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PLAYING DISABILITY

by

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A thesis submitted in partial fulfillment of the requirements  
for the degree of Master of Fine Arts of Theatre  
in the Department of Theatre  
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## ABSTRACT

Disability in performance has a long history, starting with fictional characters such as Shakespeare's Gloucester/Richard, progressing through the freak shows of the early twentieth century, and finally with artists such as Neil Marcus, Mat Fraser and Deaf West Theatre in the past twenty years. Looking to the work of disabled artists, activists, and theorists such as Petra Kuppers and Carrie Sandahl, I will examine the history of both disability in performance and the performance of disability. I will discuss my performance of Garret, a man with muscular dystrophy, in my original play, *The Sick Parents Club*. Through analysis of what playing a disability means both emotionally and physically, I will seek to answer the questions: How can an actor play a disabled character without defining them by their disability? Is it possible for a normative-bodied actor to approach authenticity playing a character with a disability?

To Jan Romano  
My Inspiration, Motivation, Champion and Mother  
*January 24, 1958 – September 14, 2019*

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Mom, Dad, and Kari

Christian DeRiemer

Cynthia White

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The cast of *The Sick Parents Club*: Shannon Burke, Emma Byrd, Oliver Flowers, Rachel Larchar, Anferny Munoz, Jena Rashid, Josh Whedon, and Ana Zambrana

Neil and Karen DeRiemer

Amanda Kelly

Steven Lane

MFA Acting Class of 2019

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## **CHAPTER ONE: INTRODUCTION**

Disability has shaped my life in innumerable ways. My mother was born with TAR syndrome (Thrombocytopenia with absent radius) – a rare genetic disorder wherein her arms present an absence of the radius bone. This presented itself in a shortened wingspan, where she generally lacked a forearm. My mother refused to view herself as disabled or even a part of the disability community; however, it is undeniable that others viewed her as such. As a child, long before I had any exposure to disability theory, my early life was shaped by things like the stare (the abled gaze). Other children would often poke fun at my mother’s appearance as she chaperoned field trips. To my adult shame, I often would not confront these children, leading my mother to admit, later in life, that she thought I was ashamed of her at times. All I was attempting to do was fit in.

I had a difficult time as a child. I was never able to form strong bonds with my classmates and often felt isolated and alienated. This lasted into college, which, perhaps, led to my first failed attempt at college at Temple University. It was not until I attended Delaware County Community College (DCCC) in Media, Pennsylvania, that I found my first group of true friends with whom I shared a deep connection. An odd commonality seemed to connect those in my social group – disability. My friends Nick and Sean both had been diagnosed with Asperger Syndrome as children, and while high functioning on the autism spectrum, associated themselves with their disability. The group was complete with the addition of Christian, who has a rare form of muscular dystrophy. Christian is wheelchair-bound, lacking range of movement in most of the muscles in his body. Unable to fully breathe on his own without assistance, he breathes with the

assistance of a ventilator, connected via a breathing tube, through a stoma in his neck, to his windpipe. And yet, despite being a motley group of people with varying degrees of disability, we clicked. We were all actors, and it was this group with whom I regained my love of theater and found my way.

Nick and Sean were the first people to bring to my attention the idea that I exhibited classic signs of autism. As a child, I had trouble making eye contact, but was able to force myself to learn through the years. At times, it still takes effort to do so. I had several obsessions as a child. My parents enjoyed telling the story of a road trip we took to Kiawah Island – a twelve-hour drive from our house near Philadelphia, Pennsylvania – during which I only allowed them to listen, repeatedly, to a dramatized *Teenage Mutant Ninja Turtles* story we owned on cassette. During high school, I spent an entire year watching the movie *Excalibur* every single day after school without fail. These obsessions are classic autism signs. Finally, and perhaps most telling, I have always struggled with nonverbal cues. My mother was always fond of saying, usually out of frustration, that I can never tell when someone is joking.

At the time, I accepted Sean and Nick’s suggested diagnosis as simply an interesting, but fleeting, thought. During my time at the University of Central Florida, I decided to undergo testing and was subsequently diagnosed with high-functioning autism (Asperger Syndrome being a now-defunct classification). I, too, was not normative. Like my mother, I have difficulties accepting myself as disabled, but rather consider myself neuroatypical. However, under current disability theory, disabilities of physical, neurological and psychological natures find themselves in an at-times uneasy alliance under the same larger classification – “disabled”.

After DCCC, Sean and Nick found themselves leaving acting behind naturally for other fields such as mathematics. Christian, instead, found that acting left him behind. While Steven Smith, the head of the theater department at DCCC, had experience dealing with actors with physical disabilities, Christian found a lack of opportunities for an actor who could not communicate clearly with his lack of mobility in his articulators and who relied on a motorized wheelchair for movement.

My final year of DCCC, my mother was diagnosed with Langerhaan's Cell Histiocytosis, a rare bone disorder which she is still currently battling. Around the same time, Christian's mother was diagnosed with cancer. Nearly simultaneously, we found that a third friend from our community college was dealing with her father's cancer diagnosis as well. The following summer was one in which we all bonded over the potential of losing a parent. By the end of the year, my mother would be the only parent of the Sick Parents Club (as we morbidly referred to ourselves) who was still alive. The bonds we forged that year, however, were stronger than any other I have ever experienced during my life. It was out of this year that the play *Sick Parents Club* was born.

With an amazing creative team, I was able to bring *Sick Parents Club* to life at the Lowndes Shakespeare Center in March 2018. The play features a fictionalized account of the events of the real Sick Parents Club, with characters based off Christian, our friend Amanda, and me. Instead of playing myself in this production, I instead played Garret Marshall, a character inspired by Christian. In doing so, I was able to examine issues of disability and representation.

I entered into the production with a great deal of trepidation, as I am a strong advocate for inclusion and representative casting, an issue which I will address in this thesis. Where, however,

do we draw the line as advocates? If my autism makes me a member of the disability community at large, am I allowed to play a character with a physical disability? Or is that something which should be reserved for people with disabilities similar to the one belonging to the character? I do not know if I was fully able to answer these difficult questions, although they will be addressed here in time.

In the end, I was searching for a way to provide authenticity to a classically underrepresented demographic. As a writer with a disability, whose life has, in many ways, been shaped by the disabilities of others, I sought to create a character with a disability who was not defined by said impairment. As an actor, I sought to live faithfully and authentically in the reality created by the play. In the end, I hope that, through this process, I will have contributed, in some small way, to a furthering of a new disability narrative, rather than relying on tropes and narratives stemming from prejudices of the past.

## CHAPTER TWO: DEFINING DISABILITY

### Three Models of Disability

Theater has a long history of characters with disabilities, most of which is fraught with stereotypes or negative portrayals. These include Shakespeare's portrayal of Richard III, Williams' Laura Wingfield, Pomerance's John Merrick, and even Schwartz and Holzman's Elphaba. For much of the early history of theater, portrayals of disability tended to reflect the antiquated societal notion that outward disabilities reflected an inward ugliness; author, English professor, and disabled performance artist Petra Kupperts writes, "While *Richard III* may be a great play, those who stage or see it must confront the assumption that a deformed body represents an evil soul...Is this kind of metaphoric representation still useful today? Is it dangerous?" ("Theatre &" 20) Today, we have mostly moved past this type of symbolism. However, before we can, with any kind of discernment, attempt to fully grasp representation of disability, the question must be asked – what is disability? The question is more difficult to answer than one might think.

The traditional way of labeling a person as disabled rests in the realm of medical treatment. "The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being" (Siebers 3). This model effectively holds up the normative body and defines any aberrations or abnormalities as an impairment. These can be physical (e.g. a person with cerebral palsy who needs a wheelchair), mental (someone with schizophrenia) or sensory (people with neuroatypicalities – those on the autism spectrum). Each is a deviation from a desired normative body and mind, and therefore needs to be cured or fixed. The medical model "understands

disability as a condition that resides or is inherent in an individual's particular impairment”

(Berger 9). This places the burden of responsibility for disability on the individual. A person in a wheelchair cannot climb stairs – this is not the fault of the medium of transportation (the stairs), but rather of the person who is unable to get up them. The individual becomes the problem. This is also a rather antiquated view of disability. The medical model does have positives – sometimes there are people with disabilities whose lives can be genuinely improved by the medical field treating their disabilities. There are others, however, like my mother, who have gained minimal, if any mobility or quality of life, despite literal scars testifying to doctors’ efforts.

Another way to define disability is through the social model. This removes the burden of responsibility from the individual and places it on society. “The social model opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice” (Siebers 25). Instead of blaming the wheelchair user, the social model places the blame on the stairs themselves, and those who see stairs as the only way to change elevation; ramps, on the other hand, can be used by *everyone*, whether they travel in a chair or with their legs. A person’s impairments are not what make them disabled in this model; instead, it is the limitations society has placed on them. This way of thinking leads to changes in society for the purpose of improving accessibility for everyone. The Americans with Disabilities Act of 1990 utilized the social model in demanding accessibility for public buildings. There are accessibility engineers who seek to make everyday objects easier to use – like Velcro clothing or self-lacing shoes.

Beyond the realm of the scientific and the physical and mental limitations society places on an individual, the social model also defines disability by how individuals treat others. In Ronald J. Berger's article, *Introducing Disability Studies*, he quotes Erving Goffman, who "posited that deviance is not a quality of the act a person commits, but rather a consequence of others' reactions" (9). Christian DeRiemer, who provided the character of Garret in *The Sick Parents Club*, tells stories of how, growing up, he encountered teachers in public schools who wanted to place him in special education classes. Christian has a form of muscular dystrophy – a physical impairment, not a mental one – but it was not the MD that was limiting him, it was the teachers' suggestions. However, his parents recognized his mental abilities, and refused to allow the school system to remove him from general education, thereby not placing further limits of disability on Christian.

There exists one further model of disability that I want to examine in light of my role in *The Sick Parents Club*, the play this thesis will focus on. That is the post-social model of disability. "Post-social modelists affirm sensitivity to individual experience which is congruent with the approach of disability practitioners" (Martin). Essentially, this theory holds that everyone is disabled in some way; "normative" does not exist, because everyone, in some way, deviates. This is how a character such as Elphaba from *Wicked* can be considered to have a disability – early in the musical, others revile her for the unique color of her skin and place her apart from the normative. In some aspects, she is no different from her sister, Nessa Rose, who is a wheelchair user in the script. In *The Sick Parents Club*, it can be seen in Garret's love interest, Shaun. They share a moment of intimacy after Garret recognizes the shared experiences between them – his obvious physical impairments, and her struggle with depression, anxiety disorders,

and self-harm. They are each disabled in some way, and only once Garret recognizes that, does he see his own self-worth.

Even defining disability with these models is problematic – in fact, one of the biggest inherent problems lies in the terminology itself. Petra Kuppers states in the book, *Disability and Contemporary Performance: Bodies on Edge*, “Disability is a deeply contested term used to describe individuals...that are in a position of difference from a center”. Disability is a term at odds with the members of its own community. The word itself contains its own perceived opposite – ability, setting up an inherent binary. Kuppers compares this binary between disability and ability to perceived binaries such as race and gender (5-6). As each of those binaries has been hotly contested and redefined in recent years, disability performance seeks to redefine the disabled/abled boundary. Extraordinary artists with disabilities have been pushing the limits of what abilities even mean.

Classically trained dancer Claire Cunningham, for example, has made a career of reclaiming the idea of ability despite her use of crutches.

“I started off as a classically trained singer and moved into theatre,” Cunningham says on the phone from her native Scotland. “I had no interest in dance. It was too abstract. I always thought there was something I wasn't getting. I suppose it's also the most body-fascist of the arts – a lot of what I saw was by and for skinny, white, able-bodied people.”

(Woodhead n.p.)

In dance, perhaps the most body-restrictive of the art forms, Cunningham has rebelled and crafted her own niche. In her show *Guide Gods*, Cunningham reclaims her agency by dancing, gliding, balancing and doing feats of strength with her crutches throughout the show,

transforming her crutches into extensions of her own body. What she is able to do with crutches, long a symbol of disability and restriction, is incredible. Normative people, on the ability side of the binary, would not naturally be able to do the things she does without long periods of training.

Disability is an outmoded term, but it is one still in common practice. Once the use of the term is accepted, what makes someone disabled becomes the biggest question. In discussion of *The Sick Parents Club*, and Garret's role therein, all three of these models will find some use. In playing the role, I had to define his disability as muscular dystrophy in order to do research and represent as authentically as I possibly can (medical model). Psychologically, I had to work through Garret's frustration that he lives in the ground floor of his house, and the fact that even in his own safe space, his house, his mobility is disabled by the limitations stairs place on him (social model). Finally, as previously mentioned, the realization Garret has that he is not alone when he realizes Shaun's deviations have, in some way, made her disabled as well (post-social model).

### The Inherent "Strangeness" of Disability

Disability, especially visible disabilities, trace their anti-authoritarian tendencies to psychological roots. Two types of discomfort present themselves when nondisabled people are faced with disability: existential and aesthetic anxiety. As Disability Studies scholar Jim Ferris writes,

*Existential anxiety* refers to the perceived threat that a disability could interfere with functional capacities thought necessary for a satisfactory life. *Aesthetic anxiety* refers to

fears of body difference, reflected in a propensity to shun those with unattractive bodily attributes (58)

This aesthetic anxiety also leads to an idealization of the normative body type, forming a sort of hierarchy of acceptability. The farther one strays from the ideal, the stronger the aesthetic anxiety. In some ways, the existence of disability, even before the presentation or staging in a theatrical setting, is anti-authoritarian.

In fighting against the inherent disability binary, first the history of how society defines disability must be addressed. Historically, there was an emphasis on the medical model of disability. This is primarily what has created the binary of disability by defining a person as “disabled by their specific physical or mental condition. [A] doctor locates what is “aberrant,” abnormal about the patient, and works towards normalizing the disabled person” (Kuppers, “Studying” 24). Led in undeniable fashion by a desire to combat aesthetic anxiety, this model defines disability as a problem in need of a solution, setting up the normative body as the authority and seeking to fix or cure the disabled body to bring it into this authoritative notion, thereby expunging the idea of aesthetic anxiety. Rather, the disability community has been moving towards another model of examining what creates disability – the social model. Kuppers defines this model as appearing “in the interaction between the impaired person and the social environment.” Instead of looking at a disability as something to be diagnosed, in the social model, “these impairments become a disability when these particular forms of being human encounter a society that favors design proportions that require long arms, visual communication, the written word, body language fluency, and fast dialogue” (27). In this model, it is not a differentiation from authority that defines a disability, but a limitation of society focusing on the

normative body. Thus, it becomes an imperative for disability art and theater to fight back against this binary, this ableist authority, thereby forcing society to reexamine its own bias. Innately, disability performance becomes a challenge to political authority. Already possessing distinct aesthetic differences, it moves disability art into the realm of the avant-garde.

In order to accomplish its goal of challenging the status quo, disability theater tends to use the *verfremdungseffekt* – a technique postulated by Bertolt Brecht. This idea of cognitive dissonance manifests itself as showing “human existence as a continual negotiation between what is familiar (*heimlich*) and defamiliar (*unheimlich*)” (Hargrave 7). In the case of disability, this sets the normative authority as the *heimlich* and the disabled as the *unheimlich*, mirroring the binary suggested by the medical model of disability. As Petra Kuppers writes,

The...*Verfremdungseffekt* or alienation effect requires the audience to rethink its own stereotypes and assumptions...No image holds, and what becomes visible instead is the construction of all images. When one image meets the edges of the next one both become unstable...The copy upsets the universality of the ‘real’ (“Disability”, 55).

Disability theater and art find a myriad of possibilities in which to enact this *verfremdungseffekt*. Simply presenting a disabled body on stage creates this effect through the existential and aesthetic anxieties present in an able-bodied audience. In addition, the able-bodied majority inevitably holds bias, assumptions, and a predisposition which disability art seeks to challenge.

### Wheelchair: Prison or Liberation?

As an instructor, one of my favorite methods of instruction for beginning students is to focus on the mechanics of walking. I utilize the concept of Viewpoints and have them create

shapes and explore how this new body functions in space. I have them observe how others in their class naturally walk and adopt elements of that walk. A favorite homework assignment is to have them observe strangers' walks, come in, adopt that walk, and then create a character around the walk. Almost universally, the students very quickly are able to come up with a character based on this specific walk. A sense of identity seems to flow from the very essence of a walk.

Bryan S. Turner, a body sociologist, wrote the following:

Walking is a capacity of the biological organism, but it is also a human creation...

Walking is rule following behavior, but we can know a particular person by his walk or by the absence of a walk...my way of walking may be as much a part of my identity as my mode of speech. Indeed, the 'walk' is a system of signs so that the stillness of the migrainous person or the limp of the gouty individual is a communication. (Turner 236)

Walks define us as individuals. Where do we hold tension? And why? What story does that tell us about the individual themselves?

With so much of our individualism and identity wrapped around our physical movements, it becomes clear why there is often a view of the wheelchair as an instrument of confinement. Julia Kristeva defines the concept of abjection as the human reaction to a threatened breakdown in meaning caused by the loss of the distinction between subject and object or between self and other. An object of rejection rather than desire, the abject "is radically excluded and draws...toward the place where meaning collapses" ("Powers" 2). We, as human beings, define ourselves by our ability to move and the movement we create. Therefore, when presented with a body that requires a wheelchair for mobility, we go through a rejection born of abjection. "Disability represents the modern face of the tragic in that it confronts us with

mortality (both individual and social)” (“Tragedy” 221) This lies in the deep-seeded fear we all inherently have that we may one day find ourselves unable to move to our fullest capacity, and the breakdown that fear causes between our identity and this ‘othering.’

The danger in this mode of thinking comes in two directions. First is the binary of holding up the normative body as the ideal – that the body either is a working, normative body, or it is a disabled body. Second, that the idea of the wheelchair is a solution – a cure – to the problem of mobility challenges. This utilizes the medical model of disability and holds that the defect of disability lies in the individual’s inability to move independently, and can only be solved with the help of an outside device.

Viewed through another lens, the wheelchair is not a prison, an emblem of what a body cannot do; rather, it becomes an extension of the body, a symbol of empowerment. At the University of Washington, Heather Feldner ran a study on the impact of powered wheelchair provision on disability identity in young children. Feldner was looking for a way to combat the internalization of society’s negative views on disability. Children tend to “internalize ableism, where negative social associations and perceptions that have been projected onto the children about their difference become intrinsically acknowledged” (132).

Sam, a child recipient of a powered wheelchair, and Teresa, his mother, were most excited about the aspects of the wheelchair that would allow Sam access to things which, to that point, had been inaccessible. For Sam, the wheelchair is a way to further his identity. In her interviews with Sam, Feldner writes:

Sam squeals and giggles as he slowly rises up to what would be equivalent to the standing height of a small adult. At his highest, Sam initially expresses a lot of

uncertainty...Excitement quickly takes over for Sam, however. “Now I’m way up high,” he says. “I am a GIANT!” (134)

Another anecdote shared by Feldner gives a sense of how Sam’s sense of humor shines through the ability granted by the wheelchair.

Heather: And how are you going to drive your chair?

Sam: I don’t know.

Teresa: What are you going to use?

Sam: My head!

Heather: Your head? That’s going to be pretty awesome.

Sam: Yes.

Heather: Are you going to be able to drive by yourself using your head?

Sam: Yes.

Teresa: So what happens when your sisters or your brother leave you somewhere – like in the basement?

Sam: I’m going to chase them!

Teresa: You’re going to chase them! Are you going to run them over?

Sam: Yes.

Teresa and Heather: (laughing simultaneously) What??? (136)

In the end, Feldner concluded that Sam and others who had received powered assistance (wheelchairs or other devices) found improved play with their siblings and exhibited emerging self-advocacy.

In my own experiences with Christian, I have found much in common with the experiences shared by Sam, Teresa and Feldner. While Christian is unable to walk on his own, thusly unable to exhibit identity in his movements, he finds a way to make his wheelchair an extension of his identity. The two of us share a form of humor around a sparring of wits, at times mockingly confrontational. At times, in addition to his words, he'll play a form of chicken – driving his powered chair straight at me to see whether I back down. As an actor, while Christian may not be able to perform physical comedy in the same way normative actors can, I distinctly remember watching a performance where he played the butler in *The Importance of Being Earnest*. Christian came out on stage and, unable to move and manipulate furniture physically, pushed it around with his powerchair. The specificity with which he exhibited the individuality of his character had the audience in stitches. It was a physicality which could only belong to Christian, and not to an abled, normative actor. It was an act of liberation, where the wheelchair was not a limiting device, but a transformative, enabling device.

### Denied Sexuality

When writing this play, I wanted to make a point to give Garret agency in his sexuality. For years, people with disabilities were “infantilized and held to be asexual (or in some cases, hypersexual), incapable of reproduction and unfit sexual/marriage partners or parents” (Addlakha 4). Even in the field of disability studies, sexuality “was a peripheral topic...until about twenty years ago” (Schaaf 114). How can this shape the worldview of a character who has, until the very moment of sexual discovery been forced into asexuality?

Sexuality among people with disabilities has often been seen as a threat to normative individuals.

Certain individuals are unable to experience “normal” sexuality, because of embodied difference...Physically disabled male sexuality especially challenges normative discourses, as male sexuality is traditionally understood as a phallogentric experience. A man with a physical disability having sex is inconsistent with the gendered discourse of male virility (Schaaf 115)

From someone who has been forced into asexuality due to assumed perceptions, any sexual assertiveness or attempted agency can often be seen as aggression.

The threat of disabled sexuality has been used throughout history to force sterility or abortions upon disabled individuals. While the field of disability studies was notably silent on the topic of sexuality until the past thirty years or so, advocates sought to combat both this and the perceived hypersexuality (aggressiveness) of people with disabilities (115).

Perhaps the disregard in disability studies for the needs of sexual reproductive rights can be traced to the move towards the social model. Whereas the medical model placed emphasis on the physical body and the limitations thereof, the social model moved away from the body, instead highlighting the limitations imposed by society on people with impairments. Some theorists “argue that the body should be ‘brought back’ into thinking about disability; impairment can restrict sexual engagement in a profound manner and this should be acknowledged and discussed (116).

Another problem in addressing sexuality among people with disabilities is a lack of sexual education. “People with disabilities are systematically denied access to knowledge about

sexuality, sexual behaviour and services leading to their sexual marginalisation” (Addlakha 5).

Denied edification regarding their own sexuality, people with disability often have found themselves lacking in their own sexual agency. In addition to perceived asexuality, this has led to people with disabilities being among the most victimized demographics in terms of sexual abuse and violence (5).

Due to all these things, sexuality among people with disabilities has tended to become internalized:

Disabled people are rarely asked to express their dreams, their sensual or sexual desires, as the standard belief is that they have none...Workshops for people with...disabilities highlight how the dreams and pleasures of this group’s lives are frequently neglected. They face restrictions by patriarchal power and by the disciplinary “activities of daily living” arranged through care organisations. (7)

The idea of sexuality as an expression of desire is therefore often lost on people with disabilities, and those that engage in sexual practices report experiencing “reduced pleasure” (7).

## CHAPTER THREE: REPRESENTATIONS OF DISABILITY

### Disability as the Avant Garde

As discussed previously, there is an inherent strangeness to disability. The representation onstage, therefore, easily lends to the theater of the Avant Garde. This is often accomplished, consciously or not by utilizing Brechtian methods. One distinct way in which disability theater has sought to utilize the *verfremdungseffekt* is in exploring the temporal and spatial differences unique to the disabled experience. Australian disability activist Anne McDonald relates her own differences in experiencing time:

I live by a different time to you...I live life in slow motion. The world I live in is one where my thoughts are as quick as anyone's, my movements are weak and erratic, and my talk is slower than a snail in quicksand. I have cerebral palsy, I can't walk or talk, I use an alphabet board, and I communicate at the rate of 450 words an hour compared to your 150 words in a minute - twenty times as slow. A slow world would be my heaven. I am forced to live in your world, a fast hard one. If slow rays flew from me I would be able to live in this world. I need to speed up, or you need to slow down. (np)

These differences are not able to be experienced in an embodied way by the able-bodied majority, so experiential disability theater seeks to relay this through imagery, repetition and tempo.

One of the most successful pieces of experiential disability theater is Robert Wilson and Philip Glass's *Einstein on the Beach*. Utilizing Glass's trademark "music with repetitive structures" (Biography), the play layers on a highly repetitive poetry, mostly written by autistic

poet Christopher Knowles. Wilson had been given a cassette tape of Knowles reading one of his poems, an event which led to a working partnership through several different productions. Performance scholar Telory Arendell describes the magnetism which drew the two together, saying,

Wilson's interest in...Knowles reflects an artistic desire to disrupt conventional representational structures. Knowles's use of autistic language patterns—repetition of sounds and phrases in echolalia, a play on word arrangements, and imitation of media banter—reinforced Wilson's own distrust of the spoken word (16).

Through this lens, Wilson introduces the *unheimlich* in *Einstein on the Beach* by defamiliarizing language. The now unfamiliar language then is repeated many times, effectively slowing down the time of communication even further. On top of this, Wilson layers on small, intricate, and sometimes awkward movements, often highly repetitive and in slow motion. In doing so, Wilson shows that “life is absurd in moments when extraordinary dimensionality becomes the norm” (Arendell 18). In transporting the audience into the realm of the *unheimlich*, allowing the audience to understand the temporal differences experienced by non-neurotypical individuals, Wilson combats the authority of the familiar.

Wilson's work, however, is not unproblematic in its use and utilization of disability. While Wilson was treated for a childhood stutter, he never self-associated as disabled, and has denied ever, in fact, having one. Also of issue is how disability was portrayed onstage both in *Einstein* and in future productions. To perform Knowles' poetry, “Wilson instructed his non-autistic performers to imitate Knowles's movements and vocal delivery” (Arendell 19).

Furthermore, Wilson and Knowles both acted onstage in *Dialog Curious George*. Richard Schechner writes of the production:

Wilson contexted his interactions with Knowles as a performance for the public who paid fancy prices to witness and admire it. Sometimes Knowles' responses...were very funny, wise, ironic, appropriate: one of those Simpleton Saints. Saint or not, Knowles was an elephant bowing at the circus – whatever his remarks meant to members of the audience they meant, or were, something else to Knowles. Because Knowles couldn't lie, he couldn't be an actor – he could only be *situated and displayed as if he were an actor* inside Wilson's show. (Schechner 38)

Wilson's use of Knowles can, in many ways, be seen as exploitative, regardless of Wilson's intentions. Despite this, *Einstein on the Beach* remains a seminal turning point in disability arts performance.

People with disabilities also experience space in a different way than the able-bodied majority. One recent play which explored this in depth was *The Curious Incident of the Dog in the Night-Time*. In opposition to *Einstein on the Beach*, *Curious Incident* presents the audience with a neuroatypical character. In experiential disability theater, the audience is put in the disabled mindspace – a shared experience. In presentational disability theater, the audience is presented with a representation of disability. *Curious Incident* deftly bridges the gap between the two. While presenting the character of Christopher, there are moments in which the play slips into his mind. Of note in spatial exploration are moments when the fellow characters, in the solidarity of a Greek chorus, lift Christopher so he is able to walk along the sides of the cube-like

walls of the set. The *unheimlich* is presented to the audience as they begin to understand the inner workings of an autistic character.

In addition to spatial and temporal explorations, disability art is often about reclaiming the disabled identity from the ableist authority. “Americans often perceive disability – therefore people with disabilities – embodying that which Americans fear most: loss of independence, of autonomy, of control; in other words, subjection to fate” (Longmore 7). Disability artists have tried to combat this familiar fear, this *heimlich*, through reclaiming their independence..

Language is another aspect of disabled identity which disabled art seeks to reclaim. In recent years, the Deaf community has seen a rise in artistic representation due to theatrical productions such as the productions of Deaf West Theatre Company. Deaf West seeks to transform musicals into spectacles of American Sign Language, juxtaposing signing not only onto dialogue, but music, creating an altogether new form of theater. Ed Waterstreet, the Founding Artistic Director of Deaf West Theater, explains the process and inspiration, saying:

I come from a hearing family, I have four brothers and a sister, all of them being hearing. And they’d always take me to church. We’d go for Christmas Eve, and I always saw a choir singing. I was the only deaf person in this huge hearing congregation. Everyone always looked like they were enjoying themselves. I would see their mouths moving along with the songs singing the lyrics, and I was so fascinated by it. They enjoyed it so much. In my mind, I would hope that someday someone would kindly sign the songs to me. It wasn’t until I started Deaf West Theatre that I realized the ways that sign language and music could coexist. But again, I always wanted not to hear, but to see the music. I wanted to see it. Eventually it occurred to me that when hearing people interpret the

music into sign language, that it was like being able to hear the music but through the eyes. (Calhoun 86-87)

In signing the music, Deaf West Theater has created a unique art form – at once musical, verbal, and, above all, visual. In its political rejection of music as only for a hearing audience, the Deaf West Theatre reclaims language, incorporating the Deaf community’s own method of communication.

Finally, in disability art, an emphasis is also placed on reclaiming the body. One of the leading performers in this area has been UK actor/author/activist Mat Fraser. Fraser was born with phocomelia due to his mother’s prenatal use of thalidomide, causing his shortened arms. In his 2001 play, *Sealboy: Freak*, Fraser puts himself in the role of mid-twentieth century freak show performer Stanislaus Berent, more commonly known by his stage name, Sealo. Fraser’s body is itself a manifestation of the *unheimlich*, and he utilizes it in the production to redefine boundaries. “In ‘Sealboy’, Fraser’s physical presence and his ‘otherness’ threaten to undermine his discourse, a fact he is aware of and plays with – often through explicit reference to the carnivalesque, grotesque, disruptive bodily realms of sexuality” (Kuppers, “Disability”, 48). Fraser often confronts the audience with his naked, disabled body. In his 2014 production of *Beauty and the Beast*, Fraser and his wife, burlesque performer Julie Atlas Muz, reinvent the classic fairy tale. Instead of being turned into an animalistic beast, Fraser’s arms and body make him naturally a beast. At one point in the play, Muz and Fraser both strip down as Beauty begins to fall in love with the Beast. In confronting the audience with such brazen sexuality in what the able-bodied majority would generally term an unsexual body, Fraser utilizes *verfremdungseffekt* in order to redefine and reclaim his own body.

### Disability Media Narratives

In the attempt to create a character that does not easily fit into prescribed stereotypes of disability, it is helpful to understand how the media has represented disability narratively in the past. From movies like *Radio* or *A Beautiful Mind*, there are several categories of stereotypes into which these narratives tend to fall. In many cases, these are not meant to be negative portrayals; however, regardless of intentions, these can reinforce negative perceptions.

When I took my first course at NYU about disability in theater, we were given an assignment – look at the news and bring in a story about disability. I chose to bring in an article about a woman who climbed a mountain despite a prosthetic leg. While, certainly, that is an accomplishment, what struck me most about it was that, were it not for the disability, it would not be a news story – people climb mountains every day without so much as a drop of ink spilled in telling their story. This is an example of the supercrip narrative. In this narrative, “individuals are focused on because of the physical characteristics of their disability...and portrayed either as ‘superhuman’ because of physical feats...or ‘amazing’ because they function ‘normally, in spite of their disabilities’” (Ellis 48). The issue with this narrative is the focus on the impairment as negative and something to be conquered. While the woman in the news story I found had certainly accomplished something worth applauding, this narrative is often used to celebrate more mundane “accomplishments,” such as simply living life.

In the 2016 pilot of the sitcom, *Speechless*, J.J. DiMeo, a teenager with cerebral palsy (played by Micah Fowler, an actor with the same disability), moves and enters a new school. Upon arriving, the class stands up and applauds for him (Silveri). The show is meant to be

satirical but is based on the reality of creator Scott Silveri's experiences with his disabled brother. While it may be an exaggeration, it is a perfect illustration of the supercrip narrative.

While it may seem that the criticism of the supercrip narrative is critical of valuing achievements, that is not the case.

Reinforcing low expectations is what makes supercrip iconography so problematic. Moreover, successes are generally judged in terms of the ability to conform to able-bodied norms: "if a person with a disability is 'successful', or seems to have a good life, he is seen as brave and courageous or special and brilliant. Given the intrinsic abnormality or awfulness of disability, anyone living a 'normal' life must be extraordinary." (qtd. in Silva, 179)

The issue with the narrative is that "supercrips are ripped of individuality, and, as a result, all the complex details and subtleties of their stories are undermined" (Silva 180).

Headlines such as the one I found for class – "Disabled Woman Climbs Mountain," place the individuality as secondary to the impairment.

Another common media narrative is the narrative of charity, or social pathology. In this narrative, "Individuals with disabilities are portrayed as disadvantaged clients who look to the state or society for economic support, which is considered a gift, not a right. The individuals are portrayed as passive recipients of government or private economic support" (Ellis 48). While this narrative will rear up its ugly head often in the realm of politics and the social safety net, perhaps the most enduring example of this narrative is found in the lasting impact of Jerry Lewis' MDA telethons. In these telethons, Lewis would present children with MDA as weak, helpless individuals, and would often use these children more as props than individuals. A group of

people living with MD, calling themselves Jerry's Orphans, would often protest Lewis' telethons. Their argument was that instead of Lewis empowering people with MD, he presented them as an object to be pitied. Lewis may have raised billions of dollars, but in many ways, the presentations hurt the people they were aiming to help.

Finally, one of the most (perhaps unintentionally) insidious narratives is inspiration porn. As an episode of *Speechless* defines the term, inspiration porn is "A portrayal of people with disabilities as one-dimensional saints who only exist to warm the hearts and open the minds of able-bodied people" (Rosen). This can present itself not only in stories, but in the "image of a person with a disability... doing something completely ordinary – like playing, or talking...carrying a caption like 'your excuse is invalid' or 'before you quit, try.'" (Young, qtd. by Grue 839). The primary objective of this media narrative is to use people with disabilities as models of inspiration, through which the life of everyday people can be enriched. The problem with this media narrative, like the previous ones, is the dehumanization of people with disabilities.

### Access on Stage and Screen

Representation has evolved with our societal understanding of gender, race, and other demographics. In Shakespeare's England, women were not allowed on stage, and female roles were played by male actors. America has a shameful history with the performance of minstrel shows – where Caucasian men would portray a caricature of blackness. These have long been written out of our history, but the same cannot be said for disability. Several able-bodied actors have won major awards for playing disabled characters – for example, Al Pacino in *Scent of a*

*Woman*, Dustin Hoffman in *Rain Man*, Daniel Day-Lewis in *My Left Foot*, Claire Danes in *Temple Grandin*, and Eddie Redmayne in *The Theory of Everything*. It has become a common challenge for an actor to play a character with a disability or impairment, and when done well, nearly guarantees accolades.

True representation of disability on stage or film, however, has mostly been relegated to experiential or Avant Garde forms. While some notable exceptions have occurred in recent years – the cases of Mickey Rowe, an actor with autism, playing the lead role in *The Curious Incident of the Dog in the Night-Time* and Ali Stroker becoming the first wheelchair user to appear on a Broadway stage, be nominated for, and win a Tony, spring to mind – one of the reasons for this lack of representation has occurred, in large part, due to lack of access.

The lack of actors with disabilities in prominent roles can be attributed, in some part, to a lack of representation in other avenues of entertainment. In an article entitled *Lights, Camera, Access*, writer Paul Chitlik recounts the story of Allen Rucker, a writer who woke up paralyzed one day due to transverse myelitis. Overnight, Rucker went from a promising television writer who had worked with Martin Mull and won Writers Guild Awards to a writer desperately looking for work. In the interview, Rucker says, “After I became paralyzed, no one ever hired me who hadn’t hired me before. For the first year or so, people were willing to hire me either because they felt sorry for me or wanted to ‘help me get on my feet’” (Chitlik). As Rucker started to work in the business again, he found himself restricted at times due to limitations such as stairs or narrow doorways, at times, even needing to be carried up the stairs to attend meetings. He points to the understanding writers with disabilities have about access to explain

the lack of disability representation. Due to their own disability, such writers are able to consider obstacles (even simple things like stairs) that may hinder disabled actors.

We can quantify the lack of disability representation in a simple way. In this golden age of television, where over three hundred shows are currently airing on networks and streaming services, the percentage of actors with disabilities does not reflect that seen in everyday life.

According to 2015 data from the U.S. Census Bureau, 12.6 percent of the population...live with significant disabilities...In contrast fewer than 2 percent of television characters have disabilities, according to a 2016 report from the Ruderman Family Foundation. Furthermore, 95 percent of disabled characters in top 10 shows were portrayed by non-disabled actors (Raftery).

This has led to frustration among disabled actors, many of whom feel that they are being held back in their entertainment career by perceptions of weakness, sickness, or inability. Tari Hartman Squire, a founder of Lights Camera Access, an organization for entertainers with disability says that the reason for these perceptions is “because people with disabilities haven’t really owned the narrative. Stories are being told by non-disabled people who have an impression about somebody with a disability.” Instead, Hartman Squire argues that “the next generation of media professionals [need] to name it, frame it, claim it, and be proud of their disability” (Raftery).

Another reason for the lack of representation can be attributed to lack of access to training. In *The Tyranny of the Neutral*, disability theorist and professor Carrie Sandahl explains how the simple act of training an actor towards neutrality (specifically in the theory of

Stanislavski), removing them of their individual quirks and idiosyncrasies inherently precludes disabled bodies.

Whatever the acting style, the notion that actors' bodies should first be stripped of individuality and idiosyncrasy as a prerequisite to creating a role undergirds them all. Bodies are considered damaged physically and emotionally from the process of living, and those bodies capable of cure are suitable actors. Disabled bodies, though, cannot be cured. They may tremor, wobble, or be asymmetrical. Implicit in the various manifestations of the neutral metaphor is the assumption that a character cannot be built from a position of physical difference (Sandahl 262).

Because of this, many acting programs and schools of training are incapable of dealing with a body that does not conform to the normative standard, rendering many disabled individuals without the means to achieve their acting goals.

## CHAPTER FOUR: ACTING DISABILITY

### Approaches to Playing Characters with Disabilities

As far as I could find, there is no handbook to playing a character with a disability or an impairment. Instead, in this section, I will be looking at several actors and how they worked to portray characters with disability.

#### *Eddie Redmayne – The Theory of Everything*

Redmayne won the Academy Award for Best Actor for his portrayal of theoretical physicist Stephen Hawking. The script was physically demanding, requiring Redmayne to portray Hawking in the various stages of his ALS. Redmayne worked on his physicality for four months, studying the intricacies of the disease with ALS specialist Dr. Katie Sidle. Every week, he would meet with people affected by the disease, talking to them and observing their physicality. To truly live in Hawking's physicality, Redmayne looked at photographs of Hawking throughout the years, took those photographs to Dr. Sidle and she helped him diagnose the physicality. ALS manifests itself in either muscle wilting or rigidity depending on how the neurons are affected. Getting extremely specific in examining which muscles he needed to tense or relax allowed Redmayne to inhabit the character.

In addition, Redmayne worked with a dancer. He “didn't want [it] to be a film about disease, because [Hawking] didn't care about the disease. It couldn't be less important to him” (“Eddie Redmayne”). Learning the physicalities like a dance and internalizing it allowed him to focus on Hawking's emotional life. His key was to fully embed the physicality in his brain so that when working with his fellow actors, he did not need to think about the physicality.

In the end, as he states in the HitFix interview, it was about portraying the character with dignity. Because he could not control his limbs at times as the character, he wanted to make sure to portray Hawking's placements as dignified, rather than in an "awkward, ungainly position," ("Eddie Redmayne"), something he observed in the Hawking photographs and in his work with ALS patients.

*Claire Danes – Temple Grandin*

In *Temple Grandin*, Danes took on a role vastly different from the ingenue roles she had played up until that point in her career. Grandin was an innovative animal behavior specialist who was diagnosed with autism. Danes admitted the difficulties in playing a character who thinks in a different way than normative minds: "She's wired in such a fundamentally different way than I'm wired that I couldn't just slip into her" (Gold).

To find a way into the character, Danes decided to focus on the voice and vocal tics.

Claire Danes spent weeks listening to recordings of Grandin on her iPod, practicing her gruff abruptness. She became so immersed in "Temple-speak," as she put it, that when she saw Grandin recently in Los Angeles to promote the film, "I slipped immediately back in Temple mode," the actress admitted (Gold).

Danes wanted to do justice to the real Grandin rather than doing an impression or imitation and worked with a dialect coach in order to perfect the voice and vocal tics. She worked on it in private, refusing to let the director hear the voice until the first day of production. In addition, Danes worked with a dance instructor to learn Grandin's "lunging physicality" (Brookes)

### *Sally Hawkins– The Shape of Water*

Hawkins played a deaf character in the Guillermo Del Toro film *The Shape of Water*. In contrast to Redmayne and Danes, she played a fictional character, and so was free to take the character in any direction she chose. In interviews, she talked about how, due to the lack of external stimulus, she made the acting choice to internalize as much as she could (“Sally Hawkins”) and imbue the character with as strong an internal life as possible. Essentially, she made the decision that the character, at the start of the film until she meets the creature, would retreat into her internal reality. She worked with an ASL teacher to learn sign language enough to not have to think about it as she worked on the film.

### Interview with Steven Lane

I had the opportunity to sit down with Steven Lane, a Florida-based actor who performed the Mark St. Germain play *Dancing Lessons* at Orlando Shakes in January 2016. In the play, Lane played the character of Ever, an autistic man, as he attempts to get dancing lessons from Senga, a dancer who had been forced out of her career because of injury. I was able to interview Lane, a neurotypical actor, about playing the role. The transcript follows:

DR: In preparing for the role, how much research into Asperger’s and Autism did you end up doing?

SL: I had to do quite a bit, actually, because most of the characters I’ve played weren’t disabled. Imagination work was enough. But I was pretty ignorant about Asperger’s,

which is a term that comes up in the play, which now [doctors] prefer now to be on the Autistic spectrum, and not actually use the term Asperger's anymore. And I guess the layman perception of Asperger's is "Autism light."

But to answer your question, I did quite a bit. For me (*laughs*). I read about it online on different websites and watched a couple movies. The movie that helped me the most was Temple Grandin. And the reason it was so important for me is that it really opened – because I had this impression that [people with Asperger's] were emotionless. But it's the exact opposite.

A lot of the behavior of autistic people like Ever are defense mechanisms against the onslaught of sensory overload. I watched [*Temple Grandin*] quite a bit, and I felt like it gave me permission to do the showier parts, as opposed to just being ignorant.

DR: That makes sense. Because one of the things in playing a character like this is that you don't want to play a caricature.

SL: Oh God, yes. I call it folding in the cake batter. Where I just – it has to be me. And that's why, as a rule, I feel I don't have to do too much research, at least for the things I have been exposed to previously. You just amplify some things and subtract other things about yourself, because we all are very similar. There's just such a similarity between all of us foundationally. But autistic people think differently.

DR: Were you able to reach out to anyone in the community?

SL: I observed. And I'm so glad you asked that question, because, as I did the research, I started to pick up signs from people in my own life that I started to think "Oh my God, they're autistic." Growing up, you know, when I would come across people that were "different," I have the feeling now, in retrospect, that they were autistic on some level. I used to think "Why are you doing that? You're making life so hard for yourself. Just be normal." And now, I understand that they had no choice, that was the only way they knew how to interact with the world. So I observed, and I would intentionally engage with people whom I had an idea were autistic. But I was afraid that I might hurt their feelings if I said "Hey! I'm playing an autistic guy, can I interview you?" Because, I don't know if they had actually come to terms with that. Because some people are adults before they realize they're autistic. So I didn't intentionally sit someone down, but I did observe them, because I thought it would inform Ever, and it did.

Actually – I completely forgot – I did interview someone. A friend of mine from church found out that I was doing this play, and she had been a mentor for this woman for years, and I asked if I could interview her. So I had dinner with her, and that was incredibly instructive because it was insanely frustrating. I remember – the spectrum is VAST, and just because somebody struggles with one aspect of interaction doesn't mean that Ever did. He was pretty high-functioning on the spectrum. So I did interact with her, and I got

to feel the frustration of a neurotypical person interacting. So I was aware of what my scene partner would be going through in the play.

DR: Do you want to say anything else about how you ended up approaching the character of Ever?

SL: Well, I was terrified that the audience was going to hate me. 'Cause he's brusque, rude, and intentionally so. I can't remember if it was Mark [St. Germain] or who, but somebody said "Oh no, don't worry about that, Steven." Because I had this internal fear – I didn't like Ever initially (*laughs*), and also I found Ever to be incredibly selfish. He doesn't mean to be, necessarily, but he needs the world to revolve around him in order for him to function. So I had to work through that. That was an important part of how I approached the character was coming to love him and let him be who he was without being worried about what the audience was going to take from it.

DR: How did you handle some of the more brusque or rude comments he makes, including sort of diagnosing Senga?

SL: Straightforward. You know the why – the want – is always important to an actor. And since I knew what I wanted, I could just say it, without judging it or thinking there was something wrong with it. It was truth – why wouldn't you deal with truth? Except, having said that – the point of Ever getting these dancing lessons is because he didn't want to

make a fool out of himself. He was very aware that he needed help in order to look “normal,” and he wanted to be “normal.”

Talking about validation – shame is hardwired into us. It’s like touching a stovetop is hardwired into us. “Oh! Don’t do that, you’ll burn yourself.” And you feel that pain of shame, that “what am I doing wrong that’s keeping me from fitting in?” Because fitting in is a survival mechanism, and if you don’t fit in, you feel that pain intensely.

DR: Considering the different way that people with autism think, how did you approach the internal monologue?

SL: I felt like Ever had a mantra inside – his want was just like a drum beating in his head “Get the dancing lessons. Get the dancing lessons.” He operated at a very simple want. Because every time [Senga] would give him a no, he’d come back with a “What about this?” – “Let me do this.” – “I can do this” – “Here’s the money.” As an actor, I try to live just in the moment, and then, I would intentionally not understand Senga, because if she was being abstract or using a metaphor, those things would just fly by Ever.

DR: So you found yourself sometimes having to force your thinking toward the character’s mindset?

SL: There's a translation that happens. Because Steven obviously has to understand what's going on. And then I would translate it into Ever-speak.

DR: We've talked a lot about inward life. How did you approach the physicality?

SL: This was the fun part. So, the spectrum's vast, and the physicality does not have to be this, this, this or this. There were things that were pervasive in a lot of [autistic] people I noticed. Not being able to make eye contact is a given in the play. That's not the case for every autistic person I've met, but for Ever, it was a given. So that was an easy choice. But Steven, as an actor, (*makes pointed eye contact*) this is what I do for a living, this is how I connect to you. So not being able to look at her did so much of the work for me. It made me squirrely. It made me uncomfortable. It made me feel out of my element. Although Ever was doing it in order to feel more comfortable, it made me, Steven, feel uncomfortable, which helped color Ever in the way he needed to be colored. So, as Ever, I would hardly ever make eye contact.

Obviously the dancing, I'm a musical theater guy –

DR: Was it difficult for you to dance badly?

SL: I'm not a great dancer, but I'm coordinated and graceful, so figuring that out was always a challenge. And I decided to just go with something and pray that it would be funny. I

am an angular person, though, and I am a sharp-moving person, so I exaggerated that movement for Ever.

The thing that was really cool that came up was – some people with autism have some form of Tourette’s as well – so I gave him a tic. And it was this (*demonstrates a tic with his neck*), and if things got more intense, it would manifest itself more. And that happened very early on in rehearsal. I’m really someone who wants things to be uber-natural, and there’s a smoothness to what I think is good in performance. So I thought “Is this going to look fake? Is this going to draw attention to me in a way it shouldn’t?” But it was the exclamation point for the character. I never got the note to stop it, I never got the note that it was too much.

As an actor, you want things to be as much an extension of you as possible. When you’re a liar, you tell the truth as much as possible within the lie so that it’s easier for you and it seems real.

DR: In the play, there’s an intimate scene. In society, very few people see a disabled body as sexually desirable. Ever talks about his fear of being touched. How did you approach that scene where something that he probably thought would never happen is, in fact, happening?

SL: He finds himself sexually attracted to Senga. He's watching her dance, and he thinks "What the hell is going on?" So once he realizes that he's sexually attracted to her, there's a desire there and he wants Senga. Which is a huge motivator for him to get past the fear of being touched. The progression from "Don't fucking touch me ever" to having sex is pretty quick. And maybe outside the bounds of logic, but it's theater, and it makes for a great story. But there's a really important scene – my favorite scene of the play – and I don't know what this says about me, but it was really easy for me for it to be difficult to touch her. So that was a very important scene for Ever, for the audience, for Senga, because she's so gentle through it. There's a trust that develops. By the time we got to the sex, Ever was willing enough to deal with the pain and activated enough towards Senga that it was pleasurable for him.

I would do "as ifs" to deal with his problem of being touched – dentist drill hitting a nerve. I just used imagination work to be "if my skin touches another person's skin." I would make them extreme, because sometimes you need a little extra dynamite to make your imagination work.

DR: How do you, as an actor, define authenticity? And do you feel as though you reached it in the character?

SL: My technique and instinct has always been to be natural. Meisner-based – truth in imaginary circumstances. I have to go through what the character is going through. And

if I'm going through it, then it's actually happening. So, that's always my goal, is truth. If my character's heart is broken, my heart has to break.

Whether or not I'm successful depends, I guess, on the viewer. And I did get a lot of positive feedback. And the most important feedback came from people who had autistic loved ones. It was a *really* important show for them. People would find me so that they could tell me. Seeing disability on stage is crazy important. Seeing someone you can really identify with, there's something magical about it, something validating about it, something life-affirming.

DR: To wrap everything up, what were your biggest takeaways from doing *Dancing Lessons*?

SL: I feel like every role you take on makes you more sensitive to the human condition. I feel like my ideas about what it means to be autistic changed. Everyone is human.

As an actor, I've done a lot of shows, and it's the one – if someone has seen me do that show and comes to see me in another show, they almost always bring that show up. So it was the first time I ever had to be someone *really* different, and at the same time, I realized I'm not all that different from Ever. It was exciting – I was terrified – [Senga] has a whole scene before Ever comes in and I would sit behind the door and be so, just scared. Whatever you're feeling, fold it into the cake batter.

### Interview with Christian DeRiemer

As discussed previously, *The Sick Parents Club* is a semi-autobiographical play, with characters based on myself and my friends. Because I am playing a character based on my friend, Christian DeRiemer, I decided to interview him as well, to gain perspective on the character of Garret.

DR: At what age did you become aware of your disability?

CD: I think I always knew, but I don't think it really stood out to me until high school.

DR: Do you remember how you came to this awareness?

CD: I just remember being acutely aware of my differences when everyone else was driving cars and getting into relationships, while none of that was happening for me. It led to a deep dark depression that resulted in a serious consideration of suicide.

DR: How did your disability affect your childhood, especially with your parents?

CD: I had different relationships with each of my parents because of my disability. My dad was the one who mostly took me out and allowed me to have a social life, while my mom was in charge of the medical and educational side of things: making sure I was getting the best care I possibly could, as well as making sure I was engaging with my schoolwork

and being the best student I could. They were both involved very intimately with my life, just in different ways.

DR: Did it affect your schooling at all?

CD: My teachers were told about my disability ahead of time, but never expected less of me for the most part. Before computers were readily accessible, either my mom or an aide would help me write when needed, as I couldn't write for long periods of time.

I was rarely made fun of or teased (except by my friends and family in a loving way), but regular kids were a bit standoffish. As I got older, I kept to myself more. I was scared to talk because of my speech. I was just afraid of what they would think.

DR: How do you view your relationship with your wheelchair?

CD: A sort of freedom. I see it both as a tool that allows me independence, and also an extension of myself. It's my version of legs.

DR: How does the "stare" affect you when you go out in public? Is there any difference between now and when you were a child?

CD: It doesn't bother me now, but it definitely did when I was a kid. I would always hate it when older kids or people would stare. I felt like they should know better. Now I know it's just because society has failed to teach people about [people with disabilities], so staring is just a form of curiosity. I always make sure to look back at them and say hello now, rather than get angry.

DR: In what ways do you feel your disability differentiates you from others?

CD: I think it gives me a unique perspective for sure. I'm forced to rely on people for almost everything, which can be both beautiful and an exercise in frustration. I get to know those people pretty quickly, and they get to know me. I like to think of it as a good example of what human relationships can be if all the ego was stripped away.

DR: How do you view your own sexuality?

CD: I think of myself as a somewhat sexual person, though it's hard to know for sure since I've never had sex or been in a relationship.

DR: How do you find others view it?

CD: I can only speculate. Though I think I can safely say that most people don't view people like me as fully cognizant individuals, let alone sexual beings. I spent a lot of my adolescence trying to make people understand that, to no avail.

DR: When your mother, Karen, was sick, did your disability shape any feelings or experiences?

CD: Not that I recall, no.

DR: Since her passing, has that changed?

CD: Her death definitely made me realize my living situation maybe wasn't as permanent I had previously thought. Once she died, my dad grew fearful of his mortality, and how that inevitability would affect me in the end. I had always just been pretty resigned to the fact that I was going to live and die at home. Being severely disabled and requiring 24/7 nursing does not necessarily lend itself well to independent living. But her death brought new possibilities to light that made me realize I might have more options than I thought. So in a way, her death gave me new life.

DR: How has your disability affected your relationship with friends?

CD: It really hasn't. My friends treat me just like anyone else, and don't baby or coddle me. They are the best support system I could ever ask for, and have done so much more to

help me and make me feel loved than I ever could have imagined possible. I am truly blessed.

DR: Has your disability affected your sense of humor?

CD: The first thing I do when meeting a new person is to try to make them laugh. I find that it immediately puts them at ease in a situation where they may be uncomfortable or unsure how to act. Like just being around me. I like making other people comfortable. I also definitely use it as a defense mechanism, like most people, to make myself feel better in stressful situations. Because of all the experiences I've had, I've learned to laugh at myself and not take things too seriously.

DR: Do you think that it is ever possible for a normative actor to approach authenticity in a role where they are playing a character with a disability?

CD: I do think it's possible. An actor's job is to inhabit a character and portray them as realistically as possible. I think if there were better disabled representation in general, there wouldn't be as much of a hubbub around it. Maybe that's just wishful thinking on my part though.

## CHAPTER FIVE: CHARACTER ANALYSIS

I have found that, in performing roles I have written, I need to take a step back and really analyze the character. I need to separate the writer from the actor. This became especially important in the role of Garret, a character inspired by a close friend of mine, in a play inspired by real events that happened to me. In my acting, I like to take bits and pieces from as many methodologies as possible, but the one I most subscribe to is the Meisner method. I strive to live as truthfully as I can within the confines of the play. I find that my way into the character's truth is to analyze their relationships not only with the other characters around them, but the world as a whole.

### Garret vs Disability

Possibly the biggest aspect of Garret's life that has formed his worldview is his disability. As the playwright, I intentionally avoided diagnosing Garret, but, as an actor, I needed to at least define Garret's disability for myself. While I purposely chose to not make Garret's disability as severe as Christian's, I chose to use muscular dystrophy as the diagnosis. Muscular dystrophy can range in severity, but the uniting impairment is muscle weakness. In many cases, this manifests itself as issues with mobility. If a person with muscular dystrophy can walk, the gait usually waddles and has a spasticity to it and can struggle with falls. Many people with muscular dystrophy use a wheelchair or crutches. In my physicality, I chose to make Garret unable to walk, mobile only with the use of a wheelchair. It is important to note that the character was not a paraplegic. He had feeling and sensation in his legs, but the weakness in his muscles precluded him from using his legs for mobility.

With that in mind, I made the choice that Garret loved his wheelchair. To him, it was an extension of his own body, having had to rely on it since birth. When he isn't in his wheelchair, he has to rely on other people for things. On page 74 of *The Sick Parents Club*, Garret has to ask Gene to help him into bed. Living in the context of the play, that meant moving from a chair into an air mattress on the floor. While, in the real world, a person unable to use their legs may have a more accessible way to get into bed, I had to live within the world of the play. While I chose to give Garret some muscle use in his arms, I also chose to not allow him to be as strong as I am. Which meant he had to rely on the kindness of friends and family to do the most basic of things.

This reliance on others is something with which I think Garret has a complicated relationship. There is an intimacy that comes into play when asking Gene to help him move his legs or get him into bed. There is the matter of physical intimacy, of being so close to someone else as they help him into such a vulnerable position; more important, however, might be the emotional intimacy. That isn't something he would ask a stranger to do. It is worth noting that he specifically asks Gene to do these things rather than Shaun. There is an emotional intimacy established with Garret that simply is not present yet with Shaun. Perhaps, as I will discuss later, part of that hesitancy lies in the fact that Garret is scared of baring himself emotionally to Shaun. There is a layer of embarrassment and frustration, as Christian stated in his interview. I think it is important to note that Garret asks for help in a way where he attempts to turn it into a joke, saying "Before you leave, you mind helping me get into bed? My ass is starting to hurt" (Romano 74). Garret's joke masks an inner insecurity, and that is part of the crux of understanding his relationship with his own disability.

Garret understood from a young age that he was different, that he was othered due to his disability. In the eulogy he gives his mother, he discusses one of his first memories of understanding he was, in fact, different:

I remember when, in middle school, she first decided to stop home-schooling me and put me in the public school system. The school wanted to put me in special education, apart from the “normal” kids (67).

He knew he was not like everyone else, and so he needed a way to combat that othering. A way to put others at ease, to show them that he was like them. As Christian talked about in his interview, humor became his way to put others at ease and get them to laugh with him, to put them at ease. I chose to take that aspect of Christian’s character and imbue it into Garret. Garret uses his humor both as a method to put people at ease around him and as a defense mechanism to deflect.

As Shaun says to Gene, “Sometimes the only way to face the gallows is to laugh” (31), and Garret seems to have taken this to heart. It is the way he deals with his disability. This, again, is an aspect I borrowed from Christian, who christened his old childhood home, made of gray stone and rising out of a grassy field in West Chester, Pennsylvania, the “Cripple Castle.” Similarly, Garret chooses not to hide his disability, instead drawing attention to it by humor and allowing others to do the same.

Christian’s childhood home was not an accessible home. He had a spacious ground floor which was completely his, but a narrow staircase led upstairs, completely inaccessible to him in his chair. Gene’s childhood home is exactly the same

GARRET: This is the only home I’ve ever known.

GENE: I understand.

GARRET: I don't mean this house. I mean this room. This one room. The rest of the house is inaccessible unless I'm literally carried up the stairs. I have photos of me being in the rest of the house when I was younger, but as I got bigger and heavier, those trips got fewer and farther between. You don't understand what it's like when you're on everyone else's time. To even leave the house, I need help. I want control of my own life for once. I love this place, but I also need to leave it behind (71).

As this demonstrates, Garret's home itself was itself part of the problem in his disability. If we consider the social model of disability, where it is not the impairment that defines the disability, but the surrounding environment, the fact that Garret's house is inaccessible to him helps to define his disability. There is a comfort there, but the layout of the house precludes him from fully being able to live his life.

Another thing I want to touch on with Garret's disability is his experience of time. As touched upon in the speech above, Garret experiences his own time on everyone else's time. People with disabilities tend to have a different experience of space and time than normative people. It takes Garret longer than most to do simple things like get dressed or get out of bed. He is forced to wait for others to come to him if he wants to see them. It is no stretch to say that Garret experiences time slower than most people. As such, Garret is forced to find things to occupy the rest of his time, which is one of the reasons why, when we first see Garret, he is playing Mortal Kombat.

Until Gene comes back to see Garret early in the play, they have been communicating online. While Garret may not be able to do some things without help from others, playing games and being online is an area where Garret can be anyone, go anywhere, do anything. It is his escape from reality – from his mother’s illness, and from his own disability.

### Garret and Shaun

For Garret, Shaun represents something he never thought he could truly have. In a world in which people with disability are seen as asexual or neutered, Garret has internalized this viewpoint and convinced himself that it was something that could and would never happen for him. As Christian stated in his interview, “I think I can safely say that most people don’t view people like me as fully cognizant individuals, let alone sexual beings.” He spent so long convincing himself that he had to deprive himself of his own sexual agency that he is unable to receive the hints Shaun sends him.

Shaun and Garret first came to know each other through Gene and the theater department at their old Community College. Garret is aware of Gene’s feelings for Shaun, and so he pushes Shaun towards Gene and away from himself. In his mind, even if he has feelings for her, Shaun is not a sexual option for him. It is the way it should be. He even distances himself from her. To everyone else, Shaun is simply Shaun. Or Shauna. Or, in Gene’s case the first time they run into each other, Shauna Rockwell. Garret calls Shaun by her last name. For him, it is a way to distance her, even to distance himself from the feelings he has for her.

Despite Garrett’s superior mental strength, Shaun disarms him. I want to take a look at an exchange the two of them have early in the play:

SHAUN: What about you? There must be someone you’re interested in.

GARRET (*Noncommittally*): Not really

SHAUN: Oh, come on. It's me. Tell me.

GARRET: Fine. There *might* be someone.

SHAUN: Who is it? Do I know her?

GARRET: You might.

SHAUN: Now you've got to tell me.

GARRET: Let's call her Jenny.

SHAUN: Jenny McCloskey?

GARRET: No. I've created a name to protect the identity of the innocent. Besides, she's not interested.

SHAUN: Have you asked her?

GARRET: No. I just know.

For anyone harboring a secret crush, this might be an awkward conversation. For Garret, it's excruciating. He wants Shaun but knows in his heart it will never happen. But, being his friend, she pries away, trying to learn his secret. And then, without knowing it, Shaun says, in response to his crush "It's me." She does not mean those words to mean the identity of his crush, rather trying to appeal to their friendship. Still, there those words are, staring Garret in the face. "It's me." So of course, Garret obfuscates and falls right into his habit of protecting himself with humor. Then he tries to end the conversation then and there. His crush is not interested in him. How could she be? But that is not enough for Shaun.

He might have convinced himself that others will never see him as a sexual being, but Shaun keeps prying, clearly not satisfied. And Garret drops the humor. His shell is gone. The scene continues:

SHAUN: I bet you're wrong (*Pause*) You still act?

GARRET: I haven't for a while, why?

SHAUN: Let's do a simple role-play. I'll be this Jenny, and you tell her how you feel.

GARRET: I'd rather not.

SHAUN (*In character*): Hi Garret, how are you today?

GARRET: Shaun. This isn't funny.

SHAUN: Who's Shaun? Are you seeing someone else? Garret, is there anything you might want to say?

GARRET: Really, cut it out.

*Shaun touches Garret*

SHAUN: 'Cause I thought that maybe you might want to –

*Garret moves away from Shaun, hastily*

GARRET: I asked you to stop.

SHAUN: I was just trying to help you out.

Garret might be closer friends with Gene, but Shaun has broken through a shell Gene could never hope to. Garret's defenses that he has steadily built up his entire life are gone, and here he is, naked emotionally in front of a woman to whom he wants to tell everything, but simply cannot. The last thing Garret can do in this moment is to admit to Shaun how he feels. To her,

this is roleplay; to him, it is reality. It is not until the touch, however, that Garret truly rejects her. The reason is because, in some ways, Shaun *scares* Garret.

Garret's entire life up until that moment has been finding ways to avoid rejection. In a world where, every time he goes out in public, he feels judgmental eyes drift towards him, Garret has built his defenses up as high as he could. He has developed his sense of humor to put others at ease and, in some way, to prevent them from rejecting him. But in this moment, with Shaun's touch, Garret experiences a moment of violent rejection. He experiences Kristeva's abjection, and his sense of self starts to break down. In the moment, he panics. It is better to reject Shaun than to admit the truth and have Shaun reject him. If he were to allow himself even a moment of hope that he may have been wrong about his sexual circumstance, he also would open himself up for rejection. Shaun's rejection, however, would be one from which Garret may not be able to recover.

GARRET: I accepted a long time ago that it just wouldn't happen for me. Finding someone.

SHAUN: Don't say that, there's someone out there.

GARRET: Someone who's willing to move me when I need to be moved, bathe me, deal with my respiratory issues? Yeah, that'll happen.

SHAUN: It might.

GARRET: Who's willing to watch me die?

SHAUN: Garret, I didn't mean to –

GARRET: Shaun, I think it's better if you go. I'll see you tomorrow, first meeting of the club, right?

SHAUN: Garret, don't.

GARRET: Please.

SHAUN: I'm sorry. (38-40)

Garret finishes his rejection of Shaun by explaining his view of his own sexuality. This form of emotional vulnerability is something he can handle. It is safe. He makes the choice to bare that part of his soul to her, and, in doing so, shut her down. In addition to convincing himself of his forced asexuality, his view on sexuality is shaped by his consciousness of his own morbidity and mortality. This may or may not be true in his mind, but it is something he allowed himself to believe to cope with his realization that he would probably never have a sexual relationship. He has convinced himself that being with someone who may not live a full, long life, such as himself, would not be fair to someone else. He has decided to make the choice for Shaun, refusing his own sexual agency by rejecting hers.

Later in the play, Shaun opens up to Garret, telling him about her mental break. This starts to bridge the gap Garret feels between them. When she tells him about being forced to take a leave of absence, Garret becomes the one to pry this time. And, for the first time in the play, calls Shaun by her first name. The barriers he has built up between them start to fall away. Shaun, this time takes matters into her own hands, touching Garret's legs.

This, for Garret, is a huge neon warning sign. It is not just that Shaun is touching him; she is touching his impairment. He can feel her touch, but his muscle weakness cannot allow him to respond. It is the part of his body where Garret is the most vulnerable. It sends red flags up Garret's spine. He is caught both instinctively knowing what she is doing but not being able to allow the thought to fully occur. His defenses are down, and he even tells Shaun that "This isn't

funny” (77). He can no longer deflect and dodge. And then, she kisses him, despite all his protestations. Even then, with all evidence telling Garret he was wrong and that he can, in fact, be a sexual being, he asks her “Are you sure?” (78) and continues interrogating her instead of allowing himself to enjoy the moment. It is only when things escalate physically, and he allows himself to touch her that he discovers her secret. His hand brushes against the hidden scars on Shaun’s thighs, and he realizes what she meant when she once told him they were not all that difference. Shaun has been suffering from depression. She, too, is disabled. While his impairment is physical and obvious, hers is mental and invisible. She can pass in society, but on some level, they are the same.

Nothing needs to be said, and nothing is said, other than her name. He does not call her Rockwell, but rather, Shaun. In this moment, they share a psychic bond, and words are meaningless. Just as she touched his legs earlier, he holds his hand on the physical manifestations of her impairment. Suddenly, all barriers are down. Through Shaun, Garret has discovered his agency.

#### Garret and Gene

Gene met Garret in community college and, as the play begins, they have been close friends for five years. When they first share a scene in the play, Garret notes that they have talked online every day. Garret has given permission to let Gene write a play about him. In a scene between Gene and Shaun, Gene states that he is considered “an unofficial member of the Marshall family,” has a toothbrush at Garret’s house and recounts the times that Karen, Garret’s mother has cooked for him. Gene is also one of the people Garret allows to share in the jokes

about his disability, also showing the capability to throw jokes right back about such personal things like Gene's history of concussions. There is obviously a level of both physical and emotional intimacy already present between the two, shown clearly in how Garret allows Gene to help him get into bed.

However, there is another level to their relationship which Garret has mostly kept to himself. There is almost a form of resentment bubbling under the surface. Garret has watched Gene go to New York and go on to greater heights than Garret has. While he undoubtedly is proud of his friend, there is a part of Garret that wants those same experiences and is jealous that Gene has succeeded. While Garret is confined to his small room, Gene has the freedom to move away. As the trio is discussing the upcoming community college reunion, Garret admits he is not actually excited:

GARRET: Because all of you have moved on to such great things. Gene went to school for theater in New York, you're a teacher now, Damien went to India and just started his own yoga studio. You've all moved on and I'm still here. In stasis.

SHAUN: But that's not what this is about.

GARRET: Bullshit. Of course that's what this is about. That's what reunions are. It's a chance to brag and exaggerate your accomplishments. What if I don't have any?

SHAUN: But you do.

GARRET: Name one. One thing I've accomplished. (36-37)

Any negative feelings Garret bears towards Gene are merely a projection of Garret's own perceived failings. But they are there, even if Garret refuses to give mind to them often.

One of the biggest uniting factors in the present for Gene and Garret are their mothers. Garret's mother was diagnosed with cancer first, but when Gene admits to Garret that his mother has Langerhaan's Cell Histiocytosis, they realize they need to support each other. Thus, the Sick Parents Club is born, with the addition of Shaun and her ailing father. Even when Karen passes, Garret knows he has to be there for Gene as he goes through his mother's sickness.

Their friendship is put to the test when Gene finds out that Garret and Shaun have been intimate. For Gene, this is a betrayal. For Garret, his best friend – one of the people that can see beyond the disability and just see the person – has failed him. Garret finally has gotten past the idea that he is not a viable sexual candidate, and Gene is rejecting that aspect of him. He understands Gene's feelings for Shaun, and that is why he can forgive Gene, but there is no denying that it hurts Garret.

When Gene's mother is taken into the hospital and the two confront each other, it becomes obvious that the love the two clearly have for each other overrules any petty squabbles. Even though Gene lashes out, Garret realizes that much of it stems from Gene's nervousness over his mother's condition, and renews the pledge to be there no matter what.

### Garret and His Mother

While Karen does not appear in the play physically, her presence is felt throughout. Garret has a complicated relationship with his mother. There is no denying that he loves her, but there are aspects of their relationship which are less than perfect.

Karen pushed Garret his entire life, never letting him rest on his laurels, and there is a part of Garret that resents her for it. Karen took the stance that Garret's disability would not

define him, and while that may have been a noble goal, it certainly made Garret's life harder and more complicated. Garret has not fully dealt with those emotions, so her cancer and pessimistic prognosis have forced him to come to terms with these unresolved issues. In the play, after Karen has died, Garret eulogizes her in an emotional scene:

Thank you all for being here today. My mom would have absolutely loved to see how she brought so many people together. People from different worlds and disciplines. She was a connector and that is exactly what she did – forge connections with each and every one of you. I'm sure so many people in this room who now consider themselves close friends wouldn't know each other if it wasn't for my mom.

I loved my mother. With all my heart. She was one of the bravest, kindest, warmest people I ever knew. My friends were never just my friends – they became family because of her. She and my father always said they had more kids than they knew what to do with. And I'm an only child.

My mom never let me settle. She was stubborn and didn't simply accept the hand she was dealt. She had a habit of multiplying – “family members,” good will, blessings, and challenges for me. I was never allowed to think of myself as disabled. I was able to do the same things as anyone else. Of course I was. I just had to take a different path to success. There were so many times I wanted to give up along the way, but she'd never let me. And part of me resented her for it. Part of me still does, if I'm completely honest. But it made me stronger, and I'm a better person for it.

I remember when, in middle school, she first decided to stop home-schooling me and put me in the public school system. The school wanted to put me in special

education, apart from the “normal” kids. My mom marched right down to the principal’s office, she dragged me in there, and she said “You will not treat my son as though he is different.” She stood up for me, and didn’t let me take the easy road. She never did.

This is really weird for me. I wasn’t supposed to live this long. I think she always expected to outlive me. Perhaps she was mentally preparing herself when I was younger. While the pain of her loss is immense, I’m glad she never had to go through that.

She truly spread love wherever she went. Whether it’s in Heaven or in some other life, I hope we meet again. I love you, mom, and I won’t let this stop me. I’ll continue to live my life without placing limits on myself, just like you taught me to do. (67)

In the end, Garret chooses to place himself in Karen’s shoes and understand what it must have been like to be told by doctors what her child would and would not be able to do.

If there was any resentment, her death forced him to let it go. Because of her, he has a strong network of friends, including Gene and Shaun. Because of her, he graduated community college, proving teachers wrong who, because of their inherent prejudices, did not believe in Garret. While it may have made his life more difficult, Garret owes a lot of his identity to Karen, and for that, he could never continue to be angry at his mother.

## CHAPTER SIX: PROCESS

### Approaching an Authenticity

Entering this production process, one question remained center in my mind: how do I reach a place of authenticity when acting a character with a physical impairment I do not possess? While my neuroatypicality does qualify me as an actor with a disability, my disability is not physical; I do not have muscular dystrophy. I needed to be able to define what authenticity would look like in my process.

In his interview, Steven Lane said that he personally defines authenticity in terms of the Meisner method he had studied – living as truthfully as one can under imaginary circumstances. I first began my acting training at age eight at the Media Theatre in Pennsylvania, where I studied under the Meisner method. I, too, would define authenticity, then, by living in the moment as much as I possibly could. In the end, though, authenticity is not defined by me, as much as it is by the audience. How do I reach an understanding with an audience comprised of people whose experience with me has been as a normative-bodied man?

The answer, possibly, lies within the concept of kinesthetic empathy. “When confronting a work of art...we employ the faculty of imagination, or “inner sensation,” to project ourselves into the art-object and inhabit its structures as if they were our own” (Garner 85). This is a concept more prevalent in dance, where the language conveyed is entirely kinesthesia. However, the acting out of disability is as pure an exercise in kinesthetic empathy as you can get:

If the kinesthetic experience of others is something for which we are hardwired, then the second- and third-hand simulations of disability that performers and audiences produce constitute a different, but important mode of knowability. Insofar as theatre foregrounds

the dynamics of embodiment and intercorporeality, it offers a space in which the boundaries of this knowability can be illuminated, examined, and—in limited ways—transcended. In this sense, all disability performance—whether conducted by those with physical impairments or those without—is a meditation on empathy: what it means (and what it takes) to enter in relation with those possessing alternative embodiments...and what it means for perception and consciousness to be constituted in and through their relation to other selves and bodies. (91)

With an audience who knows my true capabilities, I am entering into a contract even greater than that of a normal actor-audience relationship. If I am successful, disability can be examined by my performance of it.

I chose to make my entrance to creating this character with physicality, specifically that of a wheelchair. I knew, from my experiences with Christian, what a powerchair user looked like, but that was different from a hand-operated wheelchair. For this production, we were able to borrow an old wheelchair from a friend of Sarah Schreck, who directed the show. We procured the wheelchair about a week before rehearsals started, and I was able to simply live in it every day after classes were over and a rehearsal studio available. While in rehearsals, I did not leave the wheelchair during most breaks, opting to spend as much time in it as possible.

I noticed it did not just affect the way I moved around, it also affected other parts of my body as well. While I was free to use my arms as much as possible, the constant sitting forced limited use of my back, which caused me to settle into a stiff physicality.

Through movement, I gained access to the character. I consciously chose to separate the character of Garret from the person of Christian, and, in doing so, was free to create a character I

feel lived up to the standards I wanted. I set out to not play a caricature of a person with muscular dystrophy. I knew going in that there would be aspects of living twenty years in a wheelchair I could not simulate. In the end, I arrived at a place I could be proud of, which resonated with audiences.

### Rehearsal Journal

*Friday, February 16*

We have yet to begin rehearsals, but for me, the process has already begun. I mean, it kind of began months and months ago when this idea first sprang into my head for the play, but now it's begun as an actor, not just a playwright and producer.

Sarah was able to procure the wheelchair early, which I am grateful for. By March 26, when we move into the Santos Dantin, I've got to look like I have lived in a wheelchair for over 20 years. As a writer, I haven't specified what Garret's disability is, because I don't want to fall into the trap of defining him by a diagnosis (it may be useful to include this in character descriptions/stage directions if this will be produced in the future). However, since I've based him off of Christian, one of my best friends from back home, I know he's got a form of Muscular Dystrophy. It's a degenerative disease, and so, while I (Garret...this may get confusing in the future, but it helps to think of the character in the first person) may not have spent my entire life in a wheelchair, I have for most of it. I also have feeling in my legs, even though moving them is a challenge, so that's something I need to contend with. Christian will often ask me to cross one of his legs on top for him when he gets uncomfortable, so I need to be aware enough to pay attention to that as well.

At this point, I have a sort of love/hate relationship with this. I still have reservations about playing disability. I may be neuroatypical, but I'm putting on another's disability, and that is extremely intimidating. I've argued many times in favor of greater representation and even want to open a theater where part of the mission is to greater represent this demographic. I find it extremely odd, that, even in a graduate setting, where certain of my peers put up a hard wall that never should a part for a woman go to a man or that race **MUST** be represented well, that these same people cannot understand why disability representation is crucial. So, what does it mean that I'm a physically normative actor playing a disabled character? Isn't this what I've been fighting against? And yet, I **DO** have a disability whether I think of myself as "disabled" or not. As stated, I'm neuroatypical, and my migraines are covered under the ADA. Furthermore, different models of disability define disability in varied ways. In the end, I need to stop worrying about whether I *should* be doing it. Fear will only stop me from being able to fully invest in the reality of the character.

So, I spent about an hour in the wheelchair today, practicing turns, maneuverability, etc. I even set up a little obstacle course and forced myself to maneuver around it. At the moment, I'm still looking at the things I *can't* do in a wheelchair, which is understandable. But, inevitably, it's the wrong outlook for the character. Wheelchairs are actually a symbol of power. Professor X in comics is actually a great example of this (let's forget about the times when writers have ignorantly restored his ability to walk...which happens when you have many writers over decades). They allow for greater independence. In Dan's world, they take away. In Garret's world, they give. This is my home for the next month and a half. I need to really live in it.

*Monday, February 19*

First day of rehearsal! There's so much work that I've put into this, as both a playwright and a producer that it feels so great to finally embark upon this challenge.

I need to get over my insecurities. Since Gene is mostly a direct reflection of myself, there's a line of his that really isn't fiction: "I'm just that way with everything. I can't watch myself act, all I see is an awkward guy who doesn't know what he's doing. I recently watched a video one of the grads took of my singing final, and I thought about finding the biggest hammer I could and smashing the phone into a million pieces. I just find flaws in everything I do." And so, listening to the read-through today was tough. Read-throughs are almost always slow and don't contain emotional depth, but I still hear the flaws in the things I write. There are some chunky lines I know I'm going to need to edit. There are things I need to fix, but I need to also be able to see the positive and the good in what I've written. That can be hard for me.

The one place I think I need to change is the scene in which Garret gets oxygen. The end is inherently flawed as is. I think I know how to fix it.

I think we have a really great room, and I'm happy with the cast we have. I can't wait to bond more with these people.

*Wednesday, February 21*

I've spent the last two days away from *Sick Parents Club* as I finish my duties as an Original Pronunciation dialect coach for *Twelfth Night* at the Orlando Shakespeare Theater. I got to sit in on the first preview tonight, and I'm so proud of the work everyone, cast and crew, did.

We haven't been getting quite the audience response we were hoping for, but I think that's going to change when we move into the actual performances.

One thing this really has reinforced for me is how vital language is. Not just Shakespeare's language, but also his wit and how he used it in the original dialect. There are puns that are present in the language now that aren't in Standard American or RP (there's one that no one but Jim Helsinger, James Beaman [Feste], and I are going to get, where Feste says "I am resolved on two points" in a scene where they're also talking about alcohol. In this dialect point and pint are homonyms, so a fun little pun that will never get a laugh apart from people in the know...also all the whore/hour puns that Shakespeare loves). As a writer, I hope to continue my development and be able to utilize language even a fraction as well. At the moment, I've been trying to develop a style of writing casual, conversational dialogue, but after reading plays written by some close friends in a more poetic style, I'd love to dabble in that and see what happens.

*Thursday, February 22*

Back to the world of *Sick Parents Club*. I don't think I've ever been as busy as I have been this semester. Not even including my classwork, teaching assistantship assignments, and written thesis work, I've been working since January on *Twelfth Night*, finished up *Pentecost*, started rehearsals for *Play it by Ear* – another full-length I've written, which is being produced by Project Spotlight for UCF Celebrates the Arts – last week, and now *Sick Parents Club*. I feel like I'm being dragged in many different directions all at once. I'm honestly looking forward to the time when I can finish everything up and just take a huge breath.

Today, we worked Garret and Gene meeting up and then Garret's eulogy. If I haven't already explained this, Gene and Garret are very much write-ins for me and Christian. In fact, at one point, I was going to keep our actual names. Now, details about the characters and the story have both changed, but personalities are mostly intact, I think (Christian agrees, for what it's worth). And so, it's really weird seeing a character based on me played by Shannon, especially when I'm playing a character based on Christian interacting with a character based on myself. It's a funny and odd situation.

Karen's eulogy was difficult. Come March, she will have passed away three years ago. I never really thought about the timing of the performance of this play. This play is very much dedicated to my mother, but also to Karen, and I'm glad I can honor her memory in this way. Just thinking about the times I had over at Christian's with Karen made me tear up as I did the eulogy. I don't think I've ever been able to access my emotions as easily as I was with this.

I'm starting to get more comfortable in the wheelchair already and starting to use it to express myself in ways I can't on my feet. David Reed brought in a guest artist to give a workshop on Viewpoints. Now, at NYU, especially in the Playwrights Horizons Theater School (PHTS), Viewpoints are important (Mary Overlie, who created Viewpoints for dance, and Anne Bogart, who adapted it for stage, both worked at Tisch's ETW studio, which shares many things with PHTS), and I've progressed far beyond the basics with it. In fact, I've often taught Viewpoints as TA, and even as a teacher for Terence and my Acting for Non-Majors class in the Fall 2017 semester. But going back to the basics today was really great for me in the wheelchair. The idea not of just your legs leading you around the space, but any of your six limbs (head, arms, legs, tailbone), I think will be extremely useful in this play. Especially Viewpoints'

concept of using body shape to inform body language and story. Considering that three of my limbs are off the table, or at least very difficult to move for this character, I can use Viewpoints to create this new body shape. Exploring with these techniques, I can explore how I allow my head or arms to lead me around, especially as I need to wheel about the space. This is the furthest I've ever had to go physically from my base of "Dan" as an actor, and I think I'm starting to find some interesting things. I've been thinking a lot about curves in the wheelchair. And the logic isn't always the same as walking (if taking the elevator, it's better often to back up rather than turn around inside, like you do on your feet, especially if there are others on the elevator). I need to keep experimenting.

*Friday, February 23*

Rachel Larchar has found my weakness, which is that I'm extremely ticklish, and has claimed she's going to use it to her advantage as Shaun. I've told her about the fact that Garret has feeling throughout his body, but not the functionality, and so she's joked that she's going to tickle my feet, which I can't move very well in character. She's already tickling my side in one scene, and the involuntary bodily response for me is to move my legs as well as my body. I never considered that, but I'm definitely going to have to work with it.

I didn't realize how much of an ab workout this show is going to be. We're using an inflatable bed (mostly for monetary reasons), and we can't put it up against a wall, and probably a headboard isn't going to work (we'll look into it), so to sit up, I'm going to have to essentially do a sit up and hold it for a long time without using my legs for any kind of support. It's uncomfortable, but it's something that Garret would have to do on a daily basis. I've always kind

of wondered why Christian is so quickly uncomfortable. Now I understand. We use all parts of our bodies to balance and gain comfortability, so if you aren't able to move them, you can't make even the micro-adjustments that help us maintain equilibrium.

*Sunday, February 25*

We did intimacy with Brett MacKinnon today. Having been introduced to intimacy choreography last year via Tonia Sina, who led workshops at UCF and during the Tourist Trap, an entirely new world was opened up for me. I've been in situations before where things got awkward or confused or whatever when doing these scenes. It's just easy to confuse feelings when you have to do that night in and night out. Intimacy choreography codifies things and keeps everyone safe outside of the work. You need to share that intimacy during the scene but have a way to really shake it out and return to yourself once the scene is over. The choreography also, and chiefly, avoids situations like the Profiles Theater in Chicago, where sexual assault would happen onstage in front of an audience because safety protocols were never developed for intimacy like there were for combat, and some people took advantage. Now we're treating emotional safety as carefully as we treat physical safety, and I think it's long overdue. Just look how the #MeToo movement has spread so far and even touched Theatre UCF. I have a weird power dynamic as playwright, producer and actor, so I thought it especially necessary to bring Brett in, who is an aspiring combat/intimacy choreographer. Even if the power dynamics weren't what they are, this work is extremely useful and Brett's also doing it tomorrow for *Play it by Ear*, where he serves as director.

I hope (and think) a trust began to develop between Rachel and me today. We discussed things like consent and permission, and how it's important to establish safe words, etc. We really just started the process yesterday. We have not yet added in actual kisses, touching palms in a high-five instead for the time being. And yet, the intimacy was still extremely intense and affecting. The trust needs to go both ways, and I think it's certainly headed that way.

Intimacy is an interesting thing here with the physical limitations placed on the character. Beyond the emotions, physically it creates challenges between the characters because I cannot reciprocate with my full body the same way Shaun can. It creates a somewhat lopsided power dynamic that I'm excited to explore further as we get beyond choreography and into the real emotions/acting of the scene. I obviously knew what I was doing as playwright, but it's one thing to write it on page, and another entire thing to experience it as an actor.

### *Monday, February 26, Part One*

Sarah Schreck sent me questions Mark Brotherton had asked her about the play (he's doing an independent study with her in Directing for the project). She wanted my thoughts on some of the questions and thinking about them from Garret has helped me get even more into the character.

#### **What is this world?**

This is a limiting, defining world for him. He is physically incapable of accessing parts of it, even in his own house. It helps define who he is as an individual. Looking at the social model of disability – it makes him disabled. It might only be a matter of less than a hundred feet separating him from his mother in the actual physical house, but there's an entire world of

difference and separation in not being able to have access. The room where Garret spends almost all of the play is both his heaven and his hell – his prison and his haven. It's his unique space, and he knows it more intimately than anyone else ever will. It's one of the few spaces designed specifically for his access. But it still limits him – he can't go upstairs, he can't, in all practicality leave, because he can't drive away. It's isolating, which leads into question #2

### **What throws it into disorder?**

Garret's world is thrown into disarray with the arrival of Gene and Shaun. On a purely emotional level, Garret has kind of been avoiding dealing with mortality. It's something that he knows he needs to deal with but has had a habit of avoiding (because he's beaten his own mortality expectation but knows it's just a matter of time. This is something Christian and I have talked about in real life...not to be depressing, but we know this probably can't be a lifetime friendship for one of us). So, when confronted with two of his closest friends who are more able to deal with such matters, it forces him to confront it, which is why he's very hesitant about joining the SPC at the onset, and why he has that outburst with Shaun ("Who's willing to watch me die?"). Shaun being back throws his emotional world into disarray. He's long harbored feelings for her but knew she could never reciprocate. He's almost accepted that he'll live a celibate life, especially with the knowledge (even if he avoids it) of his own mortality. And now, here she is, and he's forced to relive those feelings.

### **What will put it back into order?**

*For Garret specifically*

Re: Mortality – Even though he's the most hesitant member of the SPC, having Gene and Shaun around helps him cope in ways he couldn't have imagined. They don't let him withdraw

or sink into depression when his Mom does die, and having his closest friends go through some of the same issues as he does really helps fight his feelings of isolation.

Re: Shaun/intimacy – It takes her letting him into her world in order to heal those self-inflicted wounds. I don't think the scene where they have sex works if he doesn't make the discovery he does about her (*That's not to say that people with disabilities can only be loved by other people with disabilities...that's one of the problems I have with The Shape of Water...more that, in the post-social/post-constructivist model of disability, everyone is disabled in some way or another*). He realizes he isn't alone, and that allows him to form a much deeper bond with someone than he thought possible.

#### *Monday, February 26, Part Two*

Fighting for what Garret wants, even when he can't admit it or doesn't know what it is. If I was titling these on a daily basis, that would be the title of today's entry. I'm actually off from blocking until Thursday's rehearsal, so nothing really not blocking anything new, but I am trying to dig deeper into this character. Which is always a problem when you've written the piece. At this point, I have to divorce myself as actor and playwright. And while, playwright me knows exactly what Garret wants and is fighting for, actor me (specifically the character) doesn't always know that.

In a lot of ways, Garret is repressed. He is bitter at a world which has rendered him disabled, at his own genetics, at his own perceived inability to escape that fate. But he's also got conflicting feelings about a mother who made him think he could possibly fit into a world which won't ever fully accept him. He doesn't wish to be normative, that's not what it's about. He

doesn't wish to escape his disability, but he does kind of wish he had the excuses his mother never allowed him to make for himself. In one passage, he talks about how everyone from his community college has gone on to do some successful things, going to art school, being a teacher, etc. while he hasn't done any of that. If he could use his disability as an excuse, that could easily be dismissed. But his mother never let him do that, and so the only person to blame for a lack of success is himself. And so, he has resentment, in some fashion, for his mother.

He's also repressed when it comes to romance. He's projected his own internal feelings about his disability onto everyone else and thinks there's no chance that someone could ever be interested in him sexually. That's why he pushes Shaun towards Gene, when he clearly wants to be with her. There's no chance for him, and maybe if he succeeds and Gene and Shaun become a thing, he can keep in better contact with her once she's gone. The thought that she might be more interested in him than in Gene never crosses his mind until after Shaun makes the first move.

And that's the way I can avoid the negatives and focus on the positives. It's not that I'm pushing Shaun away by guiding her to Gene, I'm trying to keep her close to me. When I snap at her earlier when she pries too much, I'm protecting my relationship with her. If she were to find out my feelings for her, she may feel so awkward that I lose her, so instead, I shut it down.

Garret wants to fit in. He wants to belong. He wants to reconcile with his mom. But above all, he wants to maintain and build connections with the two friends who mean the most to him. He might not know *or be able to admit to himself* the specifics of what he wants beyond that, but as long as I'm fighting for the things I know I want, I'm doing my job

*Wednesday, February 28*

I've spent the last two nights in rehearsal for *Play it by Ear*, so this is going to be a pretty short journal. As a playwright, there's nothing better than watching a scene come to life. It's magical, especially when it exceeds what's been in your head. That happened to me twice tonight with both *Play it by Ear*, and *Sick Parents Club*.

One of the newer scenes from *PibE* was the one that did that for me today (unlike *Sick Parents Club*, that one has been five years on-and-off in revisions. It had a workshop in 2015.), which is exciting, as I think it really improved upon what that scene replaced.

From *Sick Parents Club*, it was the scene where a frustrated and emotional Gene is confronted with his creations in his search to find his story. That was maybe the last new scene I added, and watching it tonight, I'm so glad I did. It really ties together the disparate elements of the play and I think will be the engine that really makes everything work. This isn't a Garret/thesis thing, this is a playwrighting thing, and I'm so excited after seeing that come together. There are still things I'll rewrite/fix after this workshop production, but I'm glad some things really do work.

*Thursday, March 1*

I've been a bit worried about the wordless montage scene. Cinematically, I think it could/would work, but on the stage, it's risky. I'm still a bit worried, but I like the changes Sarah suggested and consequently made to it. She essentially has "dream" versions of Shaun and me (Garret) come to life and haunt Gene as he replays his phone's recording.

The only thing I'm worried about is having Garret rise from his wheelchair during the scene. Sarah was worried about it too, but her reasoning is that when Gene thinks of Garret in his

mind, the disability isn't the thing he's thinking about. And I can't argue with that. When chatting with Christian over texts or Facebook, I don't keep thinking "I'm speaking with a disabled person", he's just Christian. It also visually should be jarring and make people realize that this isn't reality. This is a manufactured thought in Gene's head. Especially if we add some lighting, I think it'll read.

*Friday, March 2*

I ended up rewriting the hospital scene. The shape of it as it was didn't work great with the changes we made yesterday. So, I changed it. I needed Gene to be a little harsher when first dealing with Garret and Shaun. The problem is making him seem like he's lashing out because Shaun rejected him and chose Garret as a partner. There's a transition I'll need Shannon to make where it's obvious all this is out of fear of his mother. Sarah stipulated the scene needed to be roughly the same length (about 5 pages). I ended up at 6, so it still moves very quickly, but I think the shape is better.

As an actor, though, I do hate losing my line about Professor X and wheelchairs. It gives a little less info to Garret's character. But I couldn't make it work back in with the new scene.

*Monday, March 5*

We didn't have rehearsal tonight, but I still spent some time in the wheelchair. It's getting much easier for me to use, and I think my physicality is coming along. Oh, by the way, cool thing Christian and I just realized – March is the month where the MDA sells shamrocks in

grocery stores to benefit children with Muscular Dystrophy. Garret has MD, and so it's cool that we're doing this show in March.

Chris Niess, who is on my committee and teaches movement, told me that, because I cannot define my physicality by my walk, to think about three points of balance. Now that I'm more comfortable, I've been able to experiment a bit, and this is what I've found:

*Hips* – Probably the main point of balance for Garret is his hips. Because of the Muscular Dystrophy, Garret is confined to a wheelchair, which means he's sitting or lying down all the time. Especially when I'm lying in the bed, I can sit up by using my core muscles and my hip as a sort of fulcrum. That's the first point of balance for Garret

*Chest* – Mostly, the chest can act as a counterbalance for the hips. If leaning forward, there will be two points of balance – chest and hips, with the center of balance between them. I can also twist my torso when needed, and, especially in the bed, gain more freedom from moving with the chest.

*Head* – The final point of balance came down to three things – my head, arms, and wheels. When in the wheelchair, the chair definitely becomes a part of my anatomy, an extension of my own body, so the wheels are a point of balance then. But I spend two scenes in a bed, so they aren't a common point of balance. When in the bed, my arms are definitely points of balance, but not so much in the chair, where I need them to move the wheels. I'm also using them as a nervous tick for Garret when in the chair. But the head is a constant. I'm using my head differently when in the chair than when I, as Dan, walk. I'm almost forced to lead with my head in the chair whereas I lead with my chest in real life.

*Tuesday, March 6*

Maybe I'm more upset about this than I should be, but the choice to have an intermission was almost forced upon us. I can't blame Sarah or Jillian for this decision, even though they made it and presented it as a team to me. The contract with the Orlando Shakespeare Theater stipulates that if the show runs over 100 minutes there **MUST** be an intermission. And having timed all the scenes, it looks like we can get it down to 95 minutes, minimum, but that doesn't leave enough time for the show potentially running longer one day through no one's fault. So, to not be in breach of contract, we need an intermission. The problem is that I didn't write this show with a two-act structure in mind. There seems to be a good halfway point after my respiratory attack, but I would have preferred to have this function as a one-act.

We progressed the intimacy beyond hand-touching today and to kissing. I think there's a trust between Rachel and I now, and I'm really glad we have this in place. Brett's done a great job and I think this is a very important step for theater, especially with the continued news cycle.

Sarah noticed the physicality and acting choices I'm making now, which I've written about here. The fact that she can see a change and thinks the character is going in the right direction is heartening. Considering that this character is based on one of my best friends and deals with the loss of his mother, with whom I was close, means that getting this character right, regardless of thesis, is more important to me than almost any other character ever has been (and I mean that with no disrespect to any other character).

*Wednesday, March 7*

Today we essentially did a put-in rehearsal for Oliver, who will be playing Gene during our “design run” (really, our run for Cynthia White, my thesis chair, who sadly will not be able to see the show in person). Shannon was unable to play the role because he’s at SETC. It’s interesting to see the different energies Oliver and Shannon bring to the role and how it affects Garret’s relationship with them. Oliver is slightly more playful, which led to a stronger, more brotherly connection than I’ve had with Shannon (although I’d like us to get there in our own way). It may have been helped out by the fact that we had a fairly meaningful interaction during exercises for the Intimacy Workshop. He ended up in tears and I ended up close when, after a connection was established, Brett suggested we think about losing that person. I’m looking forward to doing a run featuring Oliver.

*Thursday, March 8*

Well, we didn’t get a complete run in today, which means the show took longer than two hours and thirty minutes. A LOT of that time we’ll be able to cut down when we’re not always calling for lines or pausing as much as we are (after we dismissed the cast, Sarah and I talked about doing some Italian/speed runs the week after break), but, as producer, I’m still slightly worried. We won’t have the full cast next Monday, since we’re sharing Rachel and Shannon with Terence’s thesis project, and so, at max, we’ll get in three or four runs next week. I’m sure we’ll pull it together, but as producer, playwright and actor, I am starting to get nervous.

I also had a subluxation of my right knee today. Of course, it had to be the right one and not the left, which I had previously injured last semester. Historically, it’s been my right knee

that's given me issues. And it's always been a mystery as to what actually was wrong with it. My sports medicine doctor told me today he's fairly certain that it's a subluxation, which essentially means that the knee dislocated and then immediately slid back into place. I may, in fact, need surgery in the summer to fix it and prevent it from happening in the future. In short, it sucks. The thought had crossed my mind before "what if something happened and I ended up actually needing the wheelchair in real life this semester?" Well, that happened today.

*Friday, March 9<sup>th</sup>*

We ran through most of the short plays today. They're all in good shape. Spring break started today (all of my classes for the day were cancelled), and I need it. That is all.

*Wednesday, March 14*

I watched this week's episode of *Speechless*. This show is an important step in disability representation, as Michael Fowler, who plays J.J. DiMeo in the show, has cerebral palsy. This is one of the first shows in television history to have a disabled actor front and center as a main character. This week's episode was fantastic, but it tied in with something I talked about previously in this journal.

J.J. has written a film and his is chosen from his film class to be produced, with him directing. The class, then, predictably goes completely out of their way and above and beyond to purchase him everything needed to make sure that directing will be accessible for him. After getting all this support, J.J. stops making decisions and instead allows everyone else to guide his project, which soon goes far beyond his recognition. In the end, J.J. admits that he did so because

he's afraid to fail. The (over)accommodation the class afforded him removed every excuse he had related to his Cerebral Palsy, so, if he failed, it was on him. The fear of not succeeding paralyzed him and allowed him to use his disability as a crutch. Both my mother and Christian were instilled by their parents to never use their disabilities as an excuse and rather, fight for their autonomy. The fact that *Speechless* is so respected for its representation and tackled something I'm looking at in this show makes me positive I'm on the right path.

*Saturday, March 17*

Stephen Hawking died earlier this week, and as Christian posted on Facebook, people with disabilities throughout the world lost a role model and inspiration. Inspiration in the disability community can often be a negative word, with the way normative people create "inspiration porn" around disability, but I think unequivocally that Hawking was inspirational for things that had nothing to do with his ALS. The fact that people with disabilities, wheelchair- and powerchair-users could see someone who looked like them widely accepted as one of the smartest people in the world made him someone to look up to. He seemingly wasn't defined by his disability or limited by society because of it.

Or was he? Looking at certain media narratives concerning his death, we see cartoons depicting Hawking either finally standing up or flying away from his wheelchair. Many in the disability community have decried these as ableist, as portraying death as a preferable alternative to disability. It holds normativity and able-bodied people as the ideal. It also insinuates that all people with disabilities long to be released from their diagnoses in the end and only then can be on equal footing with the rest of society. This is a wholly ableist viewpoint, and it's sad to see

Hawking not lauded for his genius, but rather people celebrating his “liberation” from his powerchair.

The reality is that, for people like Christian, like Garret, like others in the disability community, wheelchairs and powerchairs are symbols of liberation, not of disability. Professor X is the most powerful X-Man, and one of the most powerful humans in Marvel comics not despite his chair, but, in part, because of it. Without the use of my legs, I feel limited whenever I’m in the bed in this show, and embarrassed as the character to have to ask Gene to help me out of the chair and into the bed. I do feel a sense of freedom being in the wheelchair.

This week’s events really illuminated the timeliness of the questions about disability I want to discuss through this show. The world lost a great man in Stephen Hawking this week. A gifted scientist and astronomer. And one who just happened to be a wheelchair user.

*Tuesday, March 20*

As opening night approaches, I’m getting more and more nervous. I have long argued that disability representation is a problem, and the thought I’ve discussed previously about whether I should be playing someone with muscular dystrophy is something that keeps me up at night. I don’t think I’d ever want to do this again, but I also think it’s important. I think I am starting to reach a place of authenticity in my performance, but I also do not want this play to serve as a counterpoint to arguments of representation. We need more stories that don’t rely on tired disability narratives and instead simply feature characters with disabilities as just a given in the world. If theater is supposed to be a mirror to nature, as Shakespeare wrote in *Hamlet*, then

people with disabilities need to be able to see themselves represented on stage closer to their own reality. I hope *The Sick Parents Club* provides people with a good example.

*Friday, March 23*

We move into the Santos Dantin next week and still haven't gotten in a full run. I have to admit, I'm a little nervous. I think this is all going to pull together, but not getting a run in is troubling.

The thought occurred to me today that the dream sequence is playing with the Brechtian effect disability often encounters. While I may not be physically disabled in a way that triggers that effect on itself, hopefully the audience will see me as the character, disabled. Standing up in the moment should hopefully trigger a moment where the *unheimlich* takes over and throws the audience off just a bit. It's what's needed in the moment, and I like that Sarah chose that as the one moment to not lean into realism.

*Monday, March 26*

We have buttons, we have posters, this is all so real. We move into the Santos Dantin theater tonight, and I couldn't be more excited. There are certainly things about the script I would love to change, but this production is special.

Sarah, Jillian, and Lexi have been such an integral part of this process, and I couldn't imagine doing this without the team that I have. I know this will probably never be seen by them, but if it ever is, thank you so much. You will never know how much this means to me.

*Wednesday, March 28*

I have been so invested in this show that I failed to realize today is the third anniversary of Karen DeRiemer's passing. Garret's mother, Karen, was based on my relationship with the real Karen. She and her husband Neil always treated me as a part of their extended family, including giving me a cheap toothbrush they kept in the bathroom on Christian's floor of the house. I've decided to devote this weekend's performances to her memory.

The notes I got from Sarah today have to do with anticipating. Having been a part of this play the longest – from conception to writing to rehearsals, I am utterly familiar with the words. My job now is to make those words unfamiliar, and to live in the moment.

*Thursday, March 29*

I participate in an all-year dynasty baseball league. One of the owners I've befriended in the league was on vacation in Orlando, and I was able to grab a drink with them after rehearsal today. When telling him about this project, he shared with me that his brother was disabled, and as such was very interested in seeing the show. While his brother does not have muscular dystrophy like Garret, he is a wheelchair user. I can't wait to get his opinion after he sees the show.

We open tomorrow. We finally got in a full run after abbreviated tech runs the past two days. I couldn't be more excited and more nervous. Tomorrow will tell me everything I need to know about the success of this thesis.

## Performance

We performed *The Sick Parents Club* March 29<sup>th</sup> through the 30<sup>th</sup> of 2018. The first night, Sarah's friend, Kurt, from whom we borrowed the wheelchair came up to me after the performance. A wheelchair user himself, he had not been told a summary of the show or what it was about beyond the fact that it contained a character who was a wheelchair user. Despite knowing that I was able-bodied, he told me that he had never seen himself on stage like that. He proceeded to tell me that, in the romance he watched between Shaun and Garret, he saw his own story with his girlfriend. Without prompting, he told me that he "felt represented" for the first time he could remember on a stage. Kurt's family works in stagecraft, so that meant quite a lot to me.

Pat, the friend from my baseball league I discussed in my journal, saw the show on Saturday, and came up to me after the show. He told me that in the character of Garret, he easily was able to see his brother. He commented that he saw the physical work I must have done in the wheelchair, and told me that, even though he would not describe himself as a "theater lover," he really enjoyed *The Sick Parents Club*.

While there were some hiccups – on the Saturday show we recorded, about a third of the Garret and Gene scene at the beginning of the play was skipped due to some line flubs – I was proud of the performances. I chose to forgo audience feedback forms but was complimented by many audience members – students and faculty members alike. One professor told me after class it was my best performance during my time at UCF.

In November 2018, *The Sick Parents Club* received a nomination for Broadway World Orlando's Best World Premiere Production. While we did not win the award, it was an honor to

receive a nomination and the votes that we did get. Considering we did not play to large houses, the fact that we got votes at all spoke a lot to me about the success of the production.

## CHAPTER SEVEN: REFLECTION

### Goals Entering the Process

My primary goal coming into *The Sick Parents Club* was to create a character with a disability who did not conform to typical stereotypes and narratives surrounding disability. I did not want to create a character that others viewed as an inspiration for just living their life, or was reliant on others, or any other number of the common archetypes. I wanted to create a character almost unrecognizable among the current media atmosphere – a fully-fledged character who just happened to be in a wheelchair.

I wanted to approach authenticity as a wheelchair user and a disabled character. While I was playing to an audience that knew I was not physically disabled in the way Garret was, I needed them to buy into the conceptions for the duration of the production that I, in fact, had muscular dystrophy.

While I could not control the audience, my main goal was to live as truthfully as possible under imaginary circumstances as the character. I needed to live moment to moment as Garret would. I may not be able to truly experience the differences in time and space that Garret experienced, but with everything in my control, I needed to keep myself as the character in every moment of the play in every way I could control.

### Reflection

Looking back, I feel that the time I spent in the wheelchair before rehearsals started paid off in a big way. Learning to navigate the obstacle course I set up for myself went far in learning how to control my movements in the chair. Spending as much time as I did in the chair during

rehearsals, not taking time off during breaks allowed me to experience it non-stop for hours on end. While I cannot say whether it looked like I was a lifelong wheelchair user from an audience's perspective, I can say that I surely felt comfortable in my physicality as the show went into production.

I think I did the character justice. I feel like I was able to create a character with a disability who existed in the world of the play without becoming a trope or a caricature. I believe I did Christian justice with my performance.

To answer a central tenet of this thesis, I believe that I was oversimplifying the question of whether I could create a character without defining them by their disability. I was able to create a character that did not adhere to problematic narratives. Garret was not a supercrip, or a model of social pathology, nor was he used for inspiration porn – he was just a person. However, a character must always be defined by their prior experiences; in this case, there was no escaping Garret's experiences as a person with a disability. If a person is playing a character with a disability which deviates from their own experiences, there must, by the nature of acting, be character research done on that disability. In my case, I was able to find my way into the character by taking on Garret's physicality, which was informed by his disability. So the answer to the question becomes two-fold: yes, a character can exist where he is not defined in the narrative by his disability, and can just be a person; however, the actor must, in part, wrestle with that disability in the creation of said character.

This bleeds into the question of authenticity. While I tackled the character's inner life using Meisner-based techniques, Viewpoints, and relationships, only the audience can judge authenticity. The fact that not one, but two people who saw the play felt moved enough to tell me

they saw themselves represented onstage for the first time confirms that authenticity was approached, if not successfully achieved. However, I did feel uncomfortable, at times, in the role. To me, this all boils down to the question of representation – who has a right to play these characters? While it is improving, disabled actors still do not have much representation – whether from lack of opportunity or the problems of training such actors. Beyond Ali Stoker in *Oklahoma*, actors with disability are mostly relegated to roles where they are playing characters with disabilities. To me, playing this character felt at times that I was taking a role away from someone with limited opportunity. I do think that if I ever get this play performed by a professional theater, I want to put a stipulation in the play that Garret shall be played by a wheelchair user. This simply is a matter of representation.

The question then can be asked – what if a college or community theater wanted to perform this play? Should I, as a playwright, deny the use unless they could find an actor who has the correct impairment? That is a complicated question, and I do not know that I have all the answers I would need to sufficiently respond. Representation is extremely important, and the words of Kurt still ring in my ear – this was the first time he saw himself on stage. If I, as someone with an invisible disability, can do that for an audience member, that is still extremely important and meaningful. I would say that I would certainly encourage the use of an actor with a disability in that role. However, I cannot say at this moment that I would deny the use of the play if an actor with a disability cannot realistically be found. If I can make just one other person feel seen and represented, then I have achieved my goals.

Overall, I set out to represent a character that had not been seen on a stage. To represent disability in a way that few shows before have – *The Curious Incident of the Dog in the Night-*

*Time* springs to mind as a good example of disability representation. Judging by the comments from Kurt and Pat, I feel like I accomplished that goal. Hearing Kurt tell me that he felt seen and represented in a way he never had before touched me in a way no other play has ever touched me.

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