you think you have enough problems?" You know, "why do you want MS?" In fact, when I saw, when I was with him [doctor C], I thought, "I have to put you in a play." I even said that. Yeah, I just was hoping that if they did see it, they wouldn't be completely upset... I just didn't want to hurt their feelings, because I knew that they were doing the best that they could. (Lomnicki, Interview 3)

Lomnicki did not want to hurt the doctors' feelings, or make them "completely upset."

Nevertheless, she could not resist putting this doctor into her play, perhaps because she could see him as a comical character. Lomnicki reveals a paradox here. She hopes "they wouldn't be completely upset" by a piece that intentionally parodies medical experiences and her doctors, but she critiques the doctor through her parody of him, without intentionally pursuing a political attack.

In my first interview with Lomnicki, I asked her to describe her political point of view when it comes to representing herself as a disabled person. First, I phrased my question to her, asking her to "talk about politics in your work. Do you have a political point of view that comes across in any of your work?"

Lomnicki: I don't know what you mean by political point of view. Give me an example of another person maybe.

Thrower: I think of Susan Nussbaum, and I see that there is a way that you and Susan and Riva represent yourselves that is very different from what we see in the media.

Lomnicki: I think in my work I tend not to take such a political view as Susan does in that I kind of want people to know that I am like them more than not like them, you know – if that could be a political view. Yeah, I mean, that's more what I do. It's like, yeah, you are ignored by doctors as well, aren't you? It doesn't matter that I have a disability; this happens to everyone, kind of thing, I think is what my view is on disability.

(Lomnicki, Interview 1)

Basically, her political perspective is “it doesn't matter that I have a disability” because what happens to me is the same thing that happens to everyone. She expresses her primary strategy, building bridges, saying how being disabled is not so different from not being disabled. She also pulls out a universal idea from *Blurred Vision* that doctors ignore us all. However, I see more happening with her portrayal of doctors that could be construed as political.

When the scene continues, Tekki returns to playing herself and responds to Dr. C as he leaves the room, shouting:

(Tekki as self)

*But the headaches. The blurred vision. You gotta do something. What if I'm dying? What if I have early Alzheimer's? This would never have happened when I was a kid. The doctors would've listened. My parents would have made them listen. They'd do surgery. They'd fix it. (Lomnicki, *Blurred Vision*)*

Here is what she was referring to above. The doctor has ignored her concerns and she has not felt heard. In the same breath, she also references childhood memories of times that were very different. This scene also shows how the adult Tekki is frightened by the unknown and wanting, perhaps, her current doctors to “*fix it*” like when she was a kid. Yet, unlike her childhood, her parents are not around to “*make them.*” She introduces the contrast and tension of the play in this scene, where she is ignored as an adult and “*special*” as a child. As a result of her current situation, she seems to think she has no power, and everything is out of control.

As a disabled spectator, I could relate to many medical scenes in the play, and the play reframed them in a way that I could demand more respect from doctors. “And you know, a lot of non-disabled people have told me that, too, because a lot of them have had similar situations with different illnesses,” Lomnicki said in our second interview, holding fast to this universal theme: the power given to doctors by society connects us all. Also, this theme is very relatable to disabled audiences. Lomnicki’s portrayals of her doctors suggest that she wants to convey meaning and significance about the behavior and power medical professionals, and especially doctors, have. She wants to disrupt their power, lessen their status, and take her own power back.

Many disabled people can appreciate knocking doctors off their pedestals to reclaim authority over their bodies. Lomnicki portrays that she had many medical experiences, and she understands this also resonates with able-bodied people. In our first interview, I asked her if she is trying to change how disability is represented with some of her performance work. She said yes. “Just by what I choose to talk about... like how doctors treat us, or how death affects us or... how disability impacts the entire family,” (Lomnicki, Interview 1). She has chosen to create a more humanizing view of disability using these topics in her work.

I also wanted to know how doctors treat Lomnicki. In our third interview, she confirmed that she feels that doctors ignore her, but it is more a result of her impairments.

She revealed:

Sometimes I feel invisible with doctors and hospitals. It’s almost like well; she has a disability so this must be what this is about for her. I sometimes feel like I’m not taken seriously... So I feel very invisible there. (Lomnicki, Interview 3)

Of course, she can reclaim her power by turning her doctors into funny characters, parodying them accurately enough that they will be recognized. Lomnicki accomplishes a performative,

“good fun” attack on what doctors represent to her, to disabled people, and to anyone who has had similar experiences.

a. **The idealized childhood**

Moving between current and past experiences with medical professionals illustrates the distinction between now and then within the play, and this contrast is presented in multiple ways. For example, as a child, Tekki is treated “like a little princess,” was “*special*” then, and “*everyone wanted what was best*” for her. Surrounded by her parents and her nurse/mentor, she feels supported, but where are her doctors? Doctors from childhood were unseen and unheard in *Blurred Vision*, except in rare conversations that other characters have with them. In the following scene, Lomnicki as her Dad speaks to a doctor from her past. She mimes puffing a cigar, puts one hand on her hip, and makes her voice deeper and louder as Dad says:

(TRACK 4: (Voiceover) Visiting hours are now over)
(Sir visiting hours are over, you can't go in there. And sir there's no smoking in the hospital.)

(Tekki as Dad)
Don't tell me what I can and cannot do! My little girl's in there and I must see her. I demand to see the doctor. Get him here now! (To doctor) Doc, you gotta make my little girl walk. I don't care what it takes. I'll give up my goddamn pants factory if I have to.
(Lomnicki, Blurred Vision)

We see how Dad reacts to what is happening to his daughter, and how he deals with her doctors. Cussing and smoking, he demands that they make his “*little girl walk.*” This shows that Tekki saw her father as powerful, as most children do, and as someone who would “*make them listen*” and “*fix it.*” But, the doctor only exists through her father’s power.

Next, Lomnicki plays her Mom and speaks to the doctor. Her demeanor softens, her voice is smooth and song-like, and she explains their circumstances to the doctor.

(Tekki as Mom)

*Doctor you have to forgive my husband. He works late down in the city and she just waits for him to come and visit her. And you know I have two little boys that wait in the car while I'm up here, and God knows what they might do when left to their own devices. I just can't stay. So what I'm saying is, whatever you can do to look the other way, I would appreciate. Oh, and please ignore the language (like I do), his heart's in the right place. He just wants what's best for our little girl. (Lomnicki, *Blurred Vision*)*

Again, no doctor is portrayed in this scene. Lomnicki demonstrates her versatility as an actor, playing multiple characters including parents, her nurse and mentor, multiple doctors, and herself as child and adult. And while the doctors she portrays in the adult scenes are very entertaining, the audience is unaware of what the doctors were like when she was a child.

In order for Lomnicki's story to overthrow the power of doctors, she must demonstrate a power struggle. She does this by showing her adult self as powerless against doctors, while she creates a near perfect childhood in the hospital. In the following scene, Tekki visits a neurologist/ophthalmologist for her blurry vision. This doctor, also based on a real person, speaks slowly and slurs his words. His manner gives the impression that he's never seen anyone like Tekki before. He looks her up and down slowly and speaks haltingly:

*There's absolutely nothing wrong with your vision, and you don't exhibit symptoms of MS. You obviously have some form of dwarfism though. (Slide of MRI up) You see these white spots on your brain? If I went out on Michigan Avenue, grabbed 40 people and gave them all MRIs, about half of them would present these white spots and not have MS. And there is no indication here of a stroke. Mini or otherwise. To tell you the truth, I have no idea why your vision is blurred. Try cutting down on the caffeine and don't take acetaminophen or aspirin. Come back in six months. (Lomnicki, *Blurred Vision*)*

Once again, "Dr. 2" (Lomnicki, *Blurred Vision*), as this doctor is called in the script, is proficient at stating the obvious, but lousy at giving Tekki the answers she wants. He is able to second the opinion of Dr. C – an opinion that does not take her concerns seriously – and still leaves Tekki feeling frustrated and out of control. And of course, this doctor is another caricature, a cartoon-

like version of one of Lomnicki's physicians, who would likely recognize that is him in the performance. As Dr. 2 leaves her alone, Tekki exclaims:

(Tekki as herself)

Wait! Didn't you hear me? I have a headache and I can't take anything? Come back. You can't leave me alone... (Lomnicki, Blurred Vision)

Tekki uses the phrase “*you can't leave me alone*” to segue into the next childhood scene, but it also reveals that she is responding to the doctor *as if* still a child. She is scared, and without answers that make sense; she is thrown into a feeling of isolation like she had as a child. With this artistic choice, Lomnicki seems to be establishing emotional and psychological effects in the performance that linger beyond childhood. Although she is a grown woman, she still feels childlike. Her present-day doctors are treating her like a child, possibly due to her size, and causing her to revert to child-like responses requiring doctors to explain her body to her, even when not taking her seriously.

As a child, Tekki is more overt about her belief in all-powerful doctors. Having to spend so much time having surgeries to walk solidified her belief in doctors' abilities to “*fix*” her. In fact, her character tells the audience that she believed it was her primary job to “*get better.*” She says:

Everyone wanted what was best for me back then. And I got the attention I deserved. I spent the first 12 years of my life in and out of Resurrection Hospital and my sole purpose, my job, was to get better. And everyone supported me in that mission; from the moment I was born. (Lomnicki, Blurred Vision)

As a young child, Tekki's desire to “*get better*” was validated by “*everyone.*” There was no question: she was there for a reason. Getting “*the attention*” she deserved expresses the frustration with present-day doctors' lack of attention. Yet, having a “*mission*” as a kid to get better illustrates the reliance on medical expertise she learned at a very young age, which influences and reinforces her character's reliance on doctors at present.

Thus, *Blurred Vision* creates tension between the present-day conflicts with doctors and her idealized memories of medical professionals from childhood. Tekki must redefine herself and break free from her reliance on doctors in order to resolve this tension. She must reclaim herself and her body from medical authority, which, in many ways defines and controls impairment and the identities of disabled people. The narrative tension in *Blurred Vision* depends on this theme – reliance on medical authority – as both a universal and disability-specific theme in order for Lomnicki to resist and subvert it. Therefore, her character must disarm medical power, or her reliance on it, to move the story forward.

b. **“In reality, I had no powers”**

The fear of being out of control runs throughout *Blurred Vision*, and fear is also an important part of Lomnicki’s personal experience. She admits that being scared of what other people think of her has prevented her from interacting in the public sphere at times. In this play, she is dealing with the constant threat of the unknown: not knowing what is the cause of her symptoms, not knowing why doctors are not as concerned as she is, and not knowing what the future holds.

In the midst of performing this story about fear, Lomnicki was dealing with anxiety and panic attacks following a car accident. In fact, she told me in our third interview that she was being treated for post-traumatic stress disorder (PTSD) during the time of *Blurred Vision*. She said:

When I was going through my PTSD with my accident; it all came crashing because of the whole control issue. I didn’t have a car, I wasn’t in control, and I really had to ask for help. So, I was having really bad panic attacks. (Lomnicki, Interview 3)

This conversation reveals how fear, represented in her play, also functions in her life. For Lomnicki, fear is often the result of feeling out of control. In the play, she relies on her

character's need for control with constant reminders that she has very little control, especially during the adult visits with doctors. As a child, though, she felt more powerful. In the following scene Tekki is confronted with the reality of her time in the hospital as a child.

(Nurse brings out puppet strings and puts them on Tekki. Tinny carnival music plays)

*In reality, I had no powers in the hospital. My life was never my own. I was never alone. Just when I'd fall asleep, someone would wake me up. When my legs wouldn't move a certain way, they'd move them for me. I was no match for the villains. And everybody talked about me in the third person. "She didn't have a bowel movement again." "She's not getting enough fluid." "She's having a pity party, just let her cry." "Don't call Sister Thecla, she's spoiling her." (She finally snaps!). (Lomnicki, *Blurred Vision*)*

This is an important scene in the play. Lomnicki places it at about the midpoint, following several scenes in which young Tekki shows how fun and exciting her hospital days had been. But in this scene she confronts and acknowledges the truth of being confined, while the nurse fits her with puppet strings. It is like a moment of clarity and stark “reality” amidst all the rose-colored recollections of that time.

However, our heroine does not allow her lack of control to go on for very long. In the next scene, she reveals how storytelling and being a performer of her own material gives her a great deal of control. Tekki says:

*Stop it! I hate puppets. Get the hell out of here. I was in control back then, I wasn't a puppet. You made me say those things just now. In the hospital, I was the boss. My job was to get better and I did a good job. Change the lights. Bring back Sister Mary Thecla! (Hums Puff the Magic Dragon). (Lomnicki, *Blurred Vision*)*

Notice how she pushes the fourth wall aside to reveal that this is a play and her role in it. She becomes both her character and herself in this scene, speaking directly to the nurse character, and fighting for control. This is a particularly vulnerable scene because after the nurse takes the puppet strings away, she also empties that part of the stage, leaving Tekki alone. Feeling completely isolated and out of control without props is an apparently vulnerable place for Tekki.

Then, as Tekki hums the song, the nurse brings her a scarf that doubles as a nun's habit, and Tekki transforms into Sister Mary Thecla. It is a very powerful representation of fear and feeling out of control, revealing that reentering the performance provides a needed sense of control. Once the nurse returns Tekki's props, she also returns Tekki's power and control over the story.

Performance art requires the performer to be in control of the work, yet vulnerable to how the audiences perceive and respond to it. I asked Lomnicki how much control she has over audience's perceptions of her, of disability, or the work. She said, "I don't have any control over that, and yet I feel I have the power to win them over, and that's what I like to do" (Lomnicki, Interview 2). And she does win them over with her humor, charisma, and relatable stories.

By keeping her childhood doctors invisible in the performance, Lomnicki simultaneously portrays their power and overturns it. Because they are unseen and unheard, except in what others say to them, I am reminded of the wizard from *The Wizard of Oz* (Leroy & Fleming, 1939). He hid behind a black curtain in the film to keep his frailty and humanity secret. Lomnicki keeps the doctors behind the curtain in her childhood scenes, but reveals each doctor's human frailty in the adult scenes. The "all knowing, all powerful" must remain hidden to maintain the illusion of power, and this illusion is still granted by Tekki as an adult, even as Lomnicki overthrows it with her performative, political attacks. Pulling back the curtain as Lomnicki does during the adult scenes, their power is subject to scrutiny and being overthrown. Their humanity is exposed with humor and parody. Meanwhile, the powerful and invisible doctors of long ago leave a lasting impression on the little girl who is now a woman – until they do not.

4. Reclaiming power in *Blurred Vision*

At the end of *Blurred Vision*, Lomnicki makes a narrative shift. Before getting to this shift, it is important to note that her adult character will visit three more specialists in the story. Dr. Gina, who Tekki calls a “nutritionist/psychic/accupressurist/guru,” is also a hyperactive, over caffeinated, new-age doctor, who speaks very quickly. While waiting to see her, Tekki talks about how she came to know Dr. Gina.

My new age friend Debbie says that all death is really suicide. That we create everything that happens in our bodies. I don't think so! Do you? But hey, I've tried everything else in the past six months and my vision is still blurred. (Lomnicki, Blurred Vision)

Seeking a non-Western medical opinion appears to be Tekki’s final hope. With no more information than she started with, and has the same symptoms, she seems to need to exhaust every possibility for an answer. She is still skeptical, though, of this new-age option. She continues in the waiting area:

(Picks up a Conscious Choice magazine) Hmm... past life regression. (To audience) Have you had a past life regression? Me neither, but Debbie says that sometimes that helps. Maybe I did something in a past life that's causing all this. But I really think it's chronic fatigue syndrome, or fibromyalgia – but what if it's the Bird Flu? Do you think it's the Bird Flu? ... Well at least these natural doctors are more familiar with these sorts of things. Dr. Gina will listen to me. Hey, did she make you fill out this 10-page questionnaire? Jeez. (Lomnicki, Blurred Vision)

Tekki is resigned to looking at “these sorts of things” beyond the knowledge of the other specialists. At the same time, however, she is still worried that something catastrophic is going on in her body.

In the next scene, Lomnicki transforms into Dr. Gina, speaking rapidly. There is a chakra chart on the wall, and Gina flips through Tekki’s questionnaire on a clipboard. The nurse character mimes intuitive healing behind her,

So you think you're dying. Let's take a look. Un huh. Un huh. Digestive profile: Bowel movement daily. Un huh. Bad breath. Un un. Belching. Uh huh. Flatulence. Hmmm. Anal

*irritation. Oooo! Metabolic profile: Difficulty rising in the morning. Yup. Dizziness or irritability after 6 hours without food. Who wouldn't? Immune profile: Mouth ulcers, greasy skin, gritty eyes. No. No. No. Hon, if you think I'm Type A now, you should have seen me before I got healthy. Libido? The acupuncture will take care of that. Cardiovascular. Do you drink more than 2 alcoholic drinks per day? Maybe you should! Musculoskeletal. (Looks Tekki up and down and shakes her head) Emotional profile. Easily irritated? Angered? Impatient? Don't worry we're almost done. Headaches. Blurred vision. Ummm.... Could be mold. Toxins. I could come over and sniff your carpeting. But un un. Un un. Bingo. It's wheat. It's gotta be wheat. Cut out wheat chickie. And come back in six months? (Lomnicki, *Blurred Vision*)*

Once again, Lomnicki creates a comedic, albeit nontraditional, physician. Apparently, taking down medical authority is inclusive, and no one is left out. I also love that even this new age guru expresses ableism when in the process of diagnosing Tekki. Then, after the rapid monologue, Dr. Gina hits the nail on the head: “*it’s wheat.*” This is true, because Lomnicki eats a gluten-free diet and has as long as I have known her. However, in *Blurred Vision*, Tekki cannot believe this diagnosis. She exclaims:

(Tekki becomes herself again)
*Wait, but the blurred vision. The headaches. Wheat?! It can't be wheat. Besides, bread is my favorite food group. I live for pizza. I have an open box of wheat thins at home. I can't throw them away. (Lomnicki, *Blurred Vision*)*

Even when Tekki has finally been given a diagnosis, after six months of searching, she has difficulty accepting it. It’s been a long quest with many specialists: how could her answer be so simple?

Tekki is still skeptical about the wheat, and decides to confirm what she has been told. She goes to visit her new-age friend, Debbie, who recommended Dr. Gina to her. But what Debbie tells Tekki is also not what she expects to hear. Debbie says:

*What are your symptoms? Blurred vision? Let me look in my Louise Hay book. Edema, eczema exotropia. Ah... here it is... eyes. Eyes represent the capacity to see clearly – past, present, and future. Eye Problems. Not liking what you see in your own life. A refusal to look at oneself clearly. Tekki, what don't you want to look at? (Lomnicki, *Blurred Vision*)*

Debbie asks Tekki to reflect and examine her life in the way the Louise Hay book suggests. One of the interesting things about this scene is Lomnicki's use of Louise Hay. Reminiscent of another disabled performance art piece, *F**K the Disabled* by Greg Walloch (Walloch & Kabillio, 2001), he also consults a Louise Hay book to read about the spiritual significance of cerebral palsy. This, too, is unsatisfactory for him, and he says to his audience, "Fuck Louise Hay." Similarly, here's what Tekki says:

*Bullshit. I'm not afraid to look at myself. I am obviously very ill and probably dying of cancer or MS or Alzheimer's and you want me to take the blame for it. Manifest Shaminess! And as for the past, I see it clearly. I had a great childhood. I got lots of attention. People cared about me. I had the best doctors. The best nurses. They would do anything for me. I could press a button and someone would appear. I never had to touch the ground, I was carried everywhere. In the hospital, I was special. (Lomnicki, *Blurred Vision*)*

As Tekki argues for her idealized childhood and the power she believed doctors possessed, her body and her voice reveal that her fantasy about her childhood is starting to crack. She reiterates that she was "special," but then, she remembers one important fact about that time. She says:

*Once I turned 14, the doctors gave up on me. I was fired from my job of getting better. Nothing was going to change. There would be no miraculous cure. I instantly became like the kids I rode with on the handicapped bus. (Lomnicki, *Blurred Vision*)*

Here is where the narrative changes. As her childhood fantasy crumbles, and she remembers that her "doctors gave up on" her, is the moment in the play that brings childhood into focus, and Tekki sees everything more clearly. She remembers going back to school after leaving the hospital, having to ride the short bus. She recalls how the kids called her names like "ortho" and "gimp." But, nothing changed, and she admits to her audience:

And now life is... life. Working and paying bills and working and paying more bills. And living alone. And being alone. But in the hospital...

*(TRACK 18: ER Theme Up)
Yelling)*

Prep her for surgery. I need a CBC a Chem 7, get a chest film, we need a breathing tube. Stat.

(ER Theme Up Abruptly out) (Lomnicki, Blurred Vision)

Tekki plays out her fantasy of what the hospital was like, adding the familiar drama (and the music) from a common scene in the television show *ER*, and poking fun at her need for “*drama*.”

Lomnicki shifts the narrative of *Blurred Vision* with her revelation. When her doctors give up on her at 14, and “*nothing changed*,” Lomnicki reveals both the reality of her experience, and a new, more realistic trajectory of the play. Lomnicki is familiar with the ways disability stories are typically told, which is why she has been hinting at an inspirational tale that provides her some kind of “*miraculous cure*.” In the process of telling her personal story, she challenges cultural narratives of disability while taking back her power from medical authority. She reclaims identity as a disabled person for herself and for others as she also reclaims disability representations from the dominant culture.

With each scene where she parodies a doctor, Lomnicki pulls back the curtain on medical power. Her approach grabs audiences’ attention because she intentionally inserts relatable themes. But at the same time, her relatable scenes make doctors more human, and also reveal how they add to disability oppression. Lomnicki not only subverts medical power, she also reconstructs typical disability stories by telling hers, which is closer to reality than TV and film, and contributes her performance to disability culture. It is a riotously funny revolt.

D. **Disability Culture in Lomnicki’s *Blurred Vision***

1. **Introduction to this section**

Lomnicki, like many disabled people, dwells in both the nondisabled world and in disability community and culture. She has learned the language and imagery of the dominant

culture along with the contours of disability culture, and understands how disability narratives from the mainstream influence and perpetuate perceptions of disability. Lomnicki uses her knowledge to render disability culture as artistic representation, translating it for her nondisabled audiences while celebrating and connecting with disabled audiences. In other words, Lomnicki's presentation of disability culture bridges the communities she inhabits.

Many disability culture performances celebrate, share, and/or critique experiences from the performer's perspective. They become part of the fabric of disability culture as they claim and re-interpret disability. Many include origin stories – an account of how impairment began – and some may also include stories of medical interventions, normalization, and coming to terms with personal differences. *Blurred Vision* is a disability culture performance; an origin story that appeals to disabled audiences *and* general audiences. Thus, *Blurred Vision* addresses a specific portion of the population while it also speaks to the common humanity in everyone.

This section delves into the ways that Lomnicki performs disability culture in *Blurred Vision* for the communities she inhabits. How does her performance of disability culture, while not overtly political or transformative, retain power and relevance for disabled audiences? How is disability culture translated into commonalities and made accessible to nondisabled members of her audience?

2. Origin story

Blurred Vision tells Lomnicki's disability origin story. An origin story typically includes impairment onset and medical treatment. Tekki presents her beginnings as a kind of flawed miracle. Newly born but not breathing, her nurse brings her back to life:

The story made me famous at Resurrection Hospital – once Sister Mary Thecla and sprinkled that good old Chicago tap water on my forehead I came back from the dead. Cried like a banshee. And forever bore the name of Saint Thecla, a heroic martyr from Thessalonica. A pretty big legacy to live up to. I got the martyr part right. At least my

*parents had the where with all to shorten Mary Thecla – to Tekki. The story should have ended there with “and they lived happily ever after.” But my legs were twisted like those soft pretzels you get at the airport. And the story was all about making the little crippled girl walk. (Lomnicki, *Blurred Vision*)*

In her story, Lomnicki calls attention to her impairment in a minimal way during this scene.

Medical concerns are also minimally described. Lomnicki never names her condition(s), the reason for her crutches or what type of dwarfism she has. In fact, she does not talk about her body in any medically substantive way. “The only time I refer to it in the show is when I say my legs were like a twisted pretzel” (Lomnicki, Interview 2).

Blurred Vision provides little medical explanation for the causes of impairment or the extent of limitations. Other origin stories in disability culture, such as *Sassy Girl*, (Wade, 1995) leave out discussions of diagnoses and limitations as well. One reason for this could be to dispel the power that medical expertise already holds over disabled bodies, especially when the story deals directly with medical authority. Wade explained that if she stated her diagnosis, then the audience could dismiss the rest of the story because they could not relate to it (Wade, Interview 2). Apparently, discussing diagnosis and treatments needs to be pertinent to the story. In *Blurred Vision*, the audience understands that, because of Lomnicki’s legs at birth, she needed to spend many years in the hospital. This makes her disability story accessible to everyone in her audience without confusing or excluding anyone. In this way, Lomnicki allows her origin story to lead with its common humanity and carry her portrayal of disability forward with all audiences.

3. **Contextualizing disability in performance**

If a visibly disabled artist performs, is that performance considered disability culture because of the performer? Lomnicki’s visibility allows her to tell a disability story without talking about her body, since that part of her story is already evident. Like other disabled, gendered, or visibly different artists, she may find it difficult to leave out the reality of

her body in performance. Such performances become disability culture within the content and context of the artist's performed experiences.

What do I mean by contextualizing disability experiences? Lomnicki places her experiences within the framework of disability culture. This framework asserts privilege and value to disability; it foregrounds the artists disability experiences and the perspective(s) gained from them. This framework also promotes self-making for disabled people, which claims identity and community with other disabled people while rejecting imposed and oppressive definitions by able-bodied society and culture. It also rejects disability stereotypes without striving to meet (or exceed) able-bodied expectations that have been perpetrated by dominant culture and society. Generally, the disability community defines a disability culture framework through discourse: shared stories, activism, artistic practices, new representations and narratives, and cultural products and concepts for and by disabled people.

Seeing Lomnicki on the stage, it is impossible not to notice her size, how she walks and moves, or her crutches. It is obvious that she “has a disability.” The visibility of her body would always create its presence. I wondered how her visibility as a little and disabled actor could be denied. How could she possibly get around the fact of her own body? During our third interview, I followed up with Lomnicki:

OK, you would notice that I have a disability because of course I have a disability. But you might think that I'm not *aware* of it because I wouldn't talk about it. (Lomnicki, Interview 3)

Thus, she admits that in certain performance pieces, such as *The Quartermaster's Daughter* (2003, unpublished manuscript), disability is unimportant, and since she does not “talk about it,” the audience may not think she is “aware” of her size or impairments. Her role in that piece is as a daughter, and it deals with the death of her father, so the lead could, theoretically, be played by

anyone, disabled or not. Yet saying that the audience may think that this visibly disabled performer is not aware of her body is in opposition to what they see. Lomnicki's choice not to talk about it suggests that she can make disability momentarily transparent through skilled acting. Or she can render her disabled body irrelevant in a performance by failing to call attention to it.

Lomnicki frequently performs disability as given, unstated fact, and without calling attention to or talking about disability. This happens in *Blurred Vision* at the beginning of the piece, and particularly when she plays herself in the present time period. Without talking about her size or any physical barriers she encounters, she lets her physical presence explain these ideas wordlessly. She does express attitudinal, social barriers, though, by calling attention to them through other characters. Dr. C is the first character to contextualize Tekki's adult experience when he says: "*MS! Why do you want MS? Look at yourself! Don't you think you have enough problems?*" (Lomnicki, *Blurred Vision*). Up to this point, the play does not mention disability at all, except to hint at it by referring to her "*able-bodied assistants*" (Lomnicki, *Blurred Vision*). With this statement, however, Dr. C illuminates Tekki's "*problems*," In one line, Dr. C devalues Tekki's body and size, and provides the audience with a clue to how others perceive her. If the audience believed she was not aware of her body before, they know it now.

As *Blurred Vision* progresses, Tekki contextualizes her experiences. She deals with and discusses many socially and culturally ingrained messages about disability from the perspective of a little girl. As a child, she is outspoken about how she understands her own physicality and how she thinks others perceive her. In a scene where she uses the word "*crippled*" about herself, we see how the adults in her life react, and how she deals with that.

Tekki uses the word “*crippled*” in the previous scene to transform into another character: her mother. But Mom is not happy with her daughter, nearly yelling these lines:

(Tekki as Mom)

"Don't you ever ever use that word again! Where did you hear it? Tell me those boys' names and I'll go right over there and tell their mothers. You are not "crippled." Do you hear me? And what did I tell you to say? Sticks and stones may break my bones, but names will never hurt me." Say it!

(Tekki as herself)

Sticks and stones may break my bones, but names will never hurt me. I even liked the attention I got when the boys called me names. At least they noticed me. Besides, one day I wouldn't be (whispers) "crippled" or "handicapped." If I were brave enough, if I waited long enough I would be normal.

(TRACK 6: Reverb on normal). (Lomnicki, Blurred Vision)

Tekki recites the old mantra without conviction. Having an understanding that she was “*crippled*,” she enjoyed even the negative attention she received. The way she uses the term is not offensive to her. But she portrays how most people, represented by her mother, interpret that word. Mom’s reaction is typical of how society wants to avoid disability, euphemize it with nicer words, or simply not discuss it at all. Tekki’s mother’s reaction is what my mother would have said when I was a child. Perhaps avoiding this term, unable to be “*crippled*,” reinforces Tekki’s desire to be “*normal*.”

Blurred Vision addresses how the adults in young Tekki’s life influence her ideas about these terms. Yet, the play also allows this idea of “*normal*” to grow and change with the main character. In the scene above, where “*normal*” first shows up in the play, Lomnicki is playfully referencing *Heidi* (1937), her favorite film as a kid, with the technical note of “reverb” on that term. As I explain in my essay about *The Miracle* (2007), *Heidi* had a huge influence on Lomnicki, and one particular line from the film seems to recur in her performance work. “At the end of the movie, when Klara walks through the miracle of Heidi’s intervention, she delivers the

blissful lines: “I’ll be normal! Normal!” (Thrower, 2013, p. 209). I interviewed Lomnicki for this essay, and she explains how she related to Klara. She said:

I remember thinking, “Wow, here is a girl like me who can’t walk like other kids” so I related to her. Then I was impressed that she walked at the end and I was also hoping that there would be a miraculous cure for me someday. (Lomnicki, quoted in Thrower, 2013, p. 209)

In this way, the reverb on the word “*normal*” is a subtle homage to *Heidi*. What her *Blurred Vision* audience sees and hears is an echo on that word, like Klara’s repetition of it, and Tekki looking around to locate its origin. It is a funny way to incorporate this influential film while also making fun of her obsession to someday “*be normal*.” Relating to Klara and hoping for her own “miraculous cure” is a large part of the personal story Lomnicki is telling in *Blurred Vision*. Though Lomnicki really believed she would be cured, she never said this to me during our interviews. However, she does talk about her belief in being cured in the documentary film *Code of the Freaks* (Sandahl, Nussbaum, Patsavas, & Chasnoff, 2011). In the following clip, Lomnicki speaks about how she believed she would be “*normal*” in the same way she saw it happen in the movies.

And I had this, like, crazy notion that I would someday be *cured*. Now I don’t know if that meant I was gonna grow tall, or did that mean I could walk without crutches. I wasn’t quite sure. But I used to have a dream that I was tall and I did walk without crutches. (Lomnicki, quoted in Sandahl et al., 2011, emphasis mine)

Lomnicki delves further into how she reached this “crazy notion” in her performance piece *Thanksgiving* (1996). This autobiographical story deals directly with Lomnicki’s Catholic upbringing and how her mother’s faith influenced her hopes for a miracle (see Thrower, 2013, for a discussion of faith, *The Miracle*, and *Thanksgiving*). Apparently, Christians, Catholics, and other religious groups place expectations on children (and adults) with disabilities that, with

enough faith or prayer a miracle will be bestowed. This was true for me, being raised by Southern Baptists, and when I was not “cured” it felt like failure.

By contextualizing “*normal*” for herself, as the above scene depicts, Lomnicki makes *Blurred Vision* a disability culture performance. As a child, her character puts an idea of normal into play that speaks to several disability-related issues. First, it speaks to the confused messages that disabled kids can interpolate from the world about themselves, especially when these messages are about disability. Young Tekki remarks about how she likes the attention she gets from being “*crippled*” and understands that such terms are out of bounds of “*normal*.” Second, it speaks to society’s expectations – we all must measure up to what society deems “*normal*.” For young Tekki, this means that she must be cured – tall, able-bodied, and crutch-less. Finally, it speaks to an impossible standard that eludes disabled people: “*normal*” requires ability, beauty, pace, perfection, intelligence, and strength. These socially and culturally ingrained messages, while relatable to everyone, are particularly salient to disabled people who usually fail to meet the standards. Tekki contextualizes her childhood ideas of how she will achieve cultural standards: “*if I am brave enough, if I waited long enough, I would be normal*” (Lomnicki, *Blurred Vision*), yet these highly praised attributes will never make her “*normal*.”

While Lomnicki contextualizes the concept of “*normal*” in *Blurred Vision* for disabled audiences, she also frames it as a universal experience. The concept of “*normal*” is important for Lomnicki as well as for her character. In the play, Tekki herself introduces “*normal*,” but in the following scenes, the concept becomes reinterpreted by other characters in her life. From where the scene left off above, here is how it continues from Tekki’s past and into her present, just before she enters another doctor’s office.

(Tekki as Dad)

Normal? You're no different from the other kids. Stop your whining or I'll give you something to whine about. No daughter of mine is gonna be a pansy. Pretty soon you'll be up and playing baseball with your brothers.

(Tekki puts on habit)

Mary Thec, stop using that word normal. Who's normal? You think Barbie dolls are normal? They don't even look like real women. In all my years seeing women's bodies as they give birth, not even one looked like a Barbie doll. Normal!

(Tekki walks to waiting room as herself)

*I don't even know what's normal anymore. Everything's so damn blurry. (Lomnicki, *Blurred Vision*)*

Lomnicki cleverly continues this thread of “normal” through several characters. Dad says “normal” means being like everybody else. Sister Thecla tells her not to use the word, and explains how Barbie dolls fail to be normal. Both of these characters express common notions that can be applied to anyone. And for herself, she would just like her vision (and life) to go back as it was. Lomnicki is defining this concept beyond her body and toward a more universal, and unattainable, measure of being human.

In the following quote, taken from an interview with Lomnicki for *The Miracle*, Lomnicki relates how she uses ideas about “normal” in her work, including *Blurred Vision*. She said:

I wish to work against the idea that in order to be whole, functioning individuals, people with disabilities have to be cured or look like everybody else. In my work I like to reveal myself to people, crutches, short stature, emotional scars and all. It took me a long time to accept myself and stop striving to be “cured” or “normal” and I like to put that in my work. (Lomnicki, quoted in Thrower, 2013, p. 210)

Lomnicki reveals how, to “stop striving” to be “normal,” she revisits these ideas in her work, including *Blurred Vision*. These concepts have been a large part of her lived experience. In the play, issues of being “normal” stem from her size and disability, as they do in her daily life. But,

she also understands that society's concept of "normal" is for everyone. We all feel that we do not or cannot live up to society's standards and expectations.

Contextualizing experiences within a performance involves getting a sense of how she sees herself. Lomnicki likes to reveal herself in her work, expressing emotional scars, strengths, and body issues. She includes her crutches and movement, even though this is limited. She is not afraid to reveal her identity because has "come out" as a disabled little person, which I discuss later in the chapter. In *Blurred Vision*, Tekki reveals congruence with who she is, and finds her own meaning of "normal." The final line of the play is:

I took a deep breath and looked, really looked at my past, present and future – and finally saw myself. Normal. Just the way I am. Period. End of paragraph. (Lomnicki, Blurred Vision)

This closing message is in line with disability culture, which values disabled people as they are (acceptance) and allows life with disability to be defined with self-acceptance and self-determination in mind.

4. **Performing disability culture**

In addition to contextualizing disability experiences, Lomnicki also exploits her familiarity with disability culture by performing some of its tenets. This is a way that she can speak directly to this community, marking her performance a disability cultural production. Meanwhile, she also uses her ability to excavate the common ground in her stories to connect with everyone in her audiences.

Lomnicki takes on two more overt acts of disability culture in her performance. First, she engages with and redefines the "supercrip:" an inspirational over-comer, who is much admired by dominant media. Tobin Siebers, in his 2008 *Disability Theory*, has a more detailed description

of the “supercripple,” usually portrayed in biographical films and journalistic human-interest stories. He writes:

At other times, a [human-interest] story will work so hard to make its protagonist “normal” that it pictures the disabled person possessing talents and abilities only dreamed about by able-bodied people. In other words, the hero is – simultaneously and incoherently – “cripple” and “supercripple.” (Siebers, 2008, p. 111)

Blurred Vision takes on the incoherent duality of “cripple/supercripple” traits, but this time to poke fun at the character by “possessing talents and abilities” usually “only dreamed about” by *disabled people*. Lomnicki never uses the term “supercrip,” familiar to both disabled and nondisabled audiences – because her version of this parody is meant primarily for the disability community and culture.

Second, *Blurred Vision* utilizes a revolutionary tactic in solo autobiographical performance: it includes a “personal assistant” for its disabled solo artist. A personal assistant is someone hired by the disabled individual to assist her with personal tasks like bathing, dressing, cooking, cleaning, and other needs limited by impairment. The nurse character, while useful to the overall entertainment value of the show, adds accommodation and assistance via an interdependent relationship that is enacted within the performance. The assistance is real, while also performing a valuable tenet of disability culture and community. The nurse character within *Blurred Vision* becomes both a real and performed personal assistant. Next, I will explore Lomnicki’s artistic insertions of interdependence and the “supercrip.”

a. **Performing interdependence: Putting a personal assistant in the act**

Blurred Vision embodies and celebrates disability culture as Lomnicki and the nurse enact interdependence onstage. Lomnicki and “regular” sized actress and friend, MK, create a striking visual contrast to one another, as MK portrays Tekki’s many “*able-bodied assistants*” (Lomnicki, *Blurred Vision*). Dressed in a pink nurse’s uniform, wearing white fishnet

stockings and sensible white shoes, MK twirls onto the stage, ever-present, yet never speaking a single line. Her presence and the integrated ways they work together in this performance, represent “interdependence” for Lomnicki. She states:

At the beginning of the show I say, “My able-bodied assistants took many forms,” and I think that’s like a metaphor for everybody in my life. I have a big thing about interdependence. I just feel like I use the world to be there for me. Like, I’m not afraid to ask for assistance anywhere that I am. To be able to ask, I find that people really want to help and sometimes that is annoying as all get out, but when I need it I like to tap into it and that is what MK really represents. (Lomnicki, Interview 2)

Tapping into people’s willingness to help in her everyday experience is “what MK really represents.” Because the nurse character (MK) is present throughout the play, this is a prevalent theme, but it is not overt. Interdependence is seamlessly woven into the performance without any discussion or fanfare in the play, yet it underscores the entire performance. Since Lomnicki does not spell out MK’s presence in this solo play, recognizing this character’s significance requires some insight into disability community and culture, including what interdependence means for disabled people.

Lomnicki’s use of an onstage personal assistant or accommodation depicts interdependence in several ways. First, the character of the “*able-bodied assistant*,” who “*takes many forms*” in the performance facilitates the play. By acting out other characters such as an anonymous intake nurse at a doctor’s office, a doctor examining Tekki’s body, or a named character like Sister Mary Thecla, Lomnicki is able to bring this multi-faceted script to life and tell a more comprehensive story. The extra actor allows Lomnicki to enact scenes more thoroughly than she can alone. Second, the nurse acts as a prosthetic for Tekki’s body and imagination. With movement and dancing, the nurse can become the tall, able-bodied version of Tekki that she dreams of being, and can perform physically what Sister Thecla does. Third, the nurse character is an accommodation for Lomnicki, doing what Tekki cannot. For example, the

nurse character propels the wheeled office chair around the stage, carries Tekki onto a bed, and acts as a roustabout during the play, producing props for each scene. Fourth, this assistant provides contrast for a disabled/nondisabled binary, which continually emphasizes Lomnicki's size and impairments. With this able-bodied character visible alongside Tekki, the audience cannot lose sight or awareness of disability, either its represented or real lived form. Finally, interdependence is performed in each scene. The nurse character is dependent on Tekki's character(s) to speak the lines she mouths, or to give direction through the script, while Tekki's character(s) depend on the nurse for certain actions. Both actors rely on one another to help with the script. Lomnicki said:

Her energy assisted greatly: MK herself has a very light energy, a very fun energy, and just brought me up every time... I always felt safe with her because if I forgot something she could help – not with words, but with movement. (Lomnicki, Interview 2)

Thus, not only was the actor an physical accommodation for Lomnicki, the nurse also provided emotional and memory assistance during the performances.

In the next few scenes from *Blurred Vision*, I want to look closely at how interdependence, accommodation, and contrast play out during the performance. In the following scene, Tekki recalls her mentor Sister Thecla's influence. A young Tekki decides that when she grows up, she will become a nun like her nurse. Here, she also sets up the next sequence: a parody of the 1966-1973 TV series, *Mission Impossible*.

(*Tekki as herself*)
I imagined Sister Mary Thecla as Maria Von Trapp from the *Sound of Music*, innocently causing trouble in the convent.

(*TRACK 7: How do you solve a problem like Maria (from The Sound of Music) Nurse puts on habit and dances around like Maria. Tekki clears her throat as if to scold her.*)
(Lomnicki, *Blurred Vision*)

This is a cute distortion of the fourth wall. The nurse character thus far has been an object for Tekki to project whatever character Tekki was not able to inhabit, making the nurse into a living prop. But here, it is as if the nurse claims some agency, and does something she is not supposed to, like dancing “*around like Maria.*” But, I also see that the nurse in this scene becomes Tekki, playing out her dream or fantasy for the future. In this way, the future reality becomes clear: Tekki will not manifest what the nurse character so easily imitates – a tall able-bodied nun.

Tekki continues:

Pretty soon, I wanted to become a nun because I had developed a big crush on Captain Von Trapp, but really – I longed to wear a habit just like my mentor Sister Thecla and be just as rebellious as she was. Well one evening I got my chance. It was just like my favorite TV show... Mission Impossible. (Lomnicki, Blurred Vision)

Notice how young Tekki reveals she wanted to be just like her mentor, setting up the next scenes. Using a voiceover track, the audience hears Sister Thecla’s “*mission*” to “*smuggle the little girl*” through the hospital and into the nuns’ dining room.

(Nurse puts Tekki in the rolling chair and stands behind her as Sister T miming the escape. Tekki speaking very quickly)
Just before dinner one Thursday evening, she rolled a laundry bin into my room and lifted me down into it, then covered me with a clean white sheet. And we began our escape. (Lomnicki, Blurred Vision)

While Tekki is in the “*laundry bin*” the nurse is fully in character as Sister Thecla, mouthing (but not voicing) the words that Tekki delivers as the nun. In the script excerpt below, words without quotes indicate Tekki’s narration of the scene, and words within quotes are still in her voice, but are mouthed by the nurse character.

(TRACK 9: Mission Impossible Theme. TRACK 10: End of theme)
The wheels squeaked over the green linoleum and I felt every crack, my casts flying up in the air when we accidentally careened into walls. We rolled past the nurses’ station. I held my breath... “Good evening sister, got a new job in the laundry?” “Sure do... pays a lot more than nursing!” Once we got in the elevator, I peeked out from my sheet. The basement corridor was dimly lit and ominous. I heard footsteps and held my breath again. “Hello Doctor! How was surgery today?” While he answered, Sister Thecla

*parked my laundry bin in the doorway of a huge room, whose walls were lined with big metal drawers. A man was sleeping on a gurney and he looked very very pale, and he had a tag on his toe like from the Ben Franklin store. His shoes were on the floor underneath him, I remember they were black wing tips like my Dad's. All of a sudden the laundry bin jerked forward, we went up another elevator, then out into a room of ladies voices. Sister whipped the sheet off, lifted me from the bin and into a big chair at the head of a massive dining room table. She put a white napkin over my head and said "Sisters, I'd like to introduce you to our brand new novice, Sister Mary Thecla, Jr." (Lomnicki, *Blurred Vision*)*

Even though Tekki is visibly sitting in a rolling chair, it is easy to imagine her small frame in a laundry cart. The *Mission Impossible* theme is playing in the background, and as Tekki's narration and dialogue speed up, the combination adds to the comic drama of the scene. The nurse adds a great deal to the performative quality of this scene, because not only is the nurse mouthing and acting out her lines as Sister Thecla, she also moves the wheeled chair, with Tekki in it, around the stage. At the end of the scene, the nurse lifts Tekki into a regular chair and wraps the red scarf around her neck, to simulate the napkin, and then both Tekki and nurse grin widely, displaying "jazz hands" for the final words – fingers wide, palms facing out and waving to punctuate the end of the mission.

This scene is fun and very entertaining while demonstrating the interdependence between the two actors. For this scene to work as well as it does, Lomnicki needs the nurse to physically play Sister Thecla while Tekki plays her child self, since Lomnicki can only perform as a passenger in the "laundry bin" and not propel herself around the stage. The movement around the stage, along with the music and Tekki's voiced narration enhance the drama and comedy of this scene. The play retains its solo quality because Tekki is doing the voice work for both characters. This scene demonstrates interdependence through shared labor while enhancing the value of the performance, and making its audience laugh out loud.

Lomnicki and MK demonstrate their dependence on one another, which creates a synergistic and powerful performance. The word “interdependence” means “dependence between things” according to www.vocabulary.com. Yet, when speaking about interdependence among disabled people, it means so much more because it also refers to the use of a personal assistant (PA). A PA provides many things to disabled people who use them, such as: help with activities of daily living (ADLs); aid with getting into wheelchairs, reading mail, or driving a car; and support with medical tasks like testing blood sugar, using a ventilator, injections, or catheters. In many ways, PAs mean freedom, independence, and agency. In other words, interdependence, in terms of using a personal assistant in an inaccessible world, means empowerment.

In our third interview, I followed up with Lomnicki about this theme of interdependence, focusing on how it happens in her daily life. Lomnicki, as I have observed, does not seem to have any difficulty asking for what she needs from anyone who can help her, but she also likes to give to others and help people when she can. Her response to how she learned interdependence in her life, however, actually surprised me. She said:

I came to it kicking and screaming. I had a very hard time with [interdependence]. It was with my first therapist, Marsha, that I talked about in my piece *Striptease*, that where I didn't even want to be noticed as a little person or as a person with a disability. And so that meant I had to be like *supercrip* of doing everything myself even when there were others around who could help me. And she herself [Marsha] had grown up with polio, this therapist, and she knew all about that. So she called me on it. And she was like, OK your assignment this week is to ask for assistance three times. And I'm like, well what if I don't need it. And she was like ask anyway, you know, and see how it feels and how people react to you. And little by little it worked out great because I saw that it was OK to ask for help and that people were willing to do it. And then I just naturally do it now. And probably, and I find, and who was I talking to with somebody about this? It's funny because I have some way about me that even people with disabilities want to help me. I don't know what this is about me and at first I thought, well it's because I'm pathetic, you know? I don't know that it's that, it's just that people really want to take care of me and it's OK. I, I'm allowing it. I like being taken care of yet, in many ways I don't need

to be. But I don't know, maybe I have this openness to that, like I don't have a wall against it. (Lomnicki, Interview 3, emphasis mine)

It surprised me that Lomnicki said she came to being able to ask for, receive, and offer help (interdependence) “kicking and screaming” because she makes it look easy and natural. I did not know her when she was going through this, but it is interesting to hear her describe a period in her life when she felt she had to prove independence. This was when she was a “supercrip:” “that meant I had to be like *supercrip* of doing everything myself even when there were others around who could help me.” Of course, now, her attitude about receiving or asking for help is more congruent with what I have observed.

The quote above is a great lead into the next topic, which deals with the supercrip. Notice how Lomnicki defines the term as “doing everything myself.” This definition is accurate, because she is describing herself as a kind of overachiever, feeling like she needed to do everything even though she could have asked for help. For many people with disabilities, this turns into a stressful, exhausting, and symptom exacerbating situation; the supercrip's behavior is often to the “supercrip's” personal detriment. In Lomnicki's case, based on other statements she has made, her supercrip behavior was an attempt to appear, and to be, normal. Thus, being a supercrip during that time was more about how she wanted to be perceived by the able-bodied world – she had not yet come to terms with her identity. Additionally, this is what Siebers means by speaking of disabled heroes, from human-interest story fame, as “simultaneously and incoherently – ‘cripple’ and ‘supercripple’” (Siebers, 2008, p. 111). Lomnicki was disabled or “crippled” but she wanted to be seen by others as “normal,” which meant performing everyday activities as the “supercripple.”

In the next section, I continue my exploration of disability culture as it is portrayed in the “*Super Patient*” scenes from *Blurred Vision*. The “*Super Patient*” toys with the notion of the supercrip while also tapping directly into disability culture.

b. **Performing the “*Super Patient*”**

As I stated earlier, the supercrip character, which usually arises from mainstream media, also appeals to the mainstream. This idea that disability can be overcome or “wiped away” with the achievements or abilities of the disabled hero is confusing. It is, to use Siebers’ term, “incoherent” (2008). But it is an attempt by mainstream media to make disability a more comfortable topic for public consumption: less frightening, less threatening, and more realistic, while not quite representing reality.

In *Blurred Vision*, however, Lomnicki performs her version of the “supercripple”—appealing to both mainstream and disability culture. In Lomnicki’s version, she gives Super Patient super powers beyond disability. In Siebers’ model, human-interest stories turn the person’s impairment into her or his talent. The “supercripple” has developed, as a result of having disability, a talent that succeeds beyond normal people (Siebers, 2008). And while “supercripples” achieve amazing feats, like scaling a mountain or world championship surfing, the human-interest stories about them rarely address how these heroes handle more pragmatic, mundane obstacles. In Lomnicki’s story, she creates a character who is talented and able above most disabled children or adults, above most people in fact, who are stuck in the hospital.

Blurred Vision focuses on Tekki as a child, and what it was like for this “*crippled girl*,” to spend many years in the hospital “*getting better*.” While there, her nurse and mentor, Sister Thecla, tries to keep the lonely and precocious child entertained. Right after the *Mission Impossible* scene, Tekki recalls: “*If I became someone else, I didn't have to be me. I didn't have*

to be in pain. I didn't have to be a little crippled kid. I could be SUPER PATIENT!" (Lomnicki, *Blurred Vision*). This, too, is another interesting transition within the piece. Tekki and Thecla's "escape" depicted in the *Mission Impossible* sequence can also be interpreted as a kind of escape from reality, as Tekki reveals here how she needed to escape the reality of "pain" and being "a crippled kid."

And now, being addicted to "drama" she creates a new character for the next drama-induced escape from her reality: "*Super Patient*." With the theme from Superman playing and red lights flashing, Tekki ties the red scarf around her neck like a cape and says:

Able to leap out of my hospital bed in a single bound (even in a body cast), I am impervious to pain (even booster shots), I can block out horrible sounds (like the high pitched whine of the cast saw) and I can see through walls (to watch TV in another room after they shut off mine). (Lomnicki, *Blurred Vision*)

As she first describes some of the things about being hospitalized that are not pleasant—pain, booster shots, the cast saw, no TV because you are a kid—I remember such things from my childhood in hospital rooms. The "Super Patient's" abilities make these things easier to bear.

Tekki continues:

Villains beware! I take on Dr. Mask – the evil anesthetist who forces me to breathe poisonous ether and count backwards before surgery. Physical Therapy Woman who makes little crippled kids walk the parallel bars again and again – even when they tell her they're too tired. Molar Man, the diabolical dentist who drills kids' cavities without Novocain. And the most fiendish of all – Nurse Enema. (Lomnicki, *Blurred Vision*)

During this monologue, the nurse (MK) is sitting on the floor in front of Tekki. Tekki mimes knocking her over with one crutch as Dr. Mask, then throws a punch with the other crutch to hit the nurse as Physical Therapy Woman. When she gets to Molar Man, the nurse makes a sound effect like a cavity drill, and Tekki knocks her down. And when Tekki get to Nurse Enema, "Super Patient" enacts knocking out the nurse completely, and she falls to the ground. The scene continues:

Super Patient never cries. Super Patient never gags on the yucky hospital food. Super Patient never whines about not being able to play outside. Super Patient fights tirelessly for the ability to someday—BE NORMAL!

(TRACK 12: Reverb on the word "Normal") (Lomnicki, *Blurred Vision*)

And here Lomnicki ties the “supercrip” to her “Super Patient.” Tekki finishes the scene by describing all her super powers, which are very specific and relevant to a child stuck in a hospital, but also, they denote what she sacrificed in the name of being “*normal*.” Again, the play uses reverb on the word “*normal*” indicating the importance of this idea in the play, albeit ironic, and its recurrence.

“*Super Patient*” works on multiple levels. First, on the performance level, this bit is purely physical comedy. When Tekki says, “*like the high pitched whine of the cast saw*,” the nurse makes that noise, advancing toward the super hero with a mimed cast saw. With each villain, the nurse tries to come at Tekki with weapons like “*booster shots*” and “*poisonous ether*,” and each time the nurse reacts to blows, Tekki attacks her. Finally, their comedic dance ends when “*Super Patient*” knocks out “*Nurse Enema*.”

On the narrative level, “*Super Patient*” relies on a familiar disabled character: the supercrip. The supercrip must “overcome” her limitations from impairment, such as pain, fatigue, mobility or strength limitations, in order to prove that she is “*normal*.” As Siebers states above, the “supercripple” has talents and abilities “only dreamed about by able-bodied people” (2008, p. 111), which therefore makes them even more normal than most people. Indeed, Super Patient has powerful abilities that Lomnicki contextualizes within the hospital. She uses the supercrip story, and the overcoming narrative by association, to “overcome” obstacles typically found in hospitals. She turns kind, friendly medical professionals into “*villains*” that “*Super Patient*” takes down. In fact, the “*villains*” are the only direct reference to doctors in the performance of childhood scenes.

Both disabled and general audiences can relate to the terror of *Molar Man* or *Nurse Enema*. Although many disabled and nondisabled people have experienced versions of *Physical Therapy Woman* or *Dr. Mask*, disabled kids are more likely to register the particular terrors of these villains. Disabled kids, especially those who have been in a “body cast,” would fear the sound of a “cast saw,” or the threat of “booster shots” (*Blurred Vision*) more than nondisabled kids because these typify orthopedic treatments. And, “*Super Patient*” easily overcomes her institutionalization. The “*Super Patient*’s” particular powers directly resist the loss of control in the hospital.

“*Super Patient*’s” power and the link with the “supercrip” narrative works together on a disability culture level. Lomnicki is purposefully calling on the overcoming supercrip, but she is not planning to follow that character to its familiar narrative conclusion. “*Super Patient*” is not going to overcome her short stature or mobility limitations. Instead, she is going to use her superpowers against normalization and enforced ability, forces that also isolate disabled people, cause pain, and ultimately make your difference your failure. “*Super Patient*” might be stuck in the hospital, but she is taking her power back while there. In this way, “*Super Patient*” invokes the familiar supercrip character—that makes society feel better about disability with amazing feats—as a vehicle for disability culture and resistance to oppression.

Lomnicki and I discussed her use of supercrip stories for her “*Super Patient*.” She explains:

I wrote it as a double meaning, because I hate the supercrip thing, you know, and as a kid it was super patient, you know, because I was a patient. But yet, I can take on all these doctors. (Lomnicki, Interview 2)

In other words, Lomnicki wrote this character in a way that speaks to insider knowledge of disability community and culture. Her version of the character does not “overcome” to be

socially acceptable; she overcomes medical villains in order to resist their power, influence, and social/cultural authority over disabled bodies. I interpret the insertion of the “*Super Patient*” as a cultural performance created by revising Lomnicki’s memories and reproducing them in a more empowered and political way. Without being overtly political and still reaching all kinds of audiences, “*Super Patient*” simultaneously winks at her comrades in the disability rights movement, and revises supercrip narratives for everyone.

The “*Super Patient*” works as a universal theme that captures the imaginations of its nondisabled audiences as much as its disabled ones. This is what Lomnicki means by a “double meaning.” While nondisabled people recognize the supercrip, disabled people tend to resent it. The character negates the need for access while it demands that disabled people try harder to be “*normal*.” The supercripple character is a hyper-able hyper-visible representation of disability that, in place of more realistic or creative disability representations, tends to stand in for everyone with disability. It is a substitute for better social and cultural representations of disabled people who continue to struggle outside the spotlight of mainstream media.

“*Super Patient*” is a bridge between the familiar and mainstream supercrip and this new resistant but recognizable character. Without achieving supercrip’s inevitable conclusion – to overcome disability – “*Super Patient*” transforms the supercrip into a defiant, oppression-fighting figure for disabled audiences.

5. **Political perspective and disability pride**

In our third interview after discussing the theme of interdependence and the use of MK to perform as a personal assistant or PA, I suggested to Lomnicki that she must be very proud of this, since it was a clever way to perform this important piece of disability culture. She said, “yeah, I am and I didn’t even realize how cool it would be.” This statement, that she did not

realize the impact, the “coolness” factor, or the power of what she had created, also sums up Lomnicki’s political approach to her work: she often does it without realizing it.

The political power inherent in *Blurred Vision* lies in its subtle, I-had-no-idea approach to disability politics. In scenes like “*Super Patient*” as well as the performance of interdependence, Lomnicki’s political perspective is not overt. In our first interview, I asked her to describe the political point of view in her work. Lomnicki said: “I think in my work, I tend not to take a political view.” Instead, she looks for connections between people, and wants “people to know that I’m like them more than not like them,” she explains in our first interview.

Politically, Lomnicki is inclusive, and seeks an evenly balanced perspective toward both communities she inhabits. While throwing punches at medical power with “*Super Patient*,” she is still operating on a level that appeals to all in her audiences. The way she includes disability culture in this performance may not be intentional, but rather a result of her experiences. She arrives at a new definition of normal because she follows the trajectory of her own story. Her experiences as a little and disabled artist have led her to disability culture and shaped her perspective, including her subtle political approach, “coming out,” and her sense of disability pride. She sums it up this way:

In general I like to use my disability in my work... I’m proud of it now, that wasn’t always the case, but I also feel it’s really important to educate the public, too, about little people, and about what I in particular go through with walking. And I always use my crutches. In the past, I always tried to figure out ways not to use them so I could be more normal. (Lomnicki, Interview 1)

This is her condensed version of her trajectory toward disability pride. She notes that she did not always have pride about her size and impairments, and gestures to her journey of wanting to be, and trying to be more “normal.” And some of her journey has been elucidated here, since it seems to have begun with doctors trying to “*fix*” her. Poignantly, *Blurred Vision* ties up this

trajectory of her quest for “*normal*” with another journey of wanting to be “*fixed*.” Tekki comes to a different conclusion about normal in *Blurred Vision* than she may have done previously.

Interestingly, Lomnicki’s journey toward disability pride runs parallel with her discovery of disability culture. In our third interview, she explained that disability pride, or at least the idea that she could be proud of being a disabled person, came after taking a playwriting workshop with several other Chicago-based disabled artists. She explains her excitement at meeting these artists:

Yeah, the playwriting workshop: it was at the Remains Theater back then, and it was when I met them that I realized, wow! There’s like a whole world and I can be proud. A whole world of disability culture and I could be proud of this. This is a part of me. This is not just these crutches, this is me, you know, and it’s fine to have them. (Lomnicki, Interview 3)

Lomnicki also states that this was not an instantaneous pride, but it took time. At this workshop, she met and collaborated with several icons of Chicago disability culture, including: disabled actor and playwright Susan Nussbaum, playwright and activist Mike Ervin, and actor and playwright Rob Rotman. These artists influenced Lomnicki’s own performance work and made an impression on her identity and pride. This was a turning point in how she viewed herself as a disabled person. Meeting those artists figured prominently into how her work changed – she began to do solo autobiographical work about her own experiences. “The bulk of my work was after I had met them – my solo work,” she added (Lomnicki, Interview 3). After the workshop, her solo work began incorporating disability experiences; displaying her crutches, coming to terms with her size, her movement style and her limitations, and eventually claiming disability identity and pride.

While she is proud of her disabled body and incorporates it into her performance work, Lomnicki feels that disability is part of everyone’s experiences. She thinks of disability in terms

of something each individual struggles with, such as anger, feeling hurt, or fear. “I feel that everyone has some sort of disability, whether it’s being afraid to get up and talk, or they think they aren’t attractive, ...” (Lomnicki, Interview 1). This is one way to humanize disability for her audiences, making it relatable to nondisabled people. However, this approach risks diluting the very particular social, cultural and political issues at stake for disabled people’s daily lives.

Lomnicki chooses not to deal with critical political issues through her performance work. She instead portrays what I would argue as lesser “impairments” that all people deal with as a result of being human. Yet, extending the definition of “impairment” in this way dilutes disability and impairment experiences. Choosing this approach precludes Lomnicki from dealing with significant and life-altering consequences of disability in favor of making her performance more recognizable and understandable by nondisabled audience members. Equating her own chronic pain, mobility limitations, or hypervisibility with “some sort of disability” such as fear of public speaking or feeling unattractive diminishes her experience and dishonors her audience. By not tackling disability’s rich political issues, which means that not everyone is disabled, limits the meaning of her experiences and disqualifies her audiences’ ability to understand and relate to the performance. Humanizing disability may be at the core of her performance approach, and I agree that disability is a human experience, but it means that Lomnicki dilutes some disability politics in favor of building a bridge toward the humanity of being disabled. In other words, she refuses to alienate or make waves that may be construed as political in favor of creating a harmonious community among her audience members and everyone she encounters whether disabled or not.

Lomnicki’s approach to her work lacks some of the political activism she has witnessed in works by Susan Nussbaum and Mike Ervin. Her activism lies in her positive attitude about being disabled. She expects equal treatment and respect in personal interactions, extending the

opportunity to enlighten others about disability in a positive way. Yet, because she is not necessarily an activist, Lomnicki often feels uncomfortable with other “crips.” She said:

I feel very invisible in the actual crip world, when I’m with other crips. Not so much if it’s an arts event or something, because people know who I am, but we’ll see how I feel tomorrow at the disability pride parade. (Lomnicki, Interview 3)

She is expressing a couple of thoughts here, without much detail. She feels unnoticed, and perhaps unimportant to the “crip world” and to other disabled people. By “crip world”, she apparently means disabled activists, or outspoken participants of Not Dead Yet, Access Living, and Progress Center. This is the realm of the upcoming “disability pride parade” she refers to. Yet, because she inserts the caveat that she is only comfortable in the “crip world” if it is an “arts event” where “people know who I am,” Lomnicki reveals a sense of separation from more politically minded “crips.” Her performance approach is about inclusivity, finding common ground, and shared humanity, and she seems uncomfortable with separation from the mainstream. In other words, her identity and political consciousness, while limited to disability arts, culture, and disability pride in the “crip world,” are expansive and inclusive of mainstream ideas about disability that connect rather than separate. Lomnicki wants to “focus on finding the connection between myself and the average person” (Interview 1) and “building community through storytelling” (Tellin’ Tales Theatre, 2013). Both of these statements reveal her intention of “building bridges.” To Lomnicki, the “actual crip world” focuses on what’s wrong – inaccessibility, inequality, and discrimination – instead of what brings people together.

Without any political agenda about disability, Lomnicki’s work, *Blurred Vision*, nevertheless presents valuable insights about disability experiences, many political. Some of the themes in the play – interdependence, disability identity, along with a resistant supercrip character and quest for a new definition of “*normal*” – engage with similar ideas in disability

culture and the disability rights community. Because she speaks from experiences as a disabled little person, her work speaks to knowledgeable disabled people. At the same time, however, she directs her work to nondisabled audiences, directing them to understand the work as she does: beyond disability to its common humanity.

Lomnicki's theater company's mission is "building community," but her personal artistic mission is to build understanding about the humanity we all share. Lomnicki's mission, or "mission impossible," is to seek out what is fundamentally "*normal*" in all of us. It is a mission that transcends politics or culture. A possible political strategy in her work is reaching everyone with messages about what it means to be disabled, and what it means to be human.

E. **Playing Out Identity**

1. **Introduction**

According to post-positivist realist identity theorist Paula Moya, "identities are not self-evident, unchanging, and uncontested," but are subject to "a continual process of verification that takes place over the course of an individual's life through her interaction with the society she lives in" (Moya, 2000, p. 84). Through this process, identity is reassessed and often transforms several times. As *Blurred Vision* opens, the main character begins her own identity journey as she struggles with the onset of new physical symptoms. After having lived 49 years with unchanging impairments, these new symptoms threaten the stability of her identity and provoke her to enter a process of verification such as Moya describes. Yet, rather than privileging her own experiences and self-knowledge, Tekki seems to be unraveling – imagining catastrophic outcomes like brain tumors, blindness, and Alzheimer's disease – while she seeks verification of who she is (or will become) from doctors. The new symptoms make her feel out of control. Meanwhile, the doctors and specialists she sees do not seem to be taking her concerns

seriously. What will this disabled little person become if diagnosed with another disabling condition, chronic illness, or terminal disease? Will Tekki need to redefine her identity entirely, and if so, how?

In her lived experience, Lomnicki's identity has changed over time, even during the course of our three interviews. Many of these changes to her identity have to do with changes to her body, how she sees herself, and how people react to her. In addition, the various roles she plays – woman, daughter, person of faith, disabled person – shape Lomnicki's identity. In this section, I examine the identity processes portrayed in *Blurred Vision* alongside discussions with, and observations about, Lomnicki's personal identity processes.

2. Changing body, changing identity

Lomnicki's title, *Blurred Vision*, like many titles, has a double meaning. It describes one of the physical symptoms she is seeking help with, and it is also a metaphor for some of the identity processes she depicts. While identity may seem fixed, clear-cut, and distinct, it is actually more of a disjointed process of self-definition. Similarly, with the onset of blurred vision and headaches, the haziness and pain created by these symptoms make her identity harder to define. Blurred vision can cause halos around lights, lost sharpness and clarity, or make colors look washed out. It obscures perceptions and makes things appear fuzzy and unclear in the same way that the changeable process of identity can seem indistinct and uncertain.

Additionally, these terms reflect the way *Blurred Vision* is presented. The play moves unevenly between childhood and adulthood, time and space. Tekki presents contrast between her past and present, seeing herself as “*special*” because of how she is treated as a child, and being seen more like a hypochondriac when she is an adult. In both time periods, disability is the common thread: deeming her “*special*” in the hospital, driving her to be “*normal*” as she grows

up, and being perceived as an unreliable patient when she is an adult. These different “identities” are placed onto Tekki through her experiences with the world, particularly the medical world, and she must reconcile these fragments of how people see her into a cohesive identity of her own making.

One of the ways *Blurred Vision* plays out the main character’s identity process is to seek answers from doctors about her symptoms. This is framed as a way to define her identity by receiving a diagnosis that fits her symptoms. This diagnosis is likely going to change her body: how she experiences her body and how others perceive her. Tekki’s emotional responses to what could be wrong give the audience a glimpse of how the new diagnosis may affect her self-perception. For example, the following scene depicts Tekki in the present day. After speaking with her radiologist about her MRI, she discovers that she may have Multiple Sclerosis (MS). She ponders aloud to the nurse and her audience:

*I'm grateful that this doctor squeezed me in because I probably have MS. Well; the radiologist who read my MRI thinks I have MS. I mean he saw the lesions. Do you think I have MS? My friend's mom had MS and she had to use a wheelchair. I mean it took me a long time to get OUT of a wheelchair. I don't really want to go INTO one. But if I have MS, I have MS – and I mean somehow I'll get through it. Wheelchair and all. Thank God I don't have a brain tumor. The radiologist didn't see a brain tumor. I don't have a brain tumor. Do I? (Lomnicki, *Blurred Vision*)*

As Tekki grapples with changes to her body, her fear of a serious condition like a brain tumor is replaced with the possibility of MS. Either of these diagnoses threaten her current identity. She expresses how she might cope with MS, recalling how she has had experience using a wheelchair and that she has been through similar situations in the past. Even so, such a change to her body will disrupt her life.

In addition, Tekki asks the nurse for verification of her condition. She seems to need reassurance from medical authority about what is happening to her. Her own conclusions about

her symptoms lead to scary overreactions and terrifying possibilities. But because nothing is conclusive thus far, Tekki appears to feel a lot of uncertainty about her identity. In one moment, she appears able to handle the idea of Multiple Sclerosis, but in another moment, she needs to be convinced that she does not have a brain tumor. She seems all over the place emotionally. Without knowing if her body will change or how, she cannot anticipate how to reconcile her sense of self. She needs to know what is happening to her body so she can know who she is – or will become – as a result.

Yet, even with the current ambiguity of her condition, Tekki does not seem to fear the possibility of Multiple Sclerosis (MS). She cites a “friend’s mom” as a role model and her own experience with using a wheelchair, remarking that even though it had taken a long time for her to get out of the chair, she is resigned to doing it again. “*But if I have MS, I have MS – and I mean somehow I’ll get through it,*” she says. This particular remark utilizes her past disability experience, and it seems to temper her reaction to a possible diagnosis. Her perspective, influenced by her disability experiences, does not create fear the way the idea of a brain tumor does. She does not see the chronic and disabling condition of Multiple Sclerosis as being a tragic outcome, she seems to view it as something she could deal with, “*wheelchair and all.*” Without her disability experiences and the perspective gained from them, the idea of Multiple Sclerosis would probably be scarier. Apparently, her disability experiences have given her enough flexibility to consider the possibility of having another disabling condition.

In this particular scene, the play seems to address the main character’s perspective, which provides her beliefs and perceptions about being disabled: her comfort level with her body, awareness of how she is perceived, and how disability influences her thoughts and behavior. Tekki’s identity changes with her interactions with society, which are necessarily shaped by

disability. How has her identity changed as a result of impairments and disability? What are the factors that have influenced her particular disability perspective?

Lomnicki's views on disability become clearer in her interview data. While Tekki demonstrates flexibility about adding a wheelchair in *Blurred Vision*, Lomnicki seems less flexible about a similar decision in her recent history. During our second interview, Lomnicki recalled a time she had been to see her doctor at the Rehabilitation Institute of Chicago about chronic shoulder pain resulting from using crutches.

They [her doctors] were like, well, I think you better stop walking and get a scooter. I'm like, that is not going to happen. You know, I'm so glad that I am who I am now and can say nuh-uh. (Lomnicki, Interview 2)

I like this quote because Lomnicki relates her identity (“I am who I am now”) to decisions about her body. At the time of this interview, she was resistant to the idea of using a wheelchair or scooter and felt confident about refusing the doctor's suggestion. On one hand, she is demonstrating that in her lived experience, the strength of her identity helps her to resist the power of doctors and make decisions for herself. She seems proud of this in this quote. On the other hand, *Blurred Vision* depicts a version of Tekki that is easily swayed by doctors, and in fact seems to need their authority to help her figure out who she is. At the very least, she is not reluctant to use a scooter or wheelchair if that is what it means to have Multiple Sclerosis. Yet, in her lived experience, she is reluctant.

Two years after this interview, when we were completing our third, she had a brand new scooter and was getting used to using it around her downtown Chicago neighborhood. Somehow, between the second and third interviews, Lomnicki had changed her mind about using a motorized wheelchair to aid in her mobility. I asked her about what it was like for her to be more visible in her neighborhood, now that she can access it more easily. “I also feel very hypervisible

now when I'm in my scooter, like in going down Randolph Street or Michigan Avenue," she said. When I asked her to say more about that, like how she feels hypervisible, she added:

People really look at my scooter and at me. And I think in the past, I really kept myself from that big public eye... This is the first time I've been walking down the street – or riding down the street – because of my scooter, so it's a brand new experience for me. (Lomnicki, Interview 3).

When asked why she does not walk down her street with her crutches, she said it was “too hard” (Interview 3), meaning that the amount of walking is too demanding. Now, using a scooter increases her mobility and adds a new layer of disability experience to her perspective. “I never took public transportation; you know I would always just be in a car. I was pretty sheltered, really my whole life in that way of not being with the masses,” she explained (Interview 3). Being out in “the masses” with her scooter is a new and potentially disability-rich experience for her that could change her perspective in literal and figurative ways. Literally, her scooter provides opportunities to explore her own neighborhood with greater freedom of movement and spontaneity. For example, visiting Lomnicki's building one day, I saw Tekki carrying a grocery bag in her scooter. She had “walked” several blocks away to shop without getting into her car or parking it at the other end. The scooter provides this ability to move freely, which is something that most urban able-bodied people regularly enjoy. Figuratively, having been sheltered along with how much more visible she is in her scooter; she must adjust to this new scooter-using identity, where people will “really look” at her and have more opportunities to do so. Additionally, wheelchair users have greater clout and respect in the able-bodied world because most public places provide independent access for them, and do not provide such access for little people with crutches. Using a scooter not only changes her experience by reducing pain and increasing mobility, it changes her experience of being a disabled person in the world. What my analysis of the data – from the play and her interviews – reveals is that Lomnicki's impaired

body is in flux, and her identity needs to adapt along with changes to her body. In turn, her disability perspective is subject to change.

These two quotes from Lomnicki, over two interviews, reveal a changing relationship with doctors. Often, being disabled (disability identity) depends on medical knowledge to name it, diagnosis it, and “*fix*” it. Being disabled is usually ongoing, which requires ongoing relationships with doctors. However, when Lomnicki says “no” to a scooter at the time of our second interview, it signaled control over her life and her decisions. Similarly, changing her mind about using a scooter after her body changed at our third interview was also an empowered decision. In both cases, she was taking control and having the final say, rather than leaving it up to the doctors. As life and bodies change, so too must identity. Lomnicki *was* ready to accept the change to her identity that having a scooter would bring, and she accepted it in her time and on her terms.

Thus, identity is an ongoing re-evaluation that is influenced by changes to the body and fluctuations in the perspective that body and identity bring. It can cause fluxes and disruptions in confidence level, empowerment, and the ability to make decisions independently. Next, I will look at Lomnicki’s shifting storytelling process. How does Lomnicki’s “self-definition” help shape the story? How is identity shaped by experiences and intersecting roles and identities? And how does Lomnicki portray these processes in *Blurred Vision*?

3. **Shaping the story, shaping identity**

Blurred Vision is an identity story told in fragments that move between multiple characters and versions of the main character, and told from different time periods. The play presents many parts of Tekki’s identity – “crippled kid,” adult patient, little person, daughter, person of faith, disabled woman – but not a cohesive whole.

In the fragmented nature of the storytelling, stints between time periods, the story is configured to reflect an identity process that the story plays out. First, childhood scenes portray how Tekki's identity began. She demonstrates in these scenes how she viewed herself, but that the self was separated from a realistic view of her body. Returning from the past to the present, Tekki seeks answers from doctors, instead of from herself. Her identity will change, but instead of choosing it, she looks to doctors (again) to tell her who she is. She seems to put as much faith in the doctors of her present as she had as a child. Thus, Tekki's identity is fragmented or "disintegrated" (Gill 1994; Marks 1999) in the same way that Lomnicki fragments the story she is telling. Through this story, Lomnicki demonstrates how we can get separated from our knowledge of our bodies and ourselves by this whole process of meeting with doctors and being hospitalized, which is emblematic of the different time periods in childhood and adulthood.

The play addresses the many ways that identity is verified (Moya, 2000). Lomnicki's play explores how her identity is shaped by interactions with the medical system. It looks at how being a woman is continually reshaped by interactions with society and culture. And it deals with how the power of dominant cultural and societal forces shapes what it means to be disabled.

Interview data reveal, however, that Lomnicki functions with all of the pieces intact: a well-rounded person who incorporates all of her roles and social perceptions into a cohesive, approachable person. The story she tells in *Blurred Vision* seems to address, and possibly reconnoiter, all of the pieces of the main character as a way to see them afresh, and then see herself clearly and realistically.

a. **How the medical system shapes identity**

As *Blurred Vision* begins, Tekki makes an important statement about how the medical system – nurses, doctors, and the hospital –shaped her identity from a very early age.

She remembers, “*My sole purpose, my job, was to get better. And everyone supported me in that mission; from the moment I was born*” (Lomnicki, *Blurred Vision*). During most of these years in the hospital, she knew her purpose, was reinforced for it, getting the “*attention I deserved*” (*Blurred Vision*). Her nurse, Sister Thecla, who was there “*to comfort*” her, also tells her that she was “*born to be special*” (Lomnicki, *Blurred Vision*). Everything that Tekki wants to convey about these early experiences is focused on these ideas.

In the next scene, Lomnicki becomes Sister Thecla and demonstrates what she means about being there to comfort young Tekki.

(Nurse hands Tekki the nun's habit).

Shh! Shh! Your mama will be back tomorrow afternoon. Shh! Shh! (Sings) Puff the Magic Dragon lived by the sea, and traveled in the Autumn Mist to a land called Honalee... Little Jackie Paper loved that rascal Puff... Shh! So I'm not a singer! Sue me. If you quiet down I'll tell you a story about a little girl who was born to be special. (Lomnicki, *Blurred Vision*)

With so much attention and support, how could this child not feel that she was “*special*”?

Lomnicki’s memories of her childhood present she felt she mattered to her doctors: they believed in her and she believed in them. She portrays herself as a child who was certain in their power. She “*would be normal*” (Lomnicki, *Blurred Vision*). Being brave and patient, doctors will eventually “*fix*” her. This is how the little girl learns to be a “*patient*,” as if courage and patience will be rewarded. With the power and belief our society gives doctors, we all learn how to be patient “*patients*.”

In adult scenes with doctors, however, *Blurred Vision* tells a different identity story.

Tekki still seems to believe in doctors to a degree, but is more critical of how they treat her. She feels ignored. She says:

Is it normal to wait this long for the doctor? I've never been to an ophthalmologist/neurologist before, but how could it take this long? I waited two months

to see him and now he's making me wait two hours. What's he doing in there, brain surgery? Oh my God, what if I need brain surgery? (Lomnicki, Blurred Vision)

Tekki's attitude is very different from the one she displays in her childhood scenes. She seems annoyed, and feels ignored and disrespected about having to wait. This is a contrast between child and adult dealings with doctors. As this scene continues, Tekki reveals how wary she feels seeking medical opinions. She tells the intake nurse:

Are you sure the doctor is both an ophthalmologist and a neurologist because I need a second opinion from someone who knows. The first neurologist I saw at the other hospital didn't pay attention to a thing I said. I'm having blurred vision for Chrissake and he thinks I don't have MS, or Alzheimer's or an undetected brain tumor. There's something drastically wrong here and nobody cares. (Lomnicki, Blurred Vision)

Gone is her total trust of doctors that we saw in childhood scenes. She has very little trust of this doctor's skills. She needs someone "who knows" since the first doctor "didn't pay attention to a thing I said." To Tekki, something is "drastically wrong" with her and, unlike what happened when she was a kid, she feels that "nobody cares." Tekki begins to panic as she tells the nurse about her symptoms.

I think I have Retinal Vascular Thrombosis or maybe Papilledema. Please make sure he checks for that. Oh my God, what if I'm going blind? I mean I loved that movie "A Patch of Blue." Sydney Poitier, I mean I'd be lucky to meet someone like him if I went blind. But with my luck... I'd get "Wait Until Dark." And I have veins popping out on my forehead. Is that normal? See? Right here. Do you think I had a mini stroke and that's why my vision is blurred? And wait a minute; did I tell you about the headaches? (Lomnicki, Blurred Vision)

As Tekki starts to imagine catastrophic possibilities, she simultaneously tries to look at the bright side. She references the film *A Patch of Blue* (1965), about a blind girl who is befriended by Sydney Poitier who helps the girl feel better. Tekki sees this as a model for her potential blindness. But she quickly replaces it with the frightening story of a blind woman in the film *Wait Until Dark* (1967). Again, we see her need for identity coinciding with her need for answers from doctors. Knowing what is going to happen with her body will help Tekki know how to re-

imagine her identity. At this point in the story, only a doctor who knows and “cares” the way they did when she was a child can give her these important answers.

From these brief examples in the play, the medical system’s influence on Tekki’s identity is more apparent. She becomes a faithful, patient, learning to rely on doctors for help and answers about what is going on with her body. She trusted their power. Yet, as an adult she is less patient with doctors, and more wary of their power. Tekki already accepts her disabled body, while doctors try to make all of her health concerns about disability. Tension exists in the contrast between how she *was* treated and how she *is* treated now. It is as if Tekki seeks the special treatment of her past without relinquishing the skepticism she has gained as an adult. She cannot go back to the time when she had complete faith in her doctors, but what happened to change her faith in them?

As kids with disabilities, we can lose track of our bodies and identities, giving ourselves over to the unquestioned power of doctors. We learn that doctors have the final say on what is best, and therefore, the power to tell us who we are. *Blurred Vision* portrays when and how this changes for Tekki: “*Once I turned 14, the doctors gave up on me*” (*Blurred Vision*). This line speaks to a moment of failure and lost faith. She is “*fired*” and nothing “*was going to change*” or make her “*normal*.” In the moment, she realizes her identity as “another “ortho” or “gimp” or “spaz”. Another dorky girl who could never wear platform shoes or go-go boots. Brave meant getting up the nerve to even talk to a boy. And special meant retarded” (Lomnicki, *Blurred Vision*). Her trust in the power of doctors shattered, and her identity becomes “real” rather than “special.”

Lomnicki reports that even now, with years of experience with doctors, she still treads cautiously with them. She explains:

Now, I feel that it's a part of like, in *Blurred Vision*, I feel that once I turned fourteen the doctors kind of gave up on me. And it's almost like well; she has a disability so this must be what this is about for her. I sometimes feel like I'm not taken seriously. So I feel very invisible there. (Lomnicki, Interview 3)

The moment she realized that her doctors gave up was an important one for Lomnicki, but she only realized its significance while working on *Blurred Vision*. As she wrote and worked with her director, she explains how this revelation occurred. She said:

I think that once I laid it all out, then everything became clear. I guess I never really got that... my whole time in the hospital really laid the groundwork for my storytelling, and... about them giving up on me at fourteen. The director and I were going: "Past. Present. Past. Present. Past. And she asked me, what's the climax, what's the climax in your past? What's that: the doctor's gave up on me. So it all happened in the writing. I didn't know. (Lomnicki, Interview 3)

It was "the climax" of her past, the doctors giving up on trying to fix her, and also giving up on her childhood potential. The significance of her age, fourteen, is that this was when Lomnicki began menstruating. She connects becoming a woman with the loss of doctors' faith in her and her loss of faith in them. It seems that doctors were willing to fix her, but only as long as she was still full of potential.

Both in the play and in her life, this is a betrayal of trust. Today, Lomnicki still struggles with trusting doctors. If they gave up on her then, how quickly will they give up on her now? By not taking her seriously, or by turning every medical issue into something related to disability, doctors dismiss, disrespect, betray, and give up on Lomnicki as a patient.

As a turning point in her life, the climax of her childhood, it is only fitting that Lomnicki begins to turn the narrative in another direction, and reveals an intact disability identity. The child character has hinted at this identity all along, using terms like "*crippled*" and "*normal*" to point the way. "*No miraculous cure*" is yet another revelation of her identity as disabled, and as one who accepts this. Her "*crippled kid*" identity demonstrates awareness of social identity; kids

who ride the “*handicapped bus*” know exactly what regular kids call them. But Lomnicki is writing from her current perspective, relying on the disability identity she has already cultivated and integrated into her storytelling. And the story she tells in *Blurred Vision* leaves out the story of how she got there. Next, in order to find out, I will look at several aspects of her identity separately – disabled, little person, woman – through the lens of the play alongside Lomnicki’s interview data.

b. **Identity as a disabled and little person**

Using the word “*crippled*” sets off a dialogue between Tekki as a child and other characters that make it clear that she should not use “*crippled*” or “*normal*” (see “Contextualizing Normal” in this chapter’s section “Disability Culture”). The character’s use of these terms signal comfort with her disability identity, both in art and life. The play alludes to Tekki’s ease with her disability identity and affiliation with disability culture. People with disabilities who prefer terms sanctioned by the mainstream usually lack a strong disability identity or connection to disability community. Thus, both the character and the playwright are claiming identity with language.

Additionally, Dr. C, Dr. 2, and others that Tekki visits on her quest point out her “*problems*,” her “*dwarfism*,” or make her differences known in some way. It is clear in the dialogue between Tekki and doctors that she no longer seeks to be “normal.” She seeks relief from her headaches and blurred vision, as well as relief from the terrifying diagnoses she keeps imagining.

Because *Blurred Vision* is not about a miracle cure, Lomnicki could easily make this an “overcoming disability” story. Overcoming stories grant their disabled characters, and in turn, disabled people, social inclusion as long as the person demonstrates the right attitude. To the

casual observer, disability no longer hinders the person through her “sheer strength or willpower” (Linton, 2006). In this way, *Blurred Vision* appears to be a story about a disabled little person who has overcome. But throughout the adult scenes in the play Tekki acknowledges her differences rather than to appear normal. In the end, Tekki defines herself as “*normal, just the way I am*” (Lomnicki, *Blurred Vision*). With this outcome, *Blurred Vision* shows how Tekki’s differences are apparent, but are not celebrated or criticized.

What the narrative reveals about the playwright is that Lomnicki has developed her disability identity into an influential and integral aspect of her storytelling. For example, Gray (2009) argues that the assimilation story – the miraculous cure – is the most prevalent disability storyline in mainstream culture. Yet, both the assimilation and the overcoming narratives separate disability from the disabled character, leaving them without the possibility of a strong, proud identity. In assimilation, the disability is physically removed through cure, restoring the person to a “natural state.” In overcoming, disability can be overlooked, but “only conditionally” (Gray, 2009, p. 325). These two narratives coexist by defining disability as deficiency, and must be eliminated or compensated. While the main character in *Blurred Vision* is funny, endearing, and charismatic, she is not trying to compensate for what her body lacks. Lomnicki is not performing a heroic or intentionally inspirational character. Instead, she is performing a relatable one, with relatable problems, incorporating her differences as ordinary throughout the story. Thus, Tekki’s disability is integral to the performance, and as such, *Blurred Vision* resists sentimentality, and promotes disability as valuable and fundamental to experience.

In the section “Disability Culture,” I use a quote by Lomnicki about how she works against the idea that, “in order to be whole, functioning individuals, people with disabilities have to be cured or look like everybody else.” (Lomnicki quoted in Thrower, 2013, p. 210). *Blurred*

Vision suggests the “long time to accept myself” she refers to occurs somewhere between childhood and adulthood. The play demonstrates that Tekki was “striving to be ‘cured’ and ‘normal’” as a kid, but as an adult, she learned to value herself as a little and disabled person. The process between wanting to “look like everybody else” and of self-acceptance is not depicted. This process is assumed in the play, but we can look at her lived experiences to piece together this process.

In my first interview with Lomnicki, I asked her to describe the relationship between her performance work and her lived experiences. She said:

I always use my crutches. In the past, I used to try to figure out ways not to use them so I could be more “normal” on stage... and then I realized, well hell, they’re a part of me, those crutches are a part of me... (Lomnicki, Interview 1)

Making her crutches visible is symbolic of her transformation from wanting to be “normal,” and now having a disabled and little person identity. Her small, custom crutches signify disability, which is now her integrated identity and “part of me.” Lomnicki remembers how she had internalized messages about her crutches, leading her to initially hide them:

When I was a kid, and we were taking a photo, they would be like “get those crutches out of the photo!” you know? So it was sort of an ingrained thing, like these crutches can’t be there because they’re not really a part of me, or there is something wrong with you then if you have the crutches. (Lomnicki, Interview 3)

Thus, hiding her difference, “something wrong”, meant hiding her crutches to look “normal.”

This became “an ingrained thing” learned in her family. “I think I just so wanted to be mainstream, be normal so to speak – normal, normal, normal – that like I couldn’t hide it! It was so silly,” she explains (Interview 3).

While *Blurred Vision* may not depict the particularities of her identity processes, it does focus on the paradox of being both hypervisible and invisible in public spaces. Hyper-visibility refers to the ways that Lomnicki’s body and differences, like many visibly disabled people and

little people, make her extremely visible – subject to overt staring, extra helpfulness, and, sometimes, obtrusive questions from strangers. Invisibility refers to how the same sense of being extremely visible can also result in being ignored or overlooked by others. I asked her about this in our third interview.

I feel hypervisible when I'm at a school with kids because I think kids really notice everything and they're not really good at hiding their surprise and curiosity... I also feel very hypervisible now when I'm in my scooter, like in going down Randolph Street or Michigan Avenue... people really look at my scooter and at me. (Lomnicki, Interview 3)

These are the places and situations where Lomnicki notices her visibility and where her differences are reflected in other people. Adding a scooter for mobility has increased her sense of feeling hypervisible. These are examples of where staring is overt, and curious questions are asked, and she must find a way to deal with the hypervisibility she encounters.

In the play, each doctor in her adult scenes makes a gesture or a statement that indicates Tekki's obvious differences. Each doctor makes Tekki hyper-visible in the interaction. And then, without fail, each doctor ignores her current symptoms, making her "*problems*" about disability, essentially ignoring her reasons for the visit. In this way, they make the patient invisible. They do not take her seriously, which is both disrespectful and patronizing. Perhaps this is another reason that Lomnicki "feels invisible with doctors" (Interview 3). Such responses, within the same doctor visit, reveal how this paradox functions. Hyper-visibility exposes what is obviously different about a disabled person and then renders everything else about the person a function of that difference. Thus, the hyper-visibility/invisibility paradox reduces the disabled person to his or her body and removes humanity in the process.

Yet, being extremely visible and noticed in public also makes Lomnicki feel as if she needs to perform disability in a particular way. Her process of coming out, proud, and identified as a disabled and little person took many years. During that time, Lomnicki was able to see

herself more positively with help (therapy, self-help workshops) and through her work as a performer/artist. In our third interview, I asked her if feeling hypervisible in public made her also feel like she needed to perform disability in a certain way. “Yes, I do,” she said. “I feel that, especially when I’m hypervisible I feel for me, I more turn on the charm, and I’m happy. I mean I’m pleasant to people” (Lomnicki, Interview 3). I asked her to say more about that and why that is. She explains:

But even when I’m not feeling pleasant I’ll do it because I have gotten so many comments from people who say they were afraid to approach me or meet me because they have had bad experiences with other people with disabilities who were very negative. And so I really took that to heart. And then one time I took this workshop, it was a self-actualization kind of thing, and what you had to do was you had to stand up in front of the room, and just be, and then people had to shout out their first impression of you. People thought I was angry, and thought I was stuck up, and I realized I was just looking scared, because I was scared. (Lomnicki, Interview 3)

First she seems to say that she plays a role in her everyday experiences by performing disability in a positive way, even when not feeling it. This response seems to come from two reactions from others. First, she wants people to have a pleasant encounter with her, instead of a negative one, representing disabled people who cannot be charming and happy all the time. In this way, she seems to accept a responsibility to be a bridge between disabled people and everyone else.

Second, Lomnicki was given direct feedback during a workshop about how she looked to others: “angry” and “stuck up.” This feedback made her realize that what she was actually feeling was fear. While she did not talk about why she was scared, I am making the leap that part of it has to do with her history of being sheltered and away from the “big public eye.” In addition, Lomnicki told me that before she was able to be pleasant and friendly to strangers, she had felt scared “all the time” and “wouldn’t open up.”

Like someone I knew would talk to me and I was fine, but in the general public, I was not able to open up and just say hello to a stranger. I was so worried about what they thought

of me, and now it's like, well I don't care, I'm just going to be nice and pleasant and say hello to people in elevators. (Lomnicki, Interview 3).

I have watched many of Lomnicki's performances and observed her as she meets with her public following those shows. From time to time I have heard an audience member saying how "cute" or "sweet" she is in a patronizing way, only to witness Lomnicki glossing over it and turning it into a compliment. I have also seen this behavior beyond the demands of her theater company, usually playing the role of positive example.

Taking her upbeat approach a step further, Lomnicki tries to meet people at their level. In our first interview together, Lomnicki said, "I really identify with how people react to me." I followed up with her about that statement in our third interview. She said, "How people react to me is how I am in the situation." Thankfully, she explains this further:

So, like, if a bunch of little kids are around me, being curious and talking to me, I will be a different, I will react differently. That's what I mean. And I have some little people friends that criticize me for that, like they think that I should just not be nice about it. Or even adults will joke, like, "well, I could just put you in my purse" or something, that's from my show, but this one, this nurse from my new doctor, said that. She goes, "you are just so cute" she did say "I could just put you in my purse" which is hilarious because it's from my show [*Paper Doll*] you know what I mean? (Lomnicki, Interview 3)

At this point, I am laughing out loud because I have done the voiceover for *Paper Doll* on a couple of occasions, and yes, this is exactly one of the lines that a stranger says to Tekki in that piece, because I have said it. I am amazed that someone actually said this to her. Lomnicki continues:

And certain friends of mine, if you said that, would be really angry and say something snotty. For me, I just laugh, because I get that's where they're coming from. Or like somebody coming up to me and saying, it must be really hard for you to blah blah blah, and I go, yeah, sometimes it is hard. So I kind of feel, by how people react to me, I'm either the educator to teach them about dwarfism, you know? I'm either the cheerleader, you know? And very rarely will someone bug me to the extent that I'll be mean to them. It's all part of being out, you know? It's fine. (Lomnicki, Interview 3)

She says she understands “where they’re coming from” and this is how she responds. She empathizes with each new person – his or her curiosity, surprise, attempts to be kind or to understand – and responds with compassion and kindness. She is describing a technique, a strategy for diffusing awkward situations with strangers that retains both parties’ dignity. This strategy is also a bridge between Lomnicki, the positive representative of disabled and little people, and the able-bodied person who may not have ever seen anyone who looks like she does.

“It’s all part of being out, you know?” she says above. During our third interview, I asked Lomnicki to comment on the ongoing process of re-evaluating identity, and how she currently defines her identity with disability. She also explained what she means by “being out.” She said:

I think the main piece that really dealt with that was *Striptease*, the one where I really talked about coming out as a little person. And that was another really big turning point for me when I realized it was fine to be a little person. I didn’t have to hide it, even though I couldn’t hide it. It was fine to really come out as a little person. And it did remind me a lot of my friends who were gay and how happy they were after they had come out, and really I was very happy. And it’s very nice for me now to be in a relationship with someone who is a little person, even though he isn’t as small as me. (Lomnicki, Interview 3)

As she reflects on her sense of relief and happiness after she had “come out” as a little person, I can understand how it was a turning point for her. As with accepting herself with crutches and impairments, she had to come to terms with her size. For her, this meant that she did not have to hide anymore. Even though she could never hide the fact of her size from the world, she was able to hide it from herself. This is also true of how she cannot hide the fact of her disability. She explains how even though she is a little person; many other little people do not understand how disability also impacts her life. She said:

Most of them are, most little people are – I actually don’t think I know one like me who will just say; yeah I got to live in an elevator building because I just can’t do the stairs. Most little people I know, they will live on the third floor just to prove they can walk up. It’s a little person thing. (Lomnicki, Interview 3)

In this quote, I hear the difficulty she has in “being out” as both a disabled person and as a little person. Apparently, “it’s a little person thing” to prove ability. Yet, this is referencing an ability that Lomnicki does not have. While she is very happy and accepting of her size, Lomnicki’s connection with other little people seems to need a bridge as well. She suggests that many little people have an ableist perspective. With her intersecting identities, positive attitude, and empathetic approach, I have no doubt that Lomnicki is also that bridge between many little people and disabled people, educating across communities and making connections.

4. **Identity as a woman**

Lomnicki and I spent some talking about the intersection of disability and gender. I had asked her if she had developed a strong woman identity, telling her that for me, seeing myself as a woman came much later than disability identity. Agreeing that disability identity was easier for her as well, she said that she sees herself as “a woman of power... not a woman that’s swayed by what other people want me to be” (Lomnicki, Interview 2). In *Blurred Vision*, Tekki takes the audience through a sequence filled with powerful female role models. In the following scene, she is about to see her gynecologist, a woman who reminds her of Oprah Winfrey. From the waiting room, she begins ruminating on how the song, Puff the Magic Dragon, was about smoking pot, then tells her audience:

*And I can't take Tylenol?! They let cancer patients smoke pot! All I'm on is HRT. That has to be it. Those studies were right women shouldn't take anything unnatural during menopause. Are you on HRT? Maybe I don't have Retinal Vascular Thrombosis or Papilledema but I might be in the later stages of cancer induced by the hormone replacement therapy and they just haven't detected it. (Points to office) She'll know. Don't you just love her? She's the best gynecologist I've ever had. Yeah, she'll be able to figure out what this is. She reminds me of Oprah and everybody knows Oprah is well informed about everything. (Lomnicki, *Blurred Vision*)*

Tekki is again concerned that her blurred vision and headaches may be the result of cancer caused by hormone replacement therapy or HRT. She seeks answers from this specialist, who, if

she really is like Oprah, is “*well informed about everything.*” As the scene continues, I love what my copy of the script says next, as the nurse examines Tekki. Lomnicki writes:

(Nurse taps Tekki on shoulder and walks her to the doctor's office. This time a slide comes up of the human reproductive system. Nurse uses Tekki's crutches as stirrups and is under a sheet giving her an exam. Tekki speaks). (Blurred Vision)

Let me provide a visual of this scene, which the script direction above spells out. Tekki, as herself, is seated in a chair. In front of her, and with her back to us, sits the nurse on a stool. Between the two, Tekki has her legs outstretched, propped on her crutches like stirrups. Her lower body and legs are under a sheet, but we can see her feet on the crutches. The nurse, too, is under the sheet – mostly her head and shoulders. With this in mind, Tekki is speaking to the nurse while the nurse “examines” her.

What do you mean you don't feel any tumors? The studies say that HRT causes uterine cancer. Maybe I have breast cancer. My aunt Rose died of breast cancer in 1978, she was only 40 years old and her kids were little. I mean I don't want to go off the HRT because when I wasn't on it I had panic attacks and hot flashes... (Lomnicki, Blurred Vision)

All of this is going on with the nurse’s head under the sheet. She shakes her head at times in response to what Tekki is saying, until she finally emerges and removes the crutches and sheet. The scene brings uproarious laughter from the audience. It is a knowing laughter from women and possibly uncomfortable laughter from men. Then, Lomnicki plays up the comedy by performing this Oprah-like doctor. The script directs the actor this way: “*(Tekki sits up and changes her posture, somehow transforms with a prop to become her Oprah-looking gynecologist)*” (Lomnicki, *Blurred Vision*). She “*somehow transforms*” by donning an oversized pair of sunglasses and flashing a smile. Her voice becomes light with a sort of attitude, as if she has been doing media junkets all day before this appointment. She says:

Hey girlfriend. The nurse practitioner didn't feel any tumors in the breasts or uterus (Flipping through papers on clipboard) and your last mammogram and pap were

*normal. Are you sexually active? Join the club. I heard Oprah isn't either. I'm so glad we women have her as a role model now. Hey – but if you by some chance in the future, get it on, please use some form of birth control. HRT doesn't take care of that. If you want to go off the HRT that's OK with me, but I don't think it has anything to do with the headaches or blurred vision. And don't come complaining to me when you burn baby burn. Whatever you do don't go on any of that natural stuff – it's all voodoo in my book. And let me know if you want to get rid of all the plumbing down there now that you don't need it. I do surgery too. Just book it at the desk. Here's your new prescription. Try cutting down on the alcohol. Come back in six months! (Lomnicki, *Blurred Vision*)*

Lomnicki delivers another outrageous doctor who comes across as cartoonish but loveable. And again, this doctor dismisses her current symptoms, while assuming Tekki is not sexually active.

The doctor also offers to “*get rid of all the plumbing*” for her. While such remarks may not be meant as disability stereotyping, the doctor assumes Tekki is no sexually active or reproductive.

Lomnicki seems to link being a woman with her biology. As the sequence continues, Tekki segues to her childhood memories. After the visit, she says: “*No I don't want to get rid of the plumbing. I still remember back when I couldn't wait until all the plumbing started working*” (Lomnicki, *Blurred Vision*). Then, as she sits on the hospital bed holding a huge yellow purse, she talks about how she first learned about sexuality. Tekki says:

*My last surgery took place in August, when I was 13. I had already seen (whispers) "the movie" in school. You know the Disney animated one that made having your period seem somehow romantic. I couldn't wait to get mine and longed to be like the older girls who I imagined wore those elastic belts with Kotex clipped to them. I began to emulate the nurses with their short white uniforms (but what if they got their periods at work?) I especially adored teenage girls older than me and craved their attention. Suzie, my favorite Candy Striper brought me lots of it... She was a junior at Resurrection high school. She had long straight blond hair and light blue eye shadow... she wore ruffly blouses with leg o mutton sleeves, black vinyl wet-look mini skirts and those platform shoes. When she opened her macramé purse, it was like that treasure chest of prizes... Rouges. Frosted eye shadows. Eyeliner pencils. (Lomnicki, *Blurred Vision*)*

In this monologue, Tekki remembers another shift in her identity. She was starting to become a young woman, and the closest thing she had to role model was “*Suzie*.” Through interactions with her, she begins to see herself as an adult. She learns about makeup, being attractive to boys,

and imagines herself becoming someone like Suzie. In the next part of the scene, Tekki voices the part of Suzie with a valley girl lilt. Meanwhile, the nurse character acts out what Suzie does.

“Lip gloss. Like all you need is a little bit of lip-gloss. Like this. Don't move. There. White is your color! You don't need anything else. You are so pretty just the way you are.”

“Now I know you won't tell anybody, but my boyfriend Jimmy is four years older than me. Whenever I hear that song by Gary Puckett and the Union Gap I have to stop everything I'm doing and think of him.”

(TRACK 14: Young Girl by Gary Puckett and the Union Gap). (Lomnicki, Blurred Vision)

As the music plays, we hear these lyrics: “Young girl, get out of my mind/My love for you is way out of line/Better run, girl/you're much too young girl” (Fuller, 1968). While it plays, the nurse starts dancing around in a melodramatic way.

“He works at the gas station at the corner of Harlem and Devon. And he drives a motorcycle! I love sitting on the back and hugging him around the waist and smelling the leather of his jacket. If my parents ever found out, they would kill me... and if the nuns heard, I'd be excommunicated!”

(Tekki holds nurse from behind like she's riding a motorcycle). (Lomnicki, Blurred Vision)

For teenaged Tekki, Suzie's life sounds exciting, adventurous, and romantic. With Suzie as a role model, Tekki begins to form a new plan for who she will become.

In the next scenes from this sequence, Tekki reveals the identity she desires once she grows tall and “normal.” Notice how she incorporates some of her previous ideas, like being involved with “*Captain Von Trapp*,” but now also some of the dangerous elements she likes about Suzie. She says:

My desire to become a nun was fading, thanks to Suzie, Mickey Dolenz and the boys in my class. Now my fantasies about Captain Von Trapp involved him rescuing me from the convent on the back of a Harley.

That fantasy ran out of gas when I saw myself in the full-length mirror in the therapy room. I looked nothing like Julie Andrews. I was barely taller than her waist, had stringy

brown hair and a bad case of acne I tried to cover up with crusty dabs of Clearasil. But in my dreams I was a nurse right out of nursing school, who moonlighted as a cop with a body like Emma Peal's from the Avengers, wearing heavy make-up like Suzie's, I would have my period all the time, I was tall and tan and lean and lovely like the girl from Ipanema... and I could dance.

(TRACK 15: *The Girl from Ipanema*)
(*Nurse as Tall Tekki comes out and dances*). (Lomnicki, *Blurred Vision*)

While Tekki is describing her fantasy, the nurse plays them out. For example, when Tekki says:

“I was a nurse right out of nursing school, who moonlighted as a cop with a body like Emma Peal's from the Avengers,” the nurse strikes a cop pose, using her hands as a gun, and moves across the stage like a crime fighter. When Tekki says: *“I would have my period all the time,”* the nurse swings her hips in a circle to the beat of these words. In this way, the nurse is already embodying Tekki's dreams of her future self, colliding with Tekki's lines from the song “The Girl from Ipanema” and the nurse begins to dance to the song. At this point, the nurse is obviously who Tekki hopes to become. Then Tekki says:

Maybe... just maybe if the surgeries worked... I'd be her one day. Just maybe I'd be "Normal"!

(TRACK 16: *Reverb on normal*). (Lomnicki, *Blurred Vision*)

The nurse character acts as the surrogate for Tekki, embodying physical attributes and abilities Tekki hopes to have while simultaneously emphasizing Tekki's real and unchanging differences.

If we look at the beginning of this long quote, however, Tekki admits that she looks nothing like her fantasies of her future self. She even describes her reflection as having *“stringy brown hair and a bad case of acne”* (Lomnicki, *Blurred Vision*). This statement says she did not see herself as attractive, which may be the reason why in the fantasy that follows, she wears *“heavy make-up like Suzie's.”* Of course, this could be how she recalls feeling as an awkward teen. Yet, she could link feeling unattractive with being a little and disabled person. Notice that

all the role models mentioned are able-bodied and have average height. Becoming a woman for her, at that time, meant becoming tall and able to do very challenging jobs. In addition, all of these women have sex appeal – Suzie, Emma Peale, the girl from Ipanema. One of the things that Lomnicki and I discussed in her interviews was how embracing a woman identity included embracing a sense of being desirable. “I think for me, the identity of myself as a person that men would desire, you know, that’s maybe a bigger deal for me,” Lomnicki told me in our first interview. She explains further:

Being a little person, I think all of us; almost every little person I know is extremely bossy and able to take control and to take power and be noticed... but I’ve never had a problem with that. I’ve always in a way steamrolled my way through life and been noticed and not had a lot of stuff that, because I was a woman, I was discriminated against. If anything, I was discriminated against for the disability.

But that other part, that’s the part that’s really prickly for me is my identity as someone men would desire. And that’s coming lots later in life, too. And I haven’t really explored that in my work a lot yet. (Lomnicki, Interview 1)

Lomnicki is expressing a lot here. She has intersecting identities, and therefore, it can be difficult to figure out where discrimination stems from. She argues that because of her ability “to take control and take power” as a little person, she does not think being a woman plays into it. This is apparently because she sees women as the opposite of “bossy” or “steamrolling.” Thus, she finds discrimination probably comes to her because of being a little and disabled person, but not female. I find it interesting that she views discrimination this way, rather than being perceived as asexual because of her size and disability. Then she explains that having an identity as a woman, a sexual and attractive woman, is “prickly” for her. She has not worked through this identity much in her work, but skimmed the surface of it in a piece that deals with meeting her fiancée, Chris, called *Love in the time of Facebook* (2009, unpublished manuscript). Perhaps this is the first and only piece she has done that even hints at Tekki being a sexual, desirable woman.

Perhaps Lomnicki's identity as a strong, powerful woman fits better than one of a typically meek one.

Lomnicki utilizes her artistic processes to work through identity issues. One of the things she reveals with *Blurred Vision* is how much the social and cultural forces she is exposed to influence her identity. I say influence because she is clear that she is not easily "swayed by what other people want me to be" (Lomnicki, Interview 1). At the same time, Lomnicki presents identity as a fluid process, easily flowing as she interacts with others, and able to meet them on their own terms. Yet, she also presents a fragmented process, comprised of many pieces in an ever-shifting composition. Lomnicki performs a strong disability identity in *Blurred Vision* and, through this identity, presents how sometimes it originates as a desire to be "normal" and often it claims acceptance and community as a different way of being. Lomnicki puts this succinctly when she says of *Blurred Vision*: "It's not about fixing: it's about accepting yourself for who you are" (Lomnicki, Interview 2). And in the end, that is exactly what she does.

F. **Conclusion**

1. **Introduction**

Tekki Lomnicki is an artist who likes making connections with her audiences by infusing her performance work with personal experiences. As a disabled, little woman, Lomnicki emphasizes the humanity in experience to relate to everyone who attends her shows. Lomnicki is an unexpectedly complex and artful performer, and *Blurred Vision* is an important performance piece. The data revealed themes important to disability identity and culture, and to her primary strategy of building bridges. Other themes emerged from the data indicating how Lomnicki's work creates space for new images of disability within the mainstream, and subvert medical power, both aspects of the artist's perspective. Lomnicki's fundamental belief in human equality

supports the themes. In this section, I discuss additional aspects of Lomnicki's data to demonstrate her ability to transcend disability while re-imagining it. I also explain what I see as Lomnicki's standpoint; the perspective she uses to interpret her experiences and construct her performance work.

2. **Building bridges, making connections**

Lomnicki's personal experiences allow her to connect with audiences through human similarities. She states, "I feel that everyone has some sort of disability, whether it's being afraid to get up and talk, or they think they aren't attractive" (Lomnicki, Interview 1), which I interpret as general vulnerabilities more than actual physical or mental disability. Therefore, Lomnicki sees that aspects of her disability experiences are similar to most people. She prefers to reveal the "very true feelings" from her personal history as a way to seek common ground, transforming the experience into a relatable, recognizable moment. Thus, her experience remains credible and relatable to other disabled people, but also takes on an expansive quality, opening it to nondisabled people as well.

Building bridges in this way, framing her particular experience as universal vulnerability, brings Lomnicki's two worlds closer together. In *Blurred Vision*, the distance between the able-bodied and disabled communities is spanned in specific ways. Doctors focus more on her impairments than medical concerns, she throws in many references of Hollywood portrayals of disability over its reality, and the story hints at a miraculous cure at the end. Yet, the miraculous cure gets transformed into an ordinary disabled woman's life. Thus, making her story recognizable and universally relatable narrows the distance between disability representation and dominant cultural expectation. Doctors ignore everyone. We all want an extraordinary life, but live an ordinary one.

Building bridges through relatable stories, feelings, and experiences is part of Lomnicki's cunning storytelling strategy. As a storyteller, she recognizes how Hollywood films and television shows have primed her audiences for particular disability narratives. Stories that restore disabled characters to being able-bodied are hopeful, inspirational. We root for such characters, and fall for the prescriptive plot line Lomnicki sets up. Yet, Lomnicki improvises such storylines in a way that challenges audiences' perceptions. She manipulates her audiences and the narrative in three ways. First, she draws them in with a familiar plot—a cure—from the dominant perspective. Second, she nudges them by making them patiently wait for the cure. Finally, she designs a more realistic and authentic outcome for her disabled character. As a result, the audience must adjust to the unexpected yet entertaining outcome. Lomnicki's stealthy approach to storytelling, which challenges disability narratives, relies on her ability to connect with audiences of all kinds, her familiarity with mainstream disability stories, and her commitment to creating new disability stories.

In *Blurred Vision*, Lomnicki also builds bridges between her work and disability culture, while seamlessly constructing characters that appeal to both disabled and able-bodied communities. First, she quietly and cleverly adds a personal assistant (PA) to her solo performance piece. The nurse character is ubiquitous and unobtrusive, easily enacting interdependence and disability accommodations. The addition of this character facilitates Lomnicki's performance, enhances it, and allows Lomnicki to comprehensively narrate her complex disability story.

Second, Lomnicki designs a new kind of supercrip that is powerful against the forces of medical power, social paternalism, and narrative confinement for disabled people and disabled characters. By turning the supercrip into "*Super Patient*," a kind of superhero against the dark

forces of medical normalization, and social/cultural oppression, Lomnicki vividly displays her most powerful political attack.

3. **Subverting medical power**

Blurred Vision contains several examples of Lomnicki's subtle political perspective. First, as discussed, she creates the “*Super Patient*” who takes down medical villains who want to rule the world using ableist structures. Additionally, her use of personal assistant resists ableism in performance practice. Third, Lomnicki uses narrative in strategic, culturally savvy ways. Yet, most prominently in this performance piece, Lomnicki subverts medical authority using satirical representations of personal experiences. The parodies of her medical specialists disrupt their power with humor, exposing and critiquing medical dominance and oppression.

Additionally, Lomnicki weaves her evolving perspective of doctors into the narrative. Doctors had the power to “fix” her as a child—to make her walk. Her notion of someday becoming “normal” is tied their authority. As a child, Tekki's doctors are unseen, but remain powerful until reality intervenes, and the childhood story merges with her adult skepticism. Now she will *never* become “normal,” and Tekki has already revealed her criticism of each specialist, feeling ignored and disrespected. Yet, Lomnicki portrays them with skillful, hilarious exaggeration, knocking them off the pedestals she gave them when she was young. Doctors go from impossibly powerful to flawed human beings in her telling.

Overthrowing medical power is a way for Tekki to reclaim power in the play. Lomnicki overturns the authority of medical professionals to define, confine, and manipulate disabled bodies, while also resisting ideological confinement. Lomnicki's data reveals that she seeks power to choose how she is defined, to have control over her movement, and to claim her own

ideas, viewpoints, and identities. In this way, freedom, choice, community, and humanity are her political objectives.

4. **Building a political bridge to humanity**

The category of “disability” is a useful tool for Lomnicki to achieve political goals such as freedom, humanity, and connection. For example, she likes to blur the boundary of the “fourth wall” between character and audience. Moving over this boundary means Lomnicki chooses to ignore barricade between herself and her audience, which either brings audiences into the show, or breaks character to acknowledge her awareness of the constructed distance between actor and audience. Although her character is based on her personal story, the fourth wall is nevertheless assumed and preserved in theatrical performances. Yet Lomnicki tends to cross this boundary in ways that mischievously bring the audience in on the act, creating connection with them. It also creates a sense of playfulness, ignoring the “rules” of theatrical spaces in favor of freedom, or equalizing the situation. Crossing this boundary creates a communal space in which everyone can play an equal part.

In her personal life, Lomnicki suspends the fictional distance between herself and other people. Perhaps, blurring the “fourth wall of disability,” or the fictional distance between disabled and nondisabled people, reveals that, for Lomnicki, there is no distance between her experiences and others because she wants to connect on a human level. “I identify with how other people react to me,” she said in our first interview, which means that she accepts people on their terms (Lomnicki, Interview 1 & 3). She likes to be a positive role model for other disabled people, and helps others feel comfortable interacting with people with disabilities. This approach not only builds bridges between disabled and nondisabled people, it creates a network in which new ideas about disabled and little people get passed along from those who see Lomnicki’s

shows and by those who she encounters on the street. Thus, Lomnicki builds bridges to achieve her personal, political, social, and cultural objectives. She bridges the distance between herself and other people in her everyday life in a similar way to how she bridges distance between disability and able-bodiedness: she thwarts boundaries to connect on a genuine, human level, to expand the networks between people, and to claim her freedom.

Lomnicki's desire to create connections, networks, and to build bridges is, in part, refusal to be confined to any specific category, even "disabled." This refusal could also be viewed as resistance to categorization, advocating for the only acceptable category: human. Thus, Lomnicki's political, artistic, and personal choices point to a humanistic agenda. Disability may be written on her body, and she participates in the creation of disability culture, but Lomnicki campaigns for disabled people to be part of human experiences. She uses disability identity and culture to serve her humanistic goals. She reveals these goals in the apparent paradox of building bridges and community, where she relies on the particularity of her disability experiences to connect on a human stage.

5. **Lomnicki's standpoint**

Lomnicki's standpoint "challenges cultural values and power relations" (Wood, 2009, p. 397) with this simple statement: disabled people are human and equal with able-bodied people. She assumes that disabled people are similar with nondisabled people, and therefore, just as human as everyone else. This message presumes that the mainstream will make space for disabled people because, Lomnicki believes, everyone is disabled in some way.

To expound on what I see to be Lomnicki's standpoint on disability, let's look at it through the lens of ableism. If able-bodiedness is natural, the normalized formation of being fully human, then Lomnicki disagrees. She argues, according to my analyses, that disability is

just as normal, and as much human, as being able-bodied. Lomnicki expresses the desire to enter the mainstream, to be part of the natural order of society, to be included in the culture, and to live an ordinary life. She does this by focusing on what is similar, rather than emphasizing differences, even as she recognizes a gap between disabled and nondisabled perspectives, communities, and ways of being. Her artistic objective is to bridge these gaps in order to bring both sides, disabled and abled, together. Thus, if Lomnicki's standpoint can be expressed in terms of her desires or goals, it is her desire to enter the mainstream. Her performative strategy is to create space and equal, open opportunities for disabled people that appeal to the mainstream.

6. **Crafty, cunning crip artist**

In *Blurred Vision*, Lomnicki demonstrates a stealthy but sophisticated approach to resisting dominant cultural narratives of disability. Her knowledge of disability in Hollywood films and of how stories are constructed makes her a talented and cunning storyteller. Additionally, Lomnicki is crafty at getting others to look at things from her universal perspective. She uses her talent as a performer, her charm and charisma as a person, her identity and experiences as disabled and a little person, her ability to tell stories, and her strategic narrative approach. This adds up to an uncanny ability to connect while she entertains, giving her power. "I have the power to win [audiences] over" (Lomnicki, Interview 2).

In the final moments of our third interview, I could not resist asking Lomnicki to return to one of the important themes from the play. *Blurred Vision* contextualizes her disability experiences and leads her audience through her desire to be normal. So I asked her how she sees "normal" now. She rephrased the question this way:

Have I given up waiting to be normal? I think that as I'm getting older, what I wanted normal to be is to be able to have a relationship and not to have everything always bothering me and me being needy and stuff, so I think that that's what I want normal to be. And I'm achieving it. (Lomnicki, Interview 3)

Like she presents her identity in the play, as fluid and shifting, I am sure that this concept of normal will change as she does. It is great to hear this current version of what it means to her, and she feels successful in achieving it. Then, after three interviews over several years, we could not help but to play with the silliness of this concept as we concluded. Silly because normal is what we are subjected to, knowing that as disabled people we will never quite achieve it, and realizing along the way that it must be redefined and re-imagined for ourselves.

Lomnicki: So, yeah, normal. Normal! I'm almost normal.

Thrower: I know you're so normal!

Lomnicki: Coming up to normal.

Thrower: (laughing) Congratulations!

Lomnicki: Thank you. (Lomnicki, Interview 3)

And as Lomnicki redefines normal for her life, I redefine it for this chapter.

VIII. DISCUSSION

A. Introduction

The findings in this study reveal both Lomnicki and Wade as performance artists that create new representations of disability, constructing central disabled characters. Both artists achieve new disability representations in every category of my original research template, openly enlisting their disabled bodies for the works and the four categories. First, both artists' performance works interrogate cultural assumptions and inscriptions of disability (category 1). Both translate disability experiences into artistic depictions (category 2). Both claim identities as disabled women and represent body and self in the performance work (category 3), and both utilize their identities and artistic perspectives to construct disability culture (category 4) through the work. Already, these artists affirm important differences from prevailing representations, successfully demonstrating my template. Yet, these artists accomplish more than I first proposed. In this chapter, I sketch out an overall picture of the findings across both artists. I discuss their contributions, how they are similar and different, and include how they bring about my four categories, and push beyond them.

One of the first clear distinctions between Lomnicki and Wade is this: Wade is a poet, and Lomnicki is a storyteller. The two styles distinguish their performance art. Wade uses imagery, language, and contradictions to “amplify, to edify” her experiences of being a disabled woman (Wade, Interview 1). These tools help Wade to paint “haunting” images that stay with audiences, and penetrate, excavate, and enlighten her spectators to her multi-layered ideas. Lomnicki, however, has mastered the art of narrative. She understands how stories work, what people expect from good stories, and how to move stories in particular directions. Additionally, Lomnicki has mastered the art of comedy, using her face, voice, and a great line to deliver

powerful humor. She uses her comedic skills to parody authorities with ease. Lomnicki aims to please. Wade gets under the skin, transgressing the lines of what is considered “appropriate” or “pleasing.” Lomnicki perfects humor in theatrical ways, and Wade perfects the carefully crafted phrase.

B. **Transforming Representations**

As I discussed in “Methods” under “Category 1,” Garland-Thomson (1997) argues that part of the reason for “the gap” in disability representation involves how disabled characters are portrayed. Without complexity and agency, disabled characters tend to be “flattened out” and boring (Nussbaum, 2006). To counter this, Lomnicki and Wade transform typical representations by interjecting multifaceted, self-determined, and changeable characters that reflect their identities. The central characters from *Sassy Girl* and *Blurred Vision* are based on the artists who created them. Wade uses “complicated reality” to refuse any simplistic notion or portrayal of disability, adding complexity to her main character. Lomnicki complicates her character’s narrative, depicting identity processes in the play with non-linear storytelling to emulate her personal development. Both artists transform representations by creating complex disabled characters with political and cultural agency to interrogate the dominant culture’s expectations about disability, and to critique and transform ingrained stereotypical imagery of disability.

Transforming representations of disability with characters that have agency, empowerment, and subjectivity may not be enough to refute the socially and culturally entrenched “ideology of ability” (Siebers, 2008). My findings reveal that, in *Sassy Girl*, Wade seeks to, not only “critique dominant cultural assumptions” (Garoian, 1999, p. 2), but to overhaul them and the ableist origins underlying them. Wade uses “radical vulnerability,” a performance strategy that transforms disability representations, and she uses her standpoint—a political

position that transforms culturally ingrained meanings of disability. Her approach exposes ableist practices as naturalized and normalized, and resists them, while engaging deeply with her audiences. She displays both sensitivity and resilience to directly address the stresses and agitations caused by oppressive practices and social structures. Radical vulnerability requires an integrated, politically sophisticated and culturally aware disability consciousness, which Wade uses to frame her performance. Her standpoint is reflected in this approach, and demonstrates her disability activism, knowledge from disability culture, and reflexive artistic practices.

Lomnicki, in contrast, seeks narrative transformations for disability. Her strategy overturns expected narratives from the dominant culture that permeate representation. She transforms narrative in three ways. First, she makes the disabled character (Tekki) central to the story. Second, she gives this character an expected disability plot; or at least, she guides her audience there. And finally, she disrupts this plot, suddenly switching the expected trajectory with one that was unforeseen. Lomnicki's strategy is cunning—a cleverly deceitful approach that replaces familiar narrative tropes with re-imagined ones. She builds bridges between the mainstream and disability cultures, which permits her to smoothly “expose and interrogate cultural inscriptions” (Garoian, 1999, p. 5) from dominant disability representations. *Blurred Vision* exposes such depictions by enacting, then refuting it with her personal history and memory.

In *Blurred Vision*, Lomnicki constructs a story configured to mimic the experience of fragmented identity. By moving her main character between childhood and adult scenes, she performs the split pieces of identity that her story intends to resolve. With this technique, her narrative resistance, making her disabled character central, and including disability culture

portrayals, Lomnicki's performance "overcomes" disability's entrenched position as metaphor, narrative device, or typical representation.

Each performer works with personal history and experience to examine, subvert, and critique the cultural labels and suppositions of disability. Both artists reveal and challenge underlying principles that construct disability and maintain oppression. Wade shakes up and reconfigures dominant representation, re-writing mainstream images to fit her innovative vision. Lomnicki responds with her stealthy approach to stories. Her universally relatable work constructs metaphorical bridges between disability and able-bodiedness to make space for disabled people as well.

C. **Making critiques**

Lomnicki and Wade construct representations that undermine medical authority, which has primarily shaped the concept of "disability." Lomnicki and Wade use their memories and personal histories of hospitalizations and frequent medical treatments to reveal and destabilize medical power. In *Sassy Girl* and in *Blurred Vision*, childhood hospitalizations are re-visited, portraying the convergence of institutionalization with medical dominance, which overpowers and submerges the subjectivity and wholeness of both artists. Each disabled woman depicts how she reclaims identity, power, and agency while interrogating and resisting medical discourse.

Overthrowing medical power is the main focus in *Blurred Vision*. What originally began as a short piece about positive experiences in the hospital changed into a longer play that questions medical dominance over disabled people. Lomnicki's work tackles this issue in two ways. First, she constructs the medical system's unassailable power. As a child, she has complete faith in her, which is translated in adulthood as her need for medical validation. Tekki never questions her belief in medical authority as a kid. Second, Lomnicki depicts how she reclaims

her own power and identity. Weaving an identity story into the more overt medical story, Tekki must re-integrate the broken parts of her psyche. Reclaiming her identity and power occurs once she recognizes that her faith in doctors was misplaced. In both her lived and portrayed experience, she realizes that her doctors' powers were false when they see she is becoming a woman. As an adult, Tekki topples the doctors with humorous parodies, poking fun at their position.

Wade also overthrows medical power in *Sassy Girl* by depicting scenes from her childhood where she is overwhelmed by it. For example, she enacts such experience with her poem "Hospital Litany," and depicts "public stripping" in the scene about "Zeus." During the former scene, Wade exposes institutional control by repeating the language she heard that separated her body from her self. With many confusing terms coming at her from seemingly multiple voices, her performance of this poem portrays an overwhelmed, vulnerable girl who can barely resist being defined by the medical system. The poem reveals the loss of control and freedom that occurs in hospitals. During her scene about "Zeus," therefore, she says she was "*doing time*" in the hospital, comparing her experience to imprisonment.

D. **Transforming Disability**

A main component of transforming representation with performance is incorporating experiences from the artists' lives. The second category from my template, "transforming experiences into art," is concerned with ways these artists transform disability, or re-articulate experiences for the stage. Both Lomnicki and Wade use "personal memories and histories through performance" to "engage in storytelling," which frames their experiences within time and space. An important part of this transformation is when each artist "passionately revisits" experience "across a pre-existing discursive field" (Garoian, 1999, p. 5).

Experience, or the “thing done” (Diamond, 1996), is reformulated in these performance works. Original experiences are transformed to incorporate epistemic privilege, or the knowledge and meanings derived from living as disabled women. Wade transforms her disability experience to include a political and radical sense. Lomnicki transforms hers to emphasize universal qualities, making her experiences relatable. The memories performed on the stage contain re-interpreted, theory-mediated, and politically aware versions of “things done,” which have already been re-written across pre-existing discourses of disability from dominant and disability cultures. Epistemic privilege for Lomnicki and Wade comes out of the social locations and power differences they inhabit as women, and the “special advantage,” knowledge, and perspective of being white, middle-class, heterosexual, and disabled (Moya, 2000).

Epistemic privilege endures a similar “intellectual struggle” to what Wood (2009) defines for “feminist standpoint theory.” Each artist relates her disability experiences in ways that express her feminist disability standpoint. Wade rejects the dominant culture, relinquishing any need for legitimacy or approval from the mainstream. Her woman identity is tied to her disability identity, both claimed with sexual agency. Her standpoint privileges a disability identity that seeks a new cultural and social order. Lomnicki presents experiences that create space for her in the mainstream, seeking community and to humanize and equalize disability. Her standpoint privileges what is common between her and the “average person” (Lomnicki, Interview 1), claims a strong woman, disability identity, and seeks to dissolve the distinctions between disability and able-bodiedness.

Wade transforms her disability experiences through her performance strategy, radical vulnerability. She seeks to “bother” people (Wade, Interview 2), and therefore shake up her audiences enough that they will “do better.” In this way, Wade frames her experiences from her

critical disability-centric perspective with intent to transform ideas and disability perceptions. Lomnicki transforms experience by “building bridges” and her sly narrative style. By framing her particular experiences as similar to those of nondisabled people, she makes her audience comfortable, and assumes Lomnicki shares their able-bodied viewpoint. She transforms disability by transforming traditional narratives, which makes space for new ways to represent disability experiences.

E. **Performing Identity and Self-representation**

In this section, I discuss findings from the data that express my third category, identity and self-representation, in the performance work and lived experiences of Lomnicki and Wade. Both artists perform and frame their identities in ways that reflect disability studies theories of identity. One of the four types of integration in disability identity that Gill (1997) presents, “coming together,” was especially prevalent in the findings, along with psycho-emotional dimensions of disability discussed by Marks (1999) and Gill (1994, 1997). These theories account for the effects of medical influences to identity, such as the “splitting” of the self during “normalization” practices (Gill, 1997), and the task of restoring broken pieces of identity to reclaim self and body. Garoian (1999) offers specific social and cultural strategies for claiming identity, and for reclaiming self and body in performance art. Wade and Lomnicki’s work achieves some of these strategies, including: ethnographic, linguistic, political, social, and ecstatic.

Lomnicki speaks to the concept of “normal,” which organizes theories of disability and self-definition, stating it in opposition to able-bodiedness. As *Blurred Vision* contextualizes the concept of “normal,” it is made explicit by her body onstage. Contextualizing the notion of “normal” for her character exposes its oppressive structures, and links it with medical and

dominant discourse. “I wish to work against the idea that, in order to be whole, functioning individuals, people with disabilities have to be cured or look like everybody else” Lomnicki said during a personal communication (Thrower, 2013, p. 210). Meanwhile, “normal” frames her process of identity development, both in her performance and her everyday experiences. Trying to attain “normal” was damaging to her self-definition, especially once she realized it was never going to happen. She works with and against the idea of being cured to become normal, until finally claiming her body and self by accepting both. In this way, she uses a new definition of “normal” to claim self, while removing it from being “like everybody else.”

In *Sassy Girl*, Wade talks about her disabled body as an integral part of her experience and her identity. Conveying identity through “complex embodiment,” Wade makes her body central in the performance, as it is in her daily life. This centrality reflects her feminist, disability perspective, living and performing the adage that the “personal is political.” Wade politicizes the realities of impairment, thereby exposing its exclusion from the disability movement, and creating a political space for affordable, respectful care. Her identity as a disabled woman is in conversation with the disability rights movement, but also with dominant cultural notions about disability and womanhood. Her embodied identity claims subjectivity and self-definition, resisting cultural inscriptions of disability, and replacing them with alternative images and ideas about being both disabled *and* a woman.

The zigzagging identity story in *Blurred Vision* traces Tekki’s quest for self-definition. The performance is written to enact the fragmentation and reintegration of her identity, moving between present and past, and representing a “splitting of the self into acceptable and unacceptable parts” (Gill, 1994, p. 15). Such “fragmentation” often occurs with repeated medical treatments at an early age (Marks, 1999), and interferes with developing a “whole” self, causing

identity “disintegration” (Gill, 1994). Thus, the play imitates the character’s identity struggles, which create a “split” between self and body. Tekki resolves this by restoring her “sameness and differentness” (Gill, 1997), and declaring her self and body “*Normal. Just the way I am*” (Lomnicki, *Blurred Vision*).

Wade’s lived experiences are reflected in her performance to depict how identity shifts with her political consciousness. The greater her depth of political understanding, the more her writing and poetry reflect epistemic privilege and social location (Moya, 2000). Wade addresses how her identity was shaped by medical interventions as a child and teen—a performance element she shares with Lomnicki. Wade frames her identity as a “thing to be fixed” (Wade, Interview 2), and the impact to her identity by the “objectifying gaze” (Marks, 1999) and “public stripping” (Blumberg, 1994). Cheryl feels humiliated by medical power and starts repeating her “*internal mantra*”: “*don’t you dare cry, don’t you dare cry*” (Wade, *Sassy Girl*). It occurs to her to act like a “*dummy*” and she begins to mimic “*Zeus*,” turning the humiliating moment into a satirical critique, similar to Lomnicki

The findings reveal Wade deals with identity issues with biting sarcasm and critique of the medical system, as well as fluidity and flexibility. Like Lomnicki, Wade’s character expresses a sense of “splitting” (Gill, 1994) and “fragmentation” (Marks, 1999) as a result of medical authority. Wade’s identity story, both in *Sassy Girl* and interview data, expresses “coming together (internally integrating our sameness and differentness)” (Gill, 1997, p. 43), which demonstrates identity that develops from where body and self are separated, to where she reclaims both as cohesive whole. In this way, she reclaims identity and agency from medical authority.

For both Lomnicki and Wade, identity is fluid, open to revision, and mediated by experience (Moya, 2000). Both artists express identities as part of a larger disability community, and as “bicultural” (Gill, 1994) between mainstream and disability cultures. For Lomnicki, bicultural identity is particularly salient because she is driven to build a bridge between the two. Wade, however, prefers to dwell in disability culture, the mainstream perhaps too restrictive for disability. These stories retain the brokenness of disability from the dominant majority while accepting and celebrating differences in ways that transform cultural understandings of them.

Both Lomnicki and Wade express being “out” as disabled women, accepting of body and identity, yet complicated by social interactions from daily life. Lomnicki chooses to meet and interact with new people openly, pleasantly and positively using her disability identity to serve as an ambassador for other disabled or little people. She sees herself as part of the mainstream, and that the mainstream is part of disability. The identity Lomnicki reveals is interested in bridging these communities with her approach to life and performance. In contrast, Wade’s disability identity can be described as what Sandahl calls a “radical crip” (2003). Wade’s approach to rude, objectifying strangers would be based on her refusal to be anyone’s “crippled whore” (Wade, Interview 2). Her expression of identity actively redefines disability by emphasizing the complexity of her experience, her body, and shared struggles of others in the disability community. In performance, Wade identifies with, and bears witness to, historical, current, and future disabled people. She incorporates mainstream images of disability with a radical twist onstage, while extending disability community to individuals of every impairment type, age, race, ethnicity, sexual identity, class, or creed. In this way, Wade’s identity is political, fluid, multiple, complex and ever changing, epitomizing the definition of the term “crip” (Sandahl, 2003).

Wade's performance work intervenes to reclaim self and body from historically, culturally, and socially inscribed identities (Garoian, 1999), achieving several of Garoian's performance strategies I discuss in "Methods." *Sassy Girl* reveals the "physical, historical, and cultural terrain" of Wade's disabled body (Garoian, 1999, p. 12) as an "ethnographic" strategy. Wade's poetry applies her "language of identity" (Garoian, 1999) using imaginative descriptions to define and claim her self and body. The language she chooses is often unsettling and negative, but achieves her goal of exposing cultural values of disabled bodies, and simultaneously re-interpreting them. Wade's poems, "I am Not One of the" and "Cripple Lullaby," spell out identity with claims of who she is not. The poems and scenes in her performance also intervene to reposition her body and self from the margins to the center, achieving a significant "political" strategy (Garoian, 1999, p. 12). *Sassy Girl* also attains the "social" strategy by creating community and relationships with disabled people. And, the work intervenes aesthetically with the "ecstatic" strategy of performance, which interrogates beauty and physical value with re-inscription of sexuality, sexual agency, and gender as a disabled woman.

Similarly, *Blurred Vision* intervenes using Garoian's "ethnographic" strategy by examining her body's cultural terrain through depictions of medical specialists. Rather than discussing the disabled body as Wade does, Lomnicki's narrative relies on her physical presence, movements across the stage, and her personal history to probe "historically and socially embodied culture" (Garoian, 1999, p. 12). Lomnicki's approach exposes her physical limitations, making them explicit onstage. As an identity story, Lomnicki uses her play to question the meanings of her identity, choosing the term "normal" as a "linguistic strategy" to intervene and critique disability stereotypes. Lomnicki does not claim any overt "political strategy" in her performance, but covertly uses her performance to resist typical disability narratives, and to

subvert and critique doctors. Lomnicki takes an active role in what Garoian calls the “social” strategy of performance to promote community and collaboration between disabled and nondisabled groups, which may inherently intervene as a “political strategy” as well. Thus, she uses these strategies in performance to reclaim self and body from the mainstream, while opening space for herself and other disabled people.

F. **Constructing “Culture Anew”: Creating Disability Culture**

In this part, I discuss my findings in terms of how these performance artists “re-consider and construct culture anew” (Garoian, 1999, p. 5). The fourth category investigates how these artists use autobiographical performance to create disability culture. As cultural creators who engage with hybrid consciousness, both artists cross boundaries in their performances, and each applies needed tools to construct her distinctive, performed disability culture.

Throughout *Sassy Girl*, Wade claims a “cultural identity” (Peters, 2000) to create disability culture. Wade pulls from accepted disability culture imagery, values, and language, but also draws from the mainstream using re-considered and re-imagined concepts in ways that resist negative connotations. For example, Wade describes her disabled hands in “My Hands” like “*the Ivory girl’s hands after a decade of roughing it*” (*Sassy Girl*), adding her embodiment to a familiar image. Using resistance and new meanings, Wade includes ideas that reflect “complex embodiment” and involve pain, frailty, and loss, with sexuality, joy, and freedom. Such ideas are transgressive as foreign or forbidden social constructions of disability. Wade situates her concept of disability culture from her “politically informed disability subculture” perspective (Snyder & Mitchell, 2006), which transforms “*tired ideas*” into radical re-imaginings.

Lomnicki’s approach to disability culture is also compelling. Although Lomnicki wants to make disability culture a palatable, accessible idea for her able-bodied audiences, she also

inserts sophisticated elements into the work, and infuses disability culture with complexity. An example of this is her inclusion of the nurse character in the play, depicting a disability culture value by embodying an interdependent relationship between Tekki and the nurse. The meaning of the additional character may not be clear to her nondisabled audiences, but the effect is a portrayal of interdependence and accommodation.

Including the nurse also allows Lomnicki to tell a deeper disability story because the able-bodied actress represents contrast to Tekki's disabled character. This allows Lomnicki to portray complexity in disability identity: disabled people accept themselves as they are, but may contradict this at times by succumbing to the pressures of ableist practices. Thus, the nurse's reflections of Tekki's fantasies demonstrate that social and cultural forces or internal anxieties can undermine being "out" and self-accepting.

Lomnicki and Wade use hybrid consciousness to fuse different concepts and paradigms into a fresh worldview for disability culture. Lomnicki and Wade include disabled characters from Hollywood to speak directly to disabled people in their audience. Iconic film characters and Hollywood depictions speak to what is wrong with cultural and social constructions of disability, and both artists rely on disability community to comprehend this shorthand to disability culture.

Lomnicki's hybrid consciousness relies on other iconic characters, such as the "supercrip" that call upon disability culture, and, at the same time, make disability culture an accessible, relatable concept for her nondisabled audience. Wade's hybrid consciousness privileges ugly, sorrowful, or painful images of disability for disability culture, mixing dominant culture's imagery with her radical touches. For example, she pairs iconic images like, "*I'm withered legs hidden with a blanket*" with her witness of disabled people: "*I'm an icon carved from bones in a mass grave at Tiergarten, Germany.*" She intermixes lines that include deformity

with sexuality: “*I’m pink lace panties testing a stub of milk white thigh*” (*Sassy Girl*), which complicates imagery with contradictions to construct her version of disability culture. Her version transforms traditional notions of disability while it expresses a fresh disability culture.

Hybrid consciousness necessarily requires “boundary crossing,” which both Lomnicki and Wade achieve in different ways, each using “the trickster.” According to Hyde (1998), tricksters exist between what “we constantly distinguish” (p. 7). Wade engages with trickster in a direct way, and Lomnicki in an indirect way. Wade’s work moves “in-between” binaries of positive and negative, never accepting either side. This is where she “complicates reality” for her character because she endeavors to create a more realistic environment for disabled people in representation. Lomnicki lurks between nondisabled and disabled binaries, never quite landing on either side in a definitive way. Both prefer crossing the spaces “in-between.”

Trickster is also “the mythic embodiment of ambiguity and ambivalence, doubleness and duplicity, contradiction and paradox” (Hyde, 1998, p. 7). As an intelligence, a figure from folklore that “brings to the surface a distinction previously unseen” (Hyde, 1998, p. 7), trickster reveals new perspectives and possibilities. My findings have pointed out Wade’s use of paradox and contradiction to complicate her character and her story. Additionally, Lomnicki has been shown to be a duplicitous storyteller, exposing the possibility of new disability plots and stories. Lomnicki and Wade also infuse their work with the trickster-as-culture-hero energy to create culture for disability community.

Tricksters often appear in cultural stories (Hyde, 1998), for example, to teach the new people (human beings) how to find food without being eaten in the process. Trickster must kill or, at least outwit, the “large, devouring forces in this world, and... trickster’s intelligence arose not just to feed himself, but to outwit those other eaters” (Hyde, 1998, p. 22). “Large devouring

forces” signifies any dominating force, such as an overpowering, assimilating pressure that threatens self-integrity. In this story, trickster needs to satiate his hunger (create disability culture) and subvert the hunger of would-be predators (the dominant cultural).

Sassy Girl uses trickster intelligence in a similar way. In the scene about “Zeus,” which I discuss earlier, a young Cheryl must outwit the “devouring force” of medical power while in the midst of a potentially humiliating event. As “Zeus” overpowers her by manipulating her leg, and before he metaphorically consume her dignity by ignoring the teen girl attached to the leg, Cheryl attacks. Like the trickster above, she averts being devoured by striking first, making fun of Zeus by miming a “*bad ventriloquist’s dummy*” to his unintended ventriloquism. She resists assimilation by his “large devouring force.”

In the example above, Wade also transforms this moment of what she called “pulling your spine back into your body” (Interview 2), into a performed artifact of resistance for disability culture and community that represents self- and power reclamation. It exemplifies a personal act of protest for disabled people. It galvanizes the disability community with empowerment and self-worth. And it uses trickster intelligence to defeat the monster that would have eaten her first. In this way, Wade’s trickster role transforms oppressive conditions that impact disabled people and re-imagines disability culture, and the social realm, in new forms.

Lomnicki’s trickster, in contrast, builds bridges and crosses boundaries between disability and mainstream cultures. Lomnicki uses trickster intelligence to move in-between the spaces of expected stories, and mischievously change them. She creates disability culture with fresh and clever stories. Lomnicki also employs trickster energy to move boundary lines that mark divisions of disabled and able-bodied people to create new spaces for both.

1. **Making connections**

Creating disability culture, new realms, and hybrid consciousness invokes the creation of new communities, or the expansion of existing ones. While both Lomnicki and Wade seek connections and community in their work, they do so in different ways. Wade, through radical vulnerability, engages deeply with her audiences, connecting on a profound level, making them think. Lomnicki connects on a more surface level, using humor to entertain and draw her audience in. Engaging with their audiences, the two artists target different audiences. Wade targets a disabled audience, relying on her identity, disabled body and experiences to connect with other disabled people. Yet, she realizes that all disabled people do not have a similar disability perspective to hers, nor is every person in her audience disabled. As a result, her approach intends to shake her audiences out of their “disability” comfort zones. It is disability-centric, with a critical view that frames disability as a site for new possibilities, new ways of being, and innovative ideas about being human.

Lomnicki approaches her audience differently. She seeks connections with her primarily nondisabled audiences, and connects using the similarities to others from her experiences. She bridges disability community with the able-bodied world, but, while Lomnicki wants to connect her two communities, she seems to place greater emphasis on mainstream sensibilities. Thus, Wade might be considered a disability elitist, and Lomnicki could be considered a Universalist. She seeks equality and par with able-bodied, mainstream society and culture, even while simultaneously valuing the knowledge and strengths of disability culture and community.

In many ways, Lomnicki seems to straddle an in-between space where she does not quite fit with the mainstream or with the “crip world” (Lomnicki, Interview 3). She works, however, to belong in both: to be successful in both and have both as audiences and colleagues. Her work,

while addressing a primarily nondisabled group, does not neglect disability culture or aesthetic. *Blurred Vision* dispels many dominant disability tropes and narratives, and Lomnicki inserts sophisticated representations of disability experiences and culture, attracting a prominent share of disabled audience members along with her dedicated nondisabled fans.

Since Wade wants to bother her audiences with her work, she prefers that spectators be a bit on edge. She wants to “open a door” and change how people deal with, and think about disability. Lomnicki, however, does not want them to feel uncomfortable at all. Rather, she wants the audience to think of disability as part of humanity, as she smoothly shows them how both groups are similar. Wade’s strategy is riskier, because it pairs the vulnerability of what Lomnicki calls “very true feelings” with the radical purpose of disturbing people out of their rooted, “*tired ideas*.” Lomnicki’s approach allows her to have a conversation with her audience that is easy but subtly political, while Wade has no intention of being subtle. “I get to have the conversation I want to have on my terms,” Wade said in our final interview. Such a conversation, which provokes her audience toward change, speaks about disability on multiple levels, about internal and external pressures and oppressions, and about re-interpreting and re-imagining disability. *Sassy Girl* provided profound, confrontational conversations about disability and social change with “the Queen Mother of Gnarly” herself.

The conversations Lomnicki had with *Blurred Vision* audiences were potentially altering as she first puts her audiences at ease with ordinary scenes, but suggests extraordinary, magical notions of little people to move her character through the story. Lomnicki is deliberate in her desire to help nondisabled audiences understand disability in a different way. The way she uses metaphor, narrative, and other tropes of disability is familiar to most people, bringing nondisabled people in her audiences in on the joke, while the disabled members of her audiences

feel part of this performance. *Blurred Vision* is a disability story that, on the surface, entertains a nondisabled audience, while it also uses disability humor, sophisticated disability culture themes, and transformative narrative to speak to a disabled audience just beneath the surface. In the childhood scenes, familiarity and comfort are deliberate because she strives for her work to be approachable, and approachability is also her personal style. Yet, this technique sets the audience up for the sharp plot turn at the end. This approach permits an easy-going conversation, without any hard-hitting lecture or lesson, about a little person who is disabled, with subtle tie-ins to disability culture and identity.

Wade's work, in contrast to Lomnicki, has been called "in-your-face" by McRuer (2006), but this is because she flaunted her disabled body. Wade's approach called to disabled people in her audience, showing them that disability could be something to flaunt, to be proud of, as well as all of its complex meanings and significations. There is subtlety in Wade's poetry, and her performance is not a hard-hitting lesson or lecture on disability either. It achieves her goal to edify her experience because it is strategically uncomfortable. And, this deliberate discomfort is for the nondisabled members of her audience, showing them how they can do better when they deal with disabled people in their daily lives. Yet, any point in the narrative of *Sassy Girl* where Wade believed her audience might feel uncomfortable, is a place where she uplifts them or makes them laugh.

2. **Concluding thoughts**

The findings in this study affirm the initial four categories established in my template. Both artists realized the four initial themes, and each artist integrates the disabled body into the performance to influence the realization of the each category. Wade makes her disabled body explicit as she overtly includes body issues throughout the play. Her disabled body is the

primary tool with which she constructs disability culture, expresses her identity, and interrogates the dominant culture. It is also the primary aspect of her experience that she draws from to construct her performance, using it as the means for transforming representation. Lomnicki rarely discusses her body or impairment issues in her work, allowing her body's presence to speak for itself. It is part of her identity and self-representation, and the primary aspect of disability experiences she converts for the performance. Lomnicki, however, prefers to use culturally familiar characters to assist her in situating her identity, which is constantly changing. These characters provide a backdrop for her to create disability culture anew. And Lomnicki allows her physical presence to speak for her to critique the dominant culture's entrenched notions of disability.

Cheryl Marie Wade and Tekki Lomnicki have created innovative disability stories from their experiences that instill new narratives, complex characters, alternative imagery, and reclaimed language into the mainstream. As representational models, these stories claim disability as a source of empowerment and social change to re-imagine disability for their audiences and themselves. Relying on their particular disability perspectives, these artists re-work personal history and craft cultural stories that re-interpret disability in fresh ways, interrogating disability's position in the dominant culture by performing and constructing new paradigms of disability and culture.

IX. CONCLUSION

A. **Introduction**

This project, *Re-imagining Disability: Performance Art and the Artists' Perspectives*, has been an effort to understand the relationship between personal disability experience and its representation by foremost performers with disability. Through an in-depth look at solo autobiographical work by Cheryl Wade and Tekki Lomnicki, this study examined performance strategies and artistic perspectives. The strategies presented establish imaginative ways to represent disability and disabled lives, and offer new possibilities to redress the “gap between representation and reality” (Garland-Thomson, 1997, p. 12). In addition, each artist’s perspective guided her creation of alternative, transformative representations. In this chapter, I describe the most important aspects of the strategies and perspectives used by Lomnicki and Wade. I conclude with a discussion of the importance of my findings, and what additional research is needed.

B. **Performance Strategies and Artistic Perspectives**

1. **Performance strategies: Lomnicki**

Each artist employs strategies in her performance art that challenge ingrained notions of disability. At first glance, Lomnicki’s work seems to be entertaining and uncomplicated. My analysis has shown, however, that Lomnicki is crafty at her craft. In our second interview, I asked her about control over perceptions of disability. She admitted she has no control, but “the power to win them over, and that’s what I like to do” (Lomnicki, Interview 2). Getting others to look at things from her perspective—winning them over to her viewpoint—is her cunning strategy, and largely about the universality and humanity of disability.

Lomnicki is an improviser, which makes her fluid and adaptable onstage. Her tendency to play with the fourth wall, moving that curtain aside to let the audience in on the fun, is another way she charms them and wins them over. Her approach to narrative, while a transformative strategy for disability, works well because of her fluidity and humor. Making the audience feel comfortable provides the space she needs to turn her disability storyline in a new direction. Spectators are having fun, feeling at ease with Lomnicki at the helm, and therefore, they never see her sudden change of tack.

I am using the term “tack” as a sailing term, which works well as a metaphor to talk about Lomnicki’s narrative strategy. “Tacking,” refers to a maneuver that, when sailing upwind, brings a sailboat into and through the wind—the force propelling the boat—in order to change direction from one side of the boat to the other. On one tack, the audience assumes that the force propelling her story privileges an able-bodied position. Yet, when she moves through the wind (dominant cultural forces), the audience goes with her as she re-positions her story to her actual tack: her disability perspective. The audience is having such a good time that they go along with her to the new tack, and she subtly “wins them over” and hopefully, shows them another, equally important perspective.

Lomnicki’s strategy is a function of her perspectives, which land on both the able-bodied and disabled sides of culture. She straddles both sides of these two views, interpreting and performing her disability experiences in ways that bridge them together. Thus, the relationship between Lomnicki’s lived and performed experiences are a function of building bridges, which sees her experiences and artistic representations as universal, human events. Lomnicki needs to present both tacks in order to connect them and challenge them.

2. **Performance strategies: Wade**

The most important thing about Wade's work is that it is "radical." She does not simply take a radical approach, which for Wade, is not simple at all. She complicates her radical approach by excavating, exposing, and transforming how the dominant culture represents disability and the social and political consequences of such representations.

Wade excavates her experiences, thinking and reflecting about how she was shaped by the able-bodied world. She exposes the root of the dominant cultural and social conceptions that shaped her. Transforming disability begins by converting it into the reflection of her identity, which includes her flaws and her strengths. Contained in this transformation are new possibilities for disabled people and new ways to represent disability. Her strategy refutes, resists, and subverts ableist practices at the core of dominant ideology, while it also claims power and agency for herself and her community, and proposes alternative meanings and ways of being human for everybody.

Wade's radical approach is also a function of her perspective, which she has purposefully clarified and deepened through writing, performance, and activism. Her strategy of radical vulnerability represents the relationship between her lived experiences and their performances on the stage where she depicts how they have been excavated, how they expose ableism, and how she transforms them into empowered, disability-culture-centric messages.

3. **Performance strategies: Vulnerability**

Both Lomnicki and Wade use vulnerability to perform their strategies and new representations. Both manifest the strength and courage that being vulnerable garners on the performance stage—exposing frailties while also transcending them, all as a means to connect with audiences. Lomnicki connects with emotions, or "very true feelings" (Lomnicki, Interview

1), and Wade connects with past vulnerable events. Both present a state of vulnerability in the performative present that occurred in the past, and seek connections with audience members on human levels, beyond disability and able-bodiedness.

The difference between the ways each uses vulnerability, however, is at the level of engagement with the audience. Wade seeks a profound, deep connection with audiences, and women with disabilities in particular. Radical vulnerability reaches in to the core of disability oppression, and her use of vulnerability seeks a strong connection that can transform those who view her work. Lomnicki, on the other hand, is seeking community and to connect her ideas about disability to her audiences, especially those without disabilities. Her level of engagement is closer to the surface, less intimate, but still seeks to transform disability at the level of ideas, narrative, and metaphor. Both of these are important tasks achieved through their use of vulnerability, but I think this level of engagement speaks to the reason that Wade's work and performance have a more comprehensive and lasting transformative impact on her audiences.

4. **Artistic perspectives**

I have already described how each artist's perspective guided the performance strategies used. This is a fundamental finding from this study, which provides knowledge about how artists' perspectives influence performance strategies and transform meaning, interrogate assumptions, and create alternative representations. The artist's framework and point of view come through in the work, which means that each artist makes the difference. Disabled solo autobiographical performers were selected to manifest frameworks and perspectives of disability, to reproduce memories and personal histories, and to construct representations that reflect disabled people. In this art form, the artist uses her body and life to craft the work, perform it, and reflexively revise it as she goes. Like a singer/songwriter or memoirist, the artist's particular

political, cultural, and social perspective—her “cultural criticism” (Garroian, 1999)—is embedded within the creative process, influencing and guiding it. It is this perspective that makes a difference in how an audience receives the messages from the art. The works of Wade and Lomnicki challenge ingrained messages: questioning and transforming them so to “open a door” to new possibilities (Wade, Interview 2).

At the beginning of this project, I felt that the artists’ perspectives were important enough to include into my title. Recently, I witnessed how important such perspectives can be in expressing and translating them from one medium to another. To illustrate this, I will leave my research for a moment. When I read the audio version of *The Fault in Our Stars* by John Green, and after several readings, I found a new aspect of the book that revealed an embedded disability-culture perspective. Without doing a full review here, I will explain that I noticed things like disability humor, a broad awareness and preference for assistive technology (hand controls for cars, voice controlled video games), and a crip sex scene between the two primary, and disabled, characters. The book claimed a knowledgeable disability identity, allegiance to a perspective central to disability culture, and realistic portrayals of several disabled characters. But, the film version of the book failed to include this perspective. While the film mostly retained scenes from the book, the author’s disability-centric perspective was missing. It did not carry forward the enlightened, transformed way of being that the author had conveyed through his characters’ experiences with chronic illness and impairments. The filmmaker apparently failed to notice the disability-culture perspective that grabbed my attention, and the film assumed an able-bodied position for its characters and spectators.

Visual artists use “perspective” to draw or represent their embodied vantage point. From this point, the artist directs the viewer’s attention to what he or she focuses on in the work. This

vantage point offers the distance of the artists' reflections on their experiences, and a holistic viewpoint from which to see the entire, encompassing picture of their subject matter, which in this case is disability. Without the artists' particular perspectives infused into the works, these disabled artists in the study may have constructed performance art works that lacked resistance or transformation. Both had experienced and reflected on disability in a way that they could present to their audience a perspective that went beyond the obvious, beyond dominant culture, and beyond what is "normal" for both disabled people and for human beings. For instance, what if Lomnicki performed her experiences from a dominant cultural perspective, telling an inspirational, overcoming story about her own achievements as a "supercrip?" She could have given her audience everything that any able-bodied viewer expected in most disability stories. But Lomnicki includes her artistic, disability perspective into her work; even while making audiences *believe* she is more aligned with the mainstream.

Wade admits that she understands mainstream narratives and stereotypes as well, but chooses not to abide or use them in her work. She never hints at wanting to adhere to the dominant culture's notions of disability at all. Her perspective comes through from the very beginning of the performance. Wade and Lomnicki achieve transformative, empowered works of art because of their disability-culture, disability-centric frameworks.

Nussbaum argues for "an authentic disabled voice" in disability depictions that no longer infantilize disabled people, raise them up as saints, or simplify their lives down to a few quirky "mannerisms" that win Oscars (Nussbaum, 2006). She believes that changing the representational system "could be so easy." She explains:

It could be so... easy to change all this. But to do so artistic directors and TV and movie producers must make a commitment to the authentic voice of disabled characters. And the authentic voice will only come from writers with disabilities. And these authentic disabled voices must challenge the public to a new perception, a new debate – not the

simplistic, scent of a womanly, million dollar babyish garbage that insults our intelligence and drowns us all in cheap shots and cheap sentiment. (Nussbaum, 2006, p. 4)

Nussbaum's "authentic voice" also includes a disability perspective that "must challenge the public to a new perception" and open up a "new debate" about disability. Without this "new" framework pushing against the old traditions of storytelling and discourse on disability, storytelling and discourse will remain as limiting, and as limited, as it has always been.

C. **Importance of the Findings**

The dominant culture has misrepresented disability for many decades, and the notions we adhere to in social practices reflect and perpetuate ingrained, ableist concepts. Such messages continue social oppression and disabled people's undesirable social status, while they also uphold the privilege of ability, and create an environment of pity, fear, silence, and abjection. Nussbaum contends that the social consequences of disability misconceptions, stereotypes, and metaphors, which she encounters on a daily basis, continually reify ableist attitudes and practices.

This study is important, not only because it recognizes the need for honest and realistic representations that shape a better reality for disabled people, but also because it proposes new methods and models for creating them. The findings develop a rich compilation of representational strategies that can be used to write, perform, direct, and produce representations that feature complex disabled characters for many genres, including film, television, and literature. Garoian's "pedagogy of performance art" (1999) was a helpful model for unpacking and explaining what these disabled performance artists attained in their works, which they extended in terms of cultural criticism, political agency, and transformative social and cultural redress. As models, these performance art works assert a pragmatic form of cultural criticism that challenges hegemonic practices and injurious acts (Garoian, 1999). In addition, these works re-

imagine representations that will influence social constructions of disability, reformulating how disabled people are treated in social and interpersonal realms. The strategies and perspectives they create will resonate for other disabled artists as a way to appraise dominant culture and overturn hegemonic traditions.

This study is also important for disability discourse. New productive, realistic, and culturally framed disability representations have power and potential in the social realm for making social change. Culturally relevant depictions and stories about disability, with a “disability subculture perspective” (Snyder & Mitchell, 2006), not only “open a door,” as Wade said, but open new conversations, new spaces for participation and inclusion, and valuable opportunities to shift our current social and cultural worlds. Such shifts in discourse would benefit all people, because disability issues cut across gender, sexuality, age, race, class, ethnicity, and other marginalized, and privileged, social locations. Having impairment, being a disabled person has always been open to anyone, and therefore, representation needs to reflect the diversity and knowledge of disability experiences as it does for other groups’ experiences.

New conversations available through new, more authentically derived representations of disability offer greater opportunities for disabled and nondisabled people. Creating space for disabled people, disability culture and disability arts within the mainstream will enrich all. As a society, we have already discovered that the public transformations created to make environments more accessible to disabled people—curb cuts, ramps, elevators that talk, talking buses and trains, lowered counters and service desks, and many others—allow better access for all people, particularly older people, children, and mothers with strollers. Re-imagining cultural imagery, myths, and ideas, that are inclusive and honest to disability experiences, open my imagination toward a transformed, re-imagined social world. Such a world would respect the

contributions and ideas from disabled people, and would incorporate them as employees and cultural critics within a realm that values their distinct perspectives and strategies for living.

D. **Need for Further Research**

This project only scratched the surface strategies and techniques that artists can apply to transform how disability is represented. Additional research to discover and interpret representational work that re-formulates understandings and meanings of disability is needed. Investigations of other disabled performance artists with intersecting identities—men, transgender, queer, racial, and ethnic identities—could illuminate other perspectives from these disabled women artists. Thus, similar research with an iterative design to examine artists' perspectives is needed.

In addition, qualitative inquiries designed to investigate audience responses are important. Such research could discover the impact and influence of autobiographical performance works on individuals from the audience; examining pre- and post-performance variables that reveal if and how new ideas about disability are being received. Other study elements could determine what scenes had meaning for the individual audience member, descriptions of them, and how he or she might transfer this into social relationships.

Other research could look at films, documentaries, novels, short stories, and theater works that foreground disability experiences, and are created from a “politically informed disability subculture perspective” (Snyder & Mitchell, 2006, p. 9). Such inquiries could include a qualitative component to investigate how the artist's personal history and experiences, disability influences and/or role models, influenced the work. Also, it would be interesting to include discussions about artistic intentions, desires, and hopes for the works created. How do these

artists and works open conversations about disability? How do they interrogate and reformulate the ways disability is represented?

As this project suggests, I am more interested in how to create social change with cultural change than in criticizing what already exists in culture. By unveiling the powerful, alternative ways that disability can be represented, I intended this research to start conversations about new ways of thinking about, performing, representing, and discussing disability. What I would like to see is a change in culture, and I plan to continue opening conversations about new paradigms for representing disability, for understanding and producing disability culture, as well as for positively changing the lives of “real” disabled people. As Harlan Hahn says in the film *Vital Signs: Crip Culture Talks Back*, “all I want to do is change the world” (Mitchell & Snyder, 1996). Exactly.

APPENDICES

APPENDIX A

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 – Expedited Review

August 23, 2006

Terri Thrower, MS
Disability and Human Development
1640 W. Roosevelt Rd., Rm. 236
M/C 626
Chicago, IL 60608
Phone: (312) 355-0550 / Fax: (312) 996-0885

RE: Protocol # 2006-0534
“Re-imagining Disability: Performance Art and the Artists; Perspectives”

Dear Ms. Thrower:

Members of Institutional Review Board (IRB) #2 reviewed and approved your research protocol under expedited review procedures [45 CFR 46.110(b)(1)] on August 14, 2006. You may now begin your research

Your research meets the requirement(s) for the following category - Expedited Review Approval Category 45 CFR 46.110(b)(1):

Protocol reviewed under expedited review procedures [45 CFR 46.110] Category: 6, 7
(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 following information about your approved research protocol:

Protocol Approval Period: August 14, 2006 - August 13, 2007

Approved Subject Enrollment #: 4

Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.

APPENDIX A (continued)**Performance Sites:**

UIC

Sponsor:

None

Research Protocol(s):

- a) Re-imagining Disability: Performance Art and the Artists' Perspectives

Recruitment Material:

- a) Email notice - Dear Performance Artist, no version #, submitted 7/27/06

Informed Consent:

- a) Consent - Re-imagining Disability, version 1, submitted 7/27/06

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
07/27/2006	Initial Review	Expedited	08/14/2006	Approved

Please remember to:

→ Use **only the IRB-approved and stamped consent document(s) enclosed with this letter when enrolling new subjects.**

→ Use your **research protocol number** (2006-0534) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements of the, "**UIC Investigator Responsibilities, Protection of Human Research Subjects**"

Please note that the UIC IRB has the right to ask further questions, seek additional information, or monitor the conduct of your research and the consent process.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS office at (312) 996-1711 or me at (312) 413-2053. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sophia L. Radlowski, M.Ed
IRB Coordinator, IRB # 2
Office for the Protection of Research

Subjects

Enclosures:

1. UIC Investigator Responsibilities, Protection of Human Research Subjects

2. Informed Consent Document:

- a) Consent - Re-imagining Disability, version 1, submitted 7/27/06

3. Recruiting Material:

a) Email notice - Dear Performance Artist, no version #, submitted 7/27/06

Tamar Heller, Disability and Human Development, M/C 626

APPENDIX B

University of Illinois at Chicago

Consent for Participation in Research

“Re-imagining Disability: Performance art and the Artist’s Perspective”

Why am I being asked?

You are being asked to be a subject in a research study about the relationship between lived disability experiences and the ways these experiences are represented in performance art. This study is being conducted by Terri Thrower, PhD candidate in the PhD in Disability Studies program, and faculty sponsor/advisor Carol J. Gill, PhD, in the Department of Disability and Human Development at the University of Illinois at Chicago. You have been asked to participate in the research because you have been identified as a solo autobiographical performance artist with a disability and may be eligible to participate. We ask that you read this form and ask any questions you may have before agreeing to be in the research.

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.

Why is this research being done?

The purpose of this research project is to explore the relationships between “real” lived disability experiences and their artistic representations. The study will examine how people with disabilities view their lives and experiences from the perspectives of disabled performance artists. The research will include both qualitative methods (interviews) and critical analyses of performance work. You will participate in three separate individual interviews lasting approximately one hour. These interviews will take place over the course of 3 to 9 months. There are no significant direct benefits. The risk of psychological discomfort associated with discussing personal information and artistic work is possible. Also, your identity will be revealed in research reports including your name, descriptions of your work, and summaries of your responses to research questions. You may indicate your consent to this process by checking off the options you agree to on the last page of this form

What is the purpose of this research?

The purpose of this research is:

To explore the relationships between “real” lived disability experiences and the ways these are represented by disabled performance artists.

What procedures are involved?

APPENDIX B (continued)

If you agree to be in this research, we would ask you to do the following things:

Participate in three 45-60 minute audiotaped interviews.

- Interview 1: we will discuss your work and you will be asked to select one performance work for the researcher to analyze. You will be asked to provide a copy of the script of the performance selected, as well as direct the researcher to any available audio or video recordings of that performance.
- Interview 2: you will be asked questions about your work and the accuracy of the initial analysis of your work
- Interview 3: we will discuss findings and analyses so far, and you will be asked about the accuracy of these findings. You will be asked some final wrap up questions.

Approximately 4 subjects may be involved in this research at the University of Illinois at Chicago.

What are the potential risks and discomforts?

The remote possibility of psychological discomfort exists from sharing personal experiences, discussing your work, and discussing views on this topic.

Additionally, because your public work and public identity are important in this study, your identity will be revealed in research reports in the form of your name, descriptions of your work, and summaries of your responses to research questions during interviews. You have the option to: consent to this without further review of our research reports; consent to this as long as you can review the reports before indicating your written approval of them; or decline to consent to participate in this research.

Are there benefits to taking part in the research?

There are no direct benefits associated with participation in this study. Indirect benefits may involve society's increased knowledge of representations of disability that are by and about disabled people.

APPENDIX B (continued)

Will I be told about new information that may affect my decision to participate?

During the course of the study, you will be informed of any significant new findings (either good or bad), such as changes in the risks or benefits resulting from participation in the research or new alternatives to participation that might cause you to change your mind about continuing in the study. If new information is provided to you, your consent to continue participating in this study will be re-obtained.

What about privacy and confidentiality?

When the results of the research are published or discussed in conferences, information will be included that will reveal your identity. This information will include your name, descriptions of your work, and summaries of your responses to research questions.

Your interview responses will be recorded by audiotape. These recordings and any printed transcriptions of them will be stored in a locked office, accessible only to the researchers. These recordings will be erased within 1 year following the end of data collection, except for selected segments to be reserved for educational presentations. If such segments are selected, you will be contacted to give written approval of their use and preservation. Digital versions of the transcripts will be stored on password-protected computers accessible only to the researchers.

What are the costs for participating in this research?

There are no costs for participating in this study.

Will I be reimbursed for any of my expenses or paid for my participation in this research?

You will not receive payment for your participation.

Can I withdraw or be removed from the study?

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so, such as the unexpected unavailability of the researcher, equipment failure, or the discovery that you do not fit within the criteria for participation.

APPENDIX B (continued)

Who should I contact if I have questions?

The researchers conducting this study are Terri Thrower, PhD candidate and Carol J. Gill, PhD, faculty sponsor/advisor. You may ask any questions you have now. If you have questions later, you may contact the researchers at: Phone: Terri Thrower, 773-378-1073, and Carol Gill, 312-355-0550.

What are my rights as a research subject?

If you have any questions about your rights as a research subject, you may call the Office for Protection of Research Subjects at 312-996-1711.

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 or. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

You will be given a copy of this form for your information and to keep for your records.

Signature of Subject or Legally Authorized Representative

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 have been given a copy of this form.

Signature

Date

Printed Name

Signature of Researcher

Date (must be same as subject's)

APPENDIX B (continued)**PERMISSION TO DISCLOSE IDENTITY AND OTHER INFORMATION**

Because of the nature of your professional work, keeping your identity confidential will not be possible or preferable. This research is part of a dissertation project that may be submitted for publication and presented for educational purposes. The information disclosed about you will include your name, descriptions of your work, and summaries of your responses to research questions. Information about you will not be published or presented without your written permission. Therefore, you have the right to authorize the disclosure of information that identifies you, and you have the right to refuse any disclosure of such information. However, refusing this disclosure will exclude you from the research, without consequences. Please read the following options, and check the one that corresponds to your wishes:

- I consent to the disclosure of my name, descriptions of my work, and summaries of my responses to research questions.
- I consent to the disclosure of my name, descriptions of my work, and summaries of my responses to research questions ONLY after reviewing and approving this material before its use. I will grant permission, in writing, for this information to be used once I have reviewed and approved it.
- I do not consent to the disclosure of information that may identify me. I understand that this excludes me from participating in this research, and that I will be withdrawn without consequences to me or my relationship with the researchers or the University.

Signature

Date

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VITA

NAME: Terri L Thrower

EDUCATION: B.S., Rehabilitation, Wright State University, Dayton, OH, 1988

M.R.C., Rehabilitation Counseling, Wright State University, Dayton, OH, 1993

Certificate, Gender and Women's Studies Concentration, University of Illinois Chicago, Chicago, IL, 2004

Ph.D., Disability Studies, University of Illinois Chicago, Chicago, IL, 2015

TEACHING EXPERIENCE Co-instructor, "*Artistic Spaces as Welcoming Places: Creating Inclusive Environments for the Bodies of Work Festival*," Chicago, IL, 2013

Guest Lecturer, *The Work of Cheryl Marie Wade*, Interdisciplinary Seminar in Disability Studies, PhD Program in Disability Studies, University of Illinois Chicago, 2012

Invited Lecturer, *Disability Takes on the Arts*, University of Arizona, Online graduate seminar, 2010

Invited Lecturer, *Disability Takes on the Arts*, The School of the Art Institute of Chicago, Department of Art Therapy, Masters in Art Therapy program, 2009-2010

Guest Lecturer, *Re-imagining Disability: Research Overview*, Interdisciplinary Seminar in Disability Studies, PhD Program Disability Studies, University of Illinois Chicago, 2009

Guest Lecturer, *Re-imagining Disability: Research Overview*, Interdisciplinary Seminar in Disability Studies, PhD Program Disability Studies, University of Illinois Chicago, 2008

Guest Lecturer, *Disability Takes on the Arts*, The School of the Art Institute of Chicago, Department of Art Therapy, 2008

Instructor, *Reframing Disability through Performance*, Department of Medical Education, Special Topics/Medical Humanities, University of Illinois Chicago Medical School, 2006-2007

Co-instructor, *DHD 401: Foundations of Disability*, Department of Disability and Human Development, University of Illinois at Chicago, Masters in Disability Studies Program, 2004

RESEARCH
EXPERIENCE:

Principal Investigator, “Re-imagining Disability: Performance Art and the Artists’ Perspectives” University of Illinois at Chicago, 2007-2015

Research Assistant, “Experiences of Individuals with Disabilities Pursuing Careers in the Arts,” University of Illinois at Chicago, Chicago Center for Disability Research. 2004-2007

Research Assistant, University of Illinois at Chicago, Assistive Technology Unit, 2004

Research Assistant, University of Illinois at Chicago, Department of Occupational Therapy. Participatory Action Research (PAR), “Escape the Nursing Home,” 2001-2003

EMPLOYMENT
Art HISTORY:

Director of Disability and Learning Resource Center, The School of the Institute of Chicago, Chicago, IL, 2008-2009

Paid Intern, Victory Gardens Theater Access Project, Chicago, IL, 2005

Artistic Director/co-founder, “Crip Slam! Disability Takes on the Arts” University of Illinois Chicago, 2003

Vocational Rehabilitation Counselor, Washington Department of Services for the Blind, Seattle, WA, 1999-2001

Vocational Rehabilitation Counselor, Ohio Rehabilitation Services Commission, Bureau of Vocational Rehabilitation, Dayton, OH, 1989-1993

Vocational Rehabilitation Teacher, Ohio Rehabilitation Services, Bureau of Services for the Visually Impaired, Dayton, OH, 1988-1989

VOLUNTEER
EXPERIENCE:

Bodies of Work: Chicago Festival of Disability Arts and Culture, Chicago, IL, 2004-2014

Tellin’ Tales Theatre Company, Board of Directors, Chicago, Illinois, 2005-2012

Crip Slam Sundays @ Victory Gardens Theater, Chicago, Illinois 2006-2008

Young People's Festival of Disability Culture, Chicago, Illinois, 2006-2011

M&M Roll Model Program, Chicago, Illinois, Rehabilitation Institute of Chicago, 2003-2008

Step N' Go Cycles, Atlanta, GA (1996-1998) and Seattle, WA (1998-1999), 1996-1999

Not Merely Players Theater, Atlanta, GA, 1997-1998

Arthritis Foundation, Atlanta, GA, 1994-1998

Very Special Arts Alaska, Fairbanks, AK, 1994

KUAC public radio, Programming/announcer for weekly "Oldies" show, University of Alaska Fairbanks; Fairbanks, AK, 1993-1994

PUBLICATIONS: Thrower, Terri. "Overcoming the Need to Overcome: Challenging Disability Narratives in *The Miracle*." *Different Bodies: Disability in Film and Television*. Ed. Marja Mogk. Jefferson, NC: McFarland, 2013. Print.

Thrower, Terri. "Cheryl Marie Wade." *Encyclopedia of American Disability History*. Ed. Susan Burch. New York, NY: Facts on File, Inc., 2009. Print.

Thrower, Terri. "Greg Walloch." *Encyclopedia of American Disability History*. Ed. Susan Burch. New York, NY: Facts on File, Inc., 2009. Print.

Thrower, Terri. "Audio Description." *Encyclopedia of Disability*. Ed. Gary Albrecht. Thousand Oaks, CA: Sage, 2006. 140. Print.

Thrower, Terri. "Careers in the Arts for People with Disabilities." *Opening Stages: A Quarterly Newsletter for People with Disabilities Pursuing Careers in the Performing Arts* Mar-May 2006: 11-13. Print.

PRESENTATIONS: Society for Disability Studies Conference, Orlando, FL, "Overcoming the Need to Overcome: Re-Creating Lived Reality Through Film and Performance," 2013

Society for Disability Studies Conference, San Jose, CA, "Re-imagining Disability: Performance Art in the Post ADA Era," 2011

Film and History Conference, Milwaukee, WI, "Overcoming the Need to Overcome: Challenging Disability Narratives in *The Miracle*," 2010

Society for Disability Studies Conference, Seattle, WA, "Performing Disability: Representational Work in Progress and the Work of Cheryl Marie Wade," 2007

South Atlantic Modern Language Association, Charlotte, NC, "Expanding "Normal" Representation: Transforming Disability and Representation through Disability Performance," 2006

Society for Disability Studies, Bethesda, MD, "Blurred Vision: Mediating Medical Experiences of Disability through Performance," 2006

Society for Disability Studies, San Francisco, CA, "Racism, Ableism, and the Lens of Hyper-Visible 'Culture,'" 2005

Community/Performance Conference, Providence, RI, "Crip Slam! Disability Takes on the Arts: Building Community and Transforming Culture through Disability Performance," 2004

Society for Disability Studies, St. Louis, MO, "Performing Disability, Performing the Cyborg: A Model for Transgressive Identity," 2004

Society for Disability Studies Conference, Bethesda, MD, "Finding Disability Identity in Diaspora and Cyborg Myth," 2003

"Framing the Festival: A Critical Discussion on Disability Arts and Culture," Moderator, Chicago Cultural Center, Bodies of Work Festival Opening Night Panel, Chicago, IL, 2013

"Reinventing Story: Tekki Lomnicki, The Miracle, and New Disability Storytelling," Greenhouse Theater Center - part of Bodies of Work Festival 2013, Chicago, IL, 2013

"Encountering Cheryl Marie Wade" Access Living Center for Independent Living, Chicago, IL, 2013

"Disabled Performers: Challenging Stereotypes," Northern Suburban Special Education District, Temple Jeremiah, Chicago, IL, 2011

PERFORMANCES: *Six Stories Up, Up & Away!* Tellin' Tales Theater production, The Athenaeum Theatre, Chicago, IL, 2013

Just Keep Dancing, Body Language Showcase, directed by Tekki Lomnicki, Access Living, Chicago, IL, 2012

Defending My Crown, Solo Performance Showcase taught and directed by Tekki Lomnicki, Prop Thtr, Chicago, IL, 2009

- STUDENT ORGANIZATIONS: Disability History and Culture Club, Vice President, University of Illinois Chicago, 2005-2006
- Disability Studies Student Council, Vice President, University of Illinois Chicago, 2004-2005
- Disabled Students Union, Treasurer, University of Illinois Chicago, 2003-2005
- Chancellor's Committee on the Status of Persons with Disabilities (CCSPD), Executive Committee/student representative, University of Illinois Chicago, 2002-2004
- GRANTS: Illinois Humanities Council: \$2500. Bodies of Work 2013 festival, Opening Night panel and discussion, Chicago Cultural Center, Chicago, IL, 2013
- Kennedy Center Careers in the Arts Mentoring Initiative: \$4000. "Crip Slam! Disability Takes on the Arts" Festival, University of Illinois Chicago, 2003
- AWARDS: Chancellor's Student Service Award, University of Illinois at Chicago, 2005
- PROFESSIONAL MEMBERSHIPS: Society for Disability Studies
- National Women's Studies Association