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Praxis of Lust: Alternative Sexual Culture in Personal Narratives of Queer Disabled Sex

by

Caroline Emily Jackson

Under the Direction of Susan Talburt, PhD

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2021

## ABSTRACT

This thesis focuses on emotions to analyze personal narratives of queer disabled sex to understand how queer disabled people talk about sex with the goal of identifying their constructions of their sexualities and sexual practices. By analyzing how the role of discourses on disability affect how these narrators and their partners feel about disabled sex, this thesis explores how sex can be used to combat negative emotions fueled by dominant ableist discourses that cause shame and self-disgust. This thesis explores how some of these narrators employ what I call a cross-crip praxis of lust, where they describe experiencing a radical liberation from shame about their disabled bodies and increased sexual pleasure as they create alternative sexual cultures. These narrators offer insights into how the possibilities for sex and pleasure can be expanded for us all through their stories of a DIY sexuality, where creativity and agency constitute fulfilling sexual experiences.

INDEX WORDS: disability, sex, emotions, shame, disability justice, discourse, cross-crip sex

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2021

Praxis of Lust: Alternative Sexual Culture in Personal Narratives of Queer Disabled Sex

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May 2021

## **DEDICATION**

First, to my parents, William and Carol Jackson, for consistently and generously filling my cup with the love and support that makes completing a project like this possible. I hope to continue to make you proud as I progress in my academic career and follow whatever path of inquiry sparks my interest. I am so lucky to be your daughter.

Second, to all the wonderful queer people in my life. Thanks for opening the door for me to engage with our community every day and through this research.

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## 1 INTRODUCTION

Discourses on disability and sex, both academically and socially, often address topics such as reproduction, sexual violence, inappropriate or nonconsensual touching of self or others in public, disinterest in sex, and clinical issues (McRuer 167). As discourses on disability fuel stereotypes and assumptions of disabled people as asexual, unable to have sex, or infantile, many disabled adults discuss frustration at being socially and clinically discounted from sex and pleasure. Researchers and disability activists and artists strive to expand the discourse on disabled sex by focusing their work on sexual pleasure and how to access it as a disabled person. Considering that an estimated 61 million adults in the United States have reported any kind of disability, it is critical to understand the role that disabled people have in creating pleasure for themselves and their partners (Okoro et al. 882).

Expanding this discourse allows for new ways to examine pleasure. As Andrew Gurza, the self-identified queer cripple host of the podcast *Disability After Dark* says, “When I say ‘Yes,’ to somebody as a disabled person, it means allowing them into my world and it means allowing them into my experience of disability. And that’s powerful. I think just disability can help us look at pleasure in completely different ways” (Anderson-Minshall). The experience of disabled people’s sex lives is more than the reproductive and sex-as-problem discourses that are more widely researched; there is pleasure, intimacy, intensity, adventure, learning, and the myriad of other descriptors that are associated with a fulfilling sex life. Research that focuses on the pleasure of disabled sex highlights the creativity and agency that disabled people utilize to build fulfilling sex lives and craft their own alternative sexual culture, a term coined by Tobin Siebers for the experience of sex itself for disabled people, without adequate help from doctors, porn, or the varieties of sex education that non-disabled people have access to (Siebers 39).

However, the topic of affect, the emotions and feelings that disabled people report in this research, is not analyzed in depth. For many disabled people, being disregarded as worthy of sexual pleasure or able to have sex causes feelings of shame, self-hatred, and frustration. But, when disabled people resist exclusion from sex and create sexual pleasure for themselves and other people, they describe feelings of joy, satisfaction, belonging, and power alongside lingering feelings of frustration or shame. In order to better understand the new possibilities for sex and pleasure that disabled people create, it is crucial to analyze feelings that arise and are part of the creation of a fulfilling sex life, as well as the feelings that result from having accessed a fulfilling sex life.

Furthermore, the disabled people most commonly represented in research are white, cisgender, and heterosexual. Research on queer disabled people and sex is available, but due to the already taboo nature of sex, compounded with heteronormativity, research disregards disabled queer sex as less relevant than research on heterosexual relationships. How do the feelings brought on by the exclusion from sex and the resistance to that exclusion manifest differently for queer disabled people who experience their bodies, their partners, their communities, and themselves differently from cisgender, heterosexual people? How do these feelings manifest differently for queer and gender non-conforming (GNC) disabled people of color? To complicate the above questions, how do discourses on race and sex affect queer disabled people of color who are working to create a meaningful sex life for themselves and their partners? Through my thesis, I have analyzed the personal narratives of three queer disabled people talking about their creation of an alternative sexual culture to better understand the role of sex in resisting negative discourses that work to exclude disabled people. My personal narratives come from Andrew Gurza's podcast *Disability After Dark*, a collection of zines called *The Ring*

*of Fire Anthology* by E. T. Russian, and the poems and essays of Leah Lakshmi Piepzna-Samarasinha. My analysis focuses on feelings such as shame, disgust, and confidence to show how disabled people feel about the discourses excluding them from sex and how they feel about resisting those discourses in their sex lives.

I begin with a literature review on the dominant fields of disability studies and legal studies to show how those discourses on disabled sex which characterize disabled people as asexual and infantile work to exclude disabled people from sex but also are resisted by disabled people having sex and talking about it. Literature that describes the unconscious and conscious feelings, emotions, and affects that queer disabled people experience and name when talking about sex is rare. Therefore, this proposal considers affect theory and engagement with discourse to explore the pleasure possibilities of queer disabled sex. I also elaborate on the specific personal narratives that I have analyzed for the role of emotion in the narrator's sex lives.

### **1.1 Literature Review**

This review first explores some of the basics of the field of disability studies, as well as a critique offered by Black feminist scholars that disability studies must be more intersectional than its white male-centered history. Then, the review explores two main themes. First, I argue that the normalizing language of equal rights works to construct disabled people as othered subjects and to discount them as able to participate in sexual life, as seen through the surveillance of disabled people's romantic relationships in order to assess whether they qualify for valuable state-funded care. Second, I demonstrate how current literature on disability and sex reflects the negative messaging coming from healthcare providers, family, and society by focusing on professional dismissal of the sexual needs of disabled adults. Finally, I review elements of this literature that show the creativity and agency expressed by disabled people who

have found new forms of pleasure and sex that allow them to connect with themselves and their partners.

### *1.1.1 Disability Studies*

Disability studies is an interdisciplinary field composed of two well-known models of disability: the medical model, which is the idea that disability is a medical problem or shortcoming found within an individual, and the social model, which responds to the medical model by viewing disability as an issue that comes from socially constructed prejudices as opposed to an individual's medical issue. Disability studies scholars have critiqued both models, arguing that the medical model discounts the environmental and social factors that impact disabled people and the social model minimizes people's experiences of pain or difficulty completing tasks due to the medical components of their disability, regardless of social oppression (Beaudry 210-212). It is necessary to consider both models of disability; when combined, they encompass the medical and social realities of disability.

Since disability rights activism in the 60s was led by white men and currently with disability studies failing to fully consider intersections of race, gender, and sexuality, the white male subject has been at the center of academic discourse on disability. While both the disability rights movement and disability studies have some diversity in their past and present with white women being deeply involved in the disability rights movement, a white cis straight male politics is still at the forefront. During the beginning of the disability rights movement, white disabled activists such as Ed Roberts and the Rolling Quads, a group of disabled student activists at Berkley, and Patrisha Wright, were able to achieve single-issue, civil rights gains such as state funding for care attendants to aid in independent living and passage of the Americans with Disabilities Act (ADA). White men with disabilities can access the ADA and what it provides by

having the resources and privilege to fight for accessible spaces and receive care without discrimination due to their white privilege. The ADA is unable to meet the needs of disabled people who are unable to fund lawsuits to make buildings and institutions accessible, queer/trans/non-white people who fear violence or microaggressions from care attendants, and those who are sick and disabled but are unable to medically qualify for state-funded assistance (Piepzna-Samarasinha 40).

A focus on the white male subject is prevalent not only in the disability rights movement, but also within academia and research on disability, as many prominent disability studies scholars such as Lennard Davis, Rosemarie Garland-Thompson, and Paul Longmore are white. The focus within disability studies on the white male subject rejects the intersectional realities of disability within the US, as Indigenous and Black people have the highest rates of disability, and one in four women are disabled (Okoro et al. 883, 885). In order to decenter the white male subject to achieve a realistic and nuanced understanding of disabled perspectives, Black feminist scholars such as Moya Bailey and Izetta Autumn Mobley argue for a Black feminist perspective in disability studies that would “dislodge the white male body as the central normative body in Disability Studies, establishing the need to examine how bodies are raced and the ways in which this intersects with disability, disease, and bodily sovereignty” (Bailey and Mobley 27). Bailey and Mobley draw on Black feminist thought’s elaboration of the myth of the strong Black woman, which has been little explored through an ableist lens, to show how Black feminism helps to fill the gaps in disability studies: “The myth suggests that Black women are uniquely strong, able to endure pain, and surmount otherwise difficult obstacles because of their innate tenacity. Black women are disallowed disability and their survival is depoliticized” (Bailey and Mobley 21). Black women are disallowed disability through another harmful trope, the crazy

Black woman. The authors cite the use of this trope as a “weaponization of crazy” against Black women to deny psychiatric disabilities from them. In a white person, what might be diagnosed as bipolar disorder, severe depression, or addiction disorder may go undiagnosed and untreated in Black women (Bailey and Mobley 31). Through these myths of being innately tough and naturally crazy, Black women’s disabilities are often invisible to disability studies, disability rights, and to law enforcement. The denial of mental illness and label of crazy have deadly implications when disabled Black women encounter police. In 2017, Charleena Lyles, a Black woman who was raising her four children and expecting a fifth, called to report a burglary in her home. When police arrived, they found Lyles in a mental health crisis holding a knife; rather than deescalate, they shot and killed her (Levin). This tragic example of the violent consequences of denying Black women disability compounded with the brutality of police violence reflects the dire need of both disability rights and disability studies to decenter the white male subject. Other scholars, such as Angel Love Miles, Akemi Nishida, and Anjali J. Forber-Pratt, acknowledge the gap in disability studies regarding race and have called for a critical intersectional disability studies that seeks new knowledge from the perspective of disabled people of color, works to propel disabled students of color into disability studies scholarship, and maintains that unless the lives of all disabled people are improving, then the field of disability studies is failing (Miles et al. 2).

Theoretical work at the intersection of disability and race has conceptualized the two constructs in a variety of ways. Nirmala Erevelles traces the intersection of race and disability from disability studies to critical race theory. The field of disability studies often conceptualizes race and disability as analogies for each other, “in attempts to shift the experience of disability from the debilitating conceptual space of individual pathology to a broader social recognition of

disabled people as members of a political minority” (Erevelles 145). While describing disability as “like race” has been useful in the fight for civil rights for disabled people, simply theorizing these categories as interchangeable fails to recognize the nuances of both identities. Erevelles, as well as other critical race scholars, argues that race and disability can “demonstrate how they constitute one another through social, political, economic, and cultural practices that have kept seemingly marginalized groups of people in strikingly similar marginalized positions” (Erevelles 148). Race and disability work together to justify the constitution of the unwelcome Other.

Scholars at the intersection of Asian American studies and Disability studies reflect on American immigration laws, specifically in 1882 when the Chinese Exclusion Act and the Act to Regulate Immigration were passed. These separate laws respectively denied entry to Chinese immigrants and any person who could become a burden to the public, aka disabled people (Stanley et al 77). Both Asian Americans and disabled people fall outside of the “U.S. white normative population” (Stanley et al 77).

To analyze the complexities of the intersections of how race and disability are conceived as abnormal, Michelle Jarman uses the lynching of Black men, castration of disabled people, and the rhetoric of eugenics to show how, when read together, disability and race are “dynamic social and discursive processes that inform each other” (Jarman 91). Jarman turns to history and literature to show that while the methods and goals of the lynching of Black men and the surgical sterilization of disabled bodies are different, they share “intertwining narratives of rape and corporal punishment” (Jarman 92). In order to protect and advance the white race, Black men and disabled men have been subjected to a eugenic narrative of uncontrollable sexual perversion resulting from both an inherent danger and cognitive inferiority (Jarman 92). These distinct forms of violence work to normalize each other. Jarman argues that the public spectacle of



lynching made the private, medicalized practice of castration seem “benign” and both violent interventions responded to “the same culturally produced fear: that of a threat, animalistic and sexual, to the sanctity of normative white heterosexuality- a threat whose extremity necessitated drastic and violent responses” (Jarman 100). Analogizing disability to race cannot reflect the unique intersections of race and disability that constitute these subjects as nonnormative to the point of violent intervention, especially when relating to sexuality.

### *1.1.2 Equal Rights*

Disability rights activists have used equality and equal rights as the dominant framework to improve the lives of disabled people. The Americans with Disabilities Act, passed in 1990, prohibited discrimination against disabled people and mandated access to educational and work accommodations, accessible buildings, state assistance for healthcare, and other accommodations for disabled Americans whose disability is proven to the state (Americans with Disabilities Act). However, scholars within disability studies and legal studies such as Lennard Davis and Dean Spade, as well as disability justice activists such as Leah Lakshmi Piepzna-Samarasinha, have critiqued the ADA and other equal rights laws for inadequately serving people’s needs and allowing discrimination against them to persist decades after their passing. These laws fail to include people who have a marginal or flexible relationship to disability but still need care: “Some of us are in the in-between of needing some care but not fitting into the state model of either Total or Permanent Disability or fit and ready to work – so we can’t access the services that are there” (Piepzna-Samarasinha 40). Not only do these laws fail to fully provide the equality they are named for, but they work to support the norm which situates others as abnormal. They sometimes define improvement as the creation and maintenance of productive, working, citizens under a capitalist society; and they give the state power to determine what is a

disability, who is disabled, and what resources can and should be afforded to people. The entire notion of equality as a goal and framework is inherently flawed at the most basic level.

Lennard Davis, a scholar of disability studies, argues that equality and equal rights are an inadequate framework for improving the lives of disabled people. He connects the language of equal rights to its ability to solidify a standardized norm, which subjugates disabled people to further marginalization. In “The Rule of Normalcy,” Davis writes about how the creation of the modern nation-state depended on the standardization of language, which was accompanied by a standardization of bodies. In the identification of a national language and national physical type, the opposite was identified as well, the anti-national language and physical type (Davis 106). How does the identification of a national and anti-national type square with the ideal, “All men are created equal?” Davis argues that the idea of the norm makes this contradiction logical as it “permits the idea of individual variation while enforcing a homogenous standard or average” (Davis 109). The idea of the norm also applies to medical discourse, where in identifying the norm, there will always be someone put into the category of abnormal through exceeding or falling short of defined normality. Medical professionals are the only ones who can validate this norm, as it cannot be self-reported. Once validated by medical experts, the disabled become the pitiful outlier to the norm (Davis 115, 177). Able-bodied people feel this pity, who use the existence of disabled people to help enforce their personal feelings of conformity (Davis 117). Davis thus addresses disabled people who consider their struggle as one for equality:

Obviously, a civil rights paradigm is better than one that relies on pity, the reverse side of discrimination. However, if, as I have been arguing, normalcy and equality go together, then a critique of normalcy that does not critique ideological notions of equality will end up falling prey to the same problems experienced by all who are oppressed by the rule of

normalcy. In other words, people with disabilities may get their equal rights in their respective United States of Ability and join the ranks of the “privileged” normal, but with that will come the repercussions of the complex agenda. To become part of the solution, one may become part of the problem. Equal access and equal rights are certainly important, but equality is a doubled-edged sword which cuts bodies down to a convenient and usable size. (Davis 117-118)

Davis shows that by advocating for an equal rights framework, only a few lucky disabled people will be able to achieve some level of normalcy. For those disabled people who can access normalcy, they do so at the expense of other disabled people who are cast aside as perpetually abnormal. Campaigning for equal rights and the expansion of rights has been a useful tool for providing assistance and access to places that others were denied in the past; however, there will always be people excluded from these rights by virtue of citizenship, class, or other forms of difference. That exclusion can be a literal denial of access to funding through social security or an exclusion from accessing care driven by the fear that many disabled people of color and poor white disabled people have that accessing state-funded care will result in losing their kids or being removed from their independent living situations (Piepzna-Samarasinha 36-37). Privileging equality in the eyes of the state proliferates further surveillance and normalization in order to support the state’s ideal of a productive, successful, and supported body. Equal rights are a band-aid solution that only partially and inadequately addresses the issue of systematic and institutional ableism.

Other scholars have examined the failures of equal rights as a legal framework such as legal and trans studies scholar, Dean Spade, in his book *Normal Life: Administrative Violence, Critical Trans Politics, and the Limits of the Law*. In the chapter titled, “What’s Wrong with

Rights?,” Spade argues against the effectiveness of anti-discrimination laws by generalizing that while anti-discrimination laws have existed for decades on the basis of race, gender, and disability, discrimination and violence against non-white, non-male, and disabled people has not decreased (Spade 81). These anti-discrimination laws, as well as hate crime laws, perpetuate the idea that instances of transphobia exist on an individual perpetrator/victim level and deny the systemic nature of all discrimination (Spade 84). Spade writes, “Narrowing political resistance strategies to seeking inclusion in anti-discrimination law makes the mistaken assumption that gaining recognition and inclusion in this way will equalize our life chances and allow us to compete in the (assumed fair) system” (Spade 86). Equal rights laws fail to consider intersectionality and “routinely fail to protect people with more complicated relationships to marginality” (Spade 87). The failure to provide the equality envisioned by these laws and the people who have fought for them affects the lives of disabled people as well. Due to the high cost of legal fees required to take cases of discrimination to court, many disabled people are unable to even utilize the rights that anti-discrimination and accommodation laws seemingly provide (Spade 82).

### ***1.1.3 State-funded Care and Marriage***

Equal rights laws that concern state-funded care define the possibilities of the sexual and romantic lives of disabled people in the US through the regulation of marriage. Through the language of equal rights, the state surveils the romantic and sexual relationships that disabled people have and can dictate when it is no longer responsible for supporting disabled citizens. After marriage, the cost and caretaking of a disabled adult US citizen transfers to the spouse and away from the state. Disabled adults who would otherwise qualify for the Disabled Adult Child

Benefits upon the passing of their parents lose that benefit when they get married. In a blog post for the Center for Disability Rights, Dominick Evans explains:

People with disabilities need access to services. The exorbitant cost of living with a disability makes it impossible to turn those services down. All of the services I mentioned previously, SSI, Medicaid, SSDI/Medicare, Section 8, Food Stamps, and welfare are impacted, and typically lost, if the person on these programs gets married. (Evans)

While disabled people are not prohibited from getting married, the precariousness of their state-funded care results in a difficult choice. Disabled people are required to choose between two rights: marriage and access to necessary funding to stay alive. For some people this choice is an impossible one to make as they need to be married to their partner before they have sex with them. If they wish to begin or continue their sexual and romantic relationship through marriage, they will lose funding, unlike non-disabled people who are encouraged to marry and do not face the dilemma of choosing between marriage and their health. In this case, marriage is an administrative relationship that disabled people lose money for entering. Through marriage, the state controls the sexual and romantic lives of disabled people receiving state funding. Additionally, this relationship between marriage and a loss of state funding, and laws such as the Disabled Adult Child Benefits that allow the state to define what benefits disabled people have access to, construct disabled people as a burden that is shifted from the parents, to the government, and then to the non-disabled spouse. This construction of disabled people as a burden contributes to the discourse of disabled people as abnormal, undeserving of love, and a drain on society, as most disabled people cannot survive under the individualization of responsibility that neoliberalism requires. Only the disabled who are wealthy and have a high socioeconomic standing can be free from burdening the state, supply their own care, and marry

as they please without the threat of losing their health care. Additionally, for disabled people who have limited access to information regarding their benefits, they may not realize that marriage can result in a loss of state-funded care until after they have married their partner.

#### ***1.1.4 Disability Justice***

Disability justice is a movement that resists the language of equal rights and seeks to improve the lives of all disabled people, not just those seen by the government. In *Care Work: Dreaming Disability Justice*, writer, poet, and activist Leah Lakshmi Piepzna-Samarasinha explores disability justice. Piepzna-Samarasinha turns to Patty Berne, one of the founders of the disability justice movement, who writes:

Disability Justice holds a vision born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life... There has always been resistance to all forms of oppression, as we know through our bones that there have simultaneously been disabled people visioning a world where we flourish, that values and celebrates us in all our myriad beauty. (Piepzna-Samarasinha 21)

Disability justice aims to challenge what Spade describes as the rights framework's inability to address the needs of those who do not hold just one marginalized identity and what Davis views as the normalizing power of equal rights. This othering of disabled people and their resistance to it extends beyond the concepts of rights into sex as well. Disability justice is a more comprehensive movement that acknowledges the importance of sex in the struggle to improve the lives of disabled people unlike the single-issue focused disability rights movement. Adopting a justice framework in place of a failing rights framework is found in other movements such as the reproductive justice movement. The reproductive justice movement formed as a result of the

single-issue focused reproductive rights movement's failure to encompass the needs of people of color, poor people, and others who cannot access the accommodations that white-centered rights struggles are working towards.

### ***1.1.5 Queer Theory, Disability, and Crip Theory***

Many scholars at the intersections of queer theory and disability studies have explored the connections and critiques the fields share. In the entry "Queer" in *Keywords for Disability Studies*, Tim Dean first connects the terms queer and crip as labels:

Historically, the term "queer" was a stigmatizing label that often included disabled people in its purview. A century ago, for instance, someone with a missing limb or a cognitive impairment might be called "queer." In recent decades, sexual minorities have reclaimed "queer" as a badge of pride and a mark of resistance to regimes of the normal, mirroring the embrace of terms like "crip" and the capaciousness of the term "disability" itself. (Dean 143)

Not only do the terms queer and crip share similar connotations of difference, but within both fields of queer theory and disability studies, there is a fundamental critique that the notion of normalcy has unique effects on embodiment and access (Dean 143). Within the field of disability studies, the emergence of the verb form of the term cripple, or crippling, shows the connection to queer studies. Victoria Ann Lewis writes:

Both "cripping" and "queering," as interpretive strategies, spin mainstream representations or practices to reveal dominant assumptions and exclusionary effects. It is important to note that while queer theory originated in the academy, the practice of "cripping" originated in the projects of artists and activists. (Lewis 47)

This shared critique of normalization and interpretation of dominant structures appears most notably in Robert McRuer's "Compulsory Able-bodiedness and Queer/Disabled Existence," which argues that a system of compulsory able-bodiedness is "thoroughly interwoven" with Adrienne Rich's well-known concept of compulsory heterosexuality and they both constitute each other to enforce a heterosexual able-bodied norm (McRuer 301-302). Another disability studies scholar, Anna Mollow, in "Is Sex Disability?: Queer Theory and The Disability Drive," utilizes the work of queer theorist Leo Bersani to argue:

...sex in a sense "is" disability: the concepts of "sexuality" (as it is elaborated in psychoanalytic theory) and of "disability" (as it is figured in the cultural imaginary) share profound structural similarities; in some instances, they could even be described as two names for the same self-rupturing force. (Mollow 287)

This connection between sex and disability means that regardless of the sexual orientation of sexual actors, there is something queer and disabling about sex itself.

### ***1.1.6 Disability and Sex/Sexuality***

Throughout literature on disability and sex, two main themes emerge. First is the narrative that healthcare professionals, family members, and media perpetuate ideas that disabled people are either uninterested, undeserving, or incapable of having sex. Second are the agency and creativity many disabled people express when they form an alternative sexual culture for themselves and their partners. Despite the discourses on disabled sex, disabled people find ways to defy those discourses and break free through engaging in sex. Leo Bersani, in "Is the Rectum a Grave?," theorizes that through sex, specifically in the gay man's rectum, is the powerful ability to destroy the "otherwise uncontrollable identification with the murderous judgement against him" and subjectification of gay men during the AIDS crisis (Bersani 222). Sex, the very



thing gay men were morally berated for during a public health crisis, was not the problem, but a source of freedom. This powerful ability that sex has to combat the judgments against us and bring a sense of freedom to those who can have the sex lives they want becomes visible in the literature that follows on disabled people and their sex lives.

Several disability studies scholars have written on the creativity and agency of disabled sex. According to Robert McRuer, disabled people are “outside of the system of sexuality altogether,” as they are hardly represented in media about sex and paradoxically imagined as asexual and sexually excessive (McRuer 168). This exclusion from the system of sexuality, as explored in this research, brings about feelings of shame and disgust. These feelings drive the creation of what Tobin Siebers calls an “alternative sexual culture based on the artfulness of disability” (Siebers 46). Within this sexual culture, disabled people view their disability as “complex embodiment that enhances sexual activity and pleasure” (Siebers 47). The agency that many disabled people have in rejecting their status as sexual outsiders requires creative ways of having sex and experiencing pleasure that defy the rigid binary of hetero/homosexuality (McRuer 169). This alternative sexual culture includes nontraditional erogenous zones, mental orgasms, and for disabled people who require intense planning for sex, an “ebb and flow” that allows the sexual encounter to bleed into other daily activities and that rejects the strict “assembly line” of penetrative sex (Siebers 48, 49). This alternative sexual culture is relevant to able-bodied people as disability can be acquired by anyone through age or accident. More importantly, Margrit Shildrick argues, “Opening up the meanings of sex and sexuality for disabled people entails rethinking the whole nexus with respect to us all” (Shildrick 166).

Through interviews with disabled women in heterosexual relationships in Portugal, researchers Ana Cristina Santos and Ana Lucia Santos from the University of Coimbra in “Yes,

We Fuck! Challenging the Misfit Sexual Body Through Disabled Women's Narratives," found evidence of family members, healthcare professionals, and others denying the sexuality of disabled women. The women expressed this denial of sexuality in various interactions, including one woman whose family asked why she, a partially paralyzed person, even needs a boyfriend if she cannot experience pleasure, or through healthcare professionals brushing off all questions regarding sex and sexuality these women asked. The researchers found that these interactions coded the women as childlike, innocent, and infantile (Santos and Santos 309-310). However, all of the women interviewed expressed an ability to enact re-sexualization, which "presupposes a creative process of undoing normative sexuality by, for example, removing the focus on genitals during sex and eroticizing other body parts, by adapting practices to the body, or by remapping places to have sex" (Santos and Santos 310). Despite the desexualization of these women, they were able to show agency in creating pleasure for themselves and their partners through the creation of an alternative sexual culture. To reference back to the previous section, it could also be argued that the straight women studied by Santos and Santos, who work to craft fulfilling sex lives despite a lack of clinical support or instruction, are queer or are at least having queer sex.

For one queer and GNC disabled woman named Josie, in J. D. Drummond and Shari Brotman's, "Intersecting and Embodied Identities: A Queer Woman's Experience of Disability and Sexuality," kink was a formative part of her sex life. Instead of completely covering her ileostomy bag, Josie began using electrical tape to hold it in place during sex, which not only made Josie feel sexy, but opened the door for conversation with her partners about other ways to use the tape: "I guess I had been sort of vanilla before, well all of a sudden you have to deal with this altered body, you really don't have a choice but to be creative and come up with things that

work for you” (Drummond and Brotman 542). Although her disability brought new challenges to her sex life, it also opened the door to a more exciting and enriching sex life.

Piepzna-Samarasinha addresses sex and disability in the chapter, “Crip Sex Moments and the Lust of Recognition: A Conversation with E.T. Russian,” where the two women discuss having sex with other disabled partners: “Because I feel like there’s the good stuff, that’s like the secrets of like, wow, the ways that we find to have really amazing hot sex in our bodies is incredible and the kind of like cross-crip solidarity through fucking” (Piepzna-Samarasinha 120). Specifically, through the experience of having sex with other disabled people, the joy, erotic pleasure, and excitement Piepzna-Samarasinha describes when her sexual partner is able to understand her and achieve what they both consider to be “amazing hot sex” holds a power of resistance that goes against the narrative of the desexualized crip.

Personal narratives of disabled sexuality also come from disability sex educators such as Andrew Gurza and Eva Sweeney, a queer woman with cerebral palsy (CP) who utilizes a manual wheelchair and an aide to speak what Eva signals on a letter board, as she is non-verbal. Alongside his podcast, Gurza has written dozens of articles on topics such as working in porn, his experiences with sex workers, and the experience of losing the ability to masturbate as he aged, which led Gurza to co-found Handi, a sex toy company working to create sex toys accessible to physically disabled people. One of his articles specifically addresses the issue of sexual function and occupational therapy. Gurza calls upon all current and hopeful occupational therapists to learn how to help patients with a variety of needs learn to engage in whatever sex acts they are interested in. He argues, “My “fucktionality” should be just as important as my functionality” (Gurza). While creativity and agency are major components in the sex lives of disabled people, the reality of needing assistance or occupational therapy to achieve certain types

of sex is undeniable. When Sweeney was a guest on Gurza's podcast, she discussed the agency she's taken to have a sex life: "I think that attitude of 'we will just figure out how you can do it' as an adult, has been the foundation of my sex life, when I want to do something new in bed I just brainstorm to figure out the best way for my body" ("A Chat with Pleasure Professional Eva Sweeney").

The literature on disability and sex shows that personal narratives are important to understanding disabled people's lives and disabled sex. David Mitchell and Sharon Snyder consider personal narratives, or disability life writing, integral to critiquing mainstream disability narratives (Mitchell and Snyder 128). Disability life writing such as memoirs "exposes the web of seemingly benign neoliberal administrative structures that often ensnare rather than support disabled people in disciplinary relations" (Mitchell and Snyder 128). In this thesis, personal narratives have shown the same exploratory possibilities, providing a first-hand account of how these neoliberal structures, such as equal rights codified by the ADA, fail to support disabled people. Personal narratives also revealed how disabled people craft a do-it-yourself (DIY) sexual culture as a form of resistance to discourses on disability that enforce the idea of disabled people as an asexual or hypersexual burden on society.

This review has shown that many disability activists and disability and legal scholars argue that the framework of equal rights and ADA accommodations for disabled people inadequately serves disabled people's needs and helps support the discourse of disabled people as abnormal and undeserving of sex/love. Disabled people resist these discourses through creativity and agency to create an alternative sexual culture, without the help of medical professionals and others close to them. This resistance exists both in the DIY sexual culture that disabled people craft in their personal lives and in the discourses on disabled sex by disabled sex

activists and educators such as Gurza and Sweeney when they openly talk about their own sexual experiences and share interviews with other disabled people about their sex lives with their audiences.

### *1.1.7 Research Questions*

Considering the scarcity of understandings of disabled people beyond an equal rights framework and the dominant negation of their sexualities in social imaginaries, this thesis has analyzed personal narratives of queer disabled sex, asking:

- (1) How do queer disabled people talk about sex?
- (2) How do they describe the ways sex affects their perceptions of the self and the body?
- (3) How do they describe the ways sex affects their perceptions of their relationships to others?

Analysis of their narratives with a focus on disabled people's descriptions and the meanings they create related to sex, perceptions of self, the body, and their relations to others has enabled me to theorize what queer disabled sex does: how creativity, agency, resistance, and other forces surface through queer disabled sex. The feelings and emotions found in disabled sex and talking about disabled sex are relational, with partners affecting partners and narrators affecting their audience and vice versa. Emotions offer a path to answering these questions and understanding disabled sex, as emotions support and move through discourses that negatively affect disabled people's sex lives and are produced and move through disabled people during sex and between disabled speakers and their audiences as they talk about sex. In order to answer these questions, I considered how discourses on disabled sex produce and are produced by affect, by close reading and analyzing personal narratives that include in-depth, detailed discussions by queer disabled people about their sex lives. This thesis focuses on physical disabilities as

physically disabled people are excluded in unique ways that connect explicitly to desirability and sex. However, I do not reject the existence of mental illness and neurodivergence among people with physical disabilities and believe future research should consider what ways, if any, disabled people discuss how mental illness and neurodivergence affect their sex lives and manifest in bodily reactions and sensations during and around sex.

Answering these questions is valuable on a larger scale as this research aids in redefining sex and pleasure for everyone, regardless of their identification with disability or not. This thesis addresses, among other feelings, the role of shame in relation to hindering great sex and how positive sexual experiences can help thwart feelings of shame, which apply to more than just the disabled community. Also, by investigating the ways that disabled sex can reject mainstream notions of what constitutes sex, such as timeframes, erogenous zones, and certain sex acts, this thesis offers important contributions to work that encourages all of us to think creatively about sex and pleasure.

## **1.2 Methodology**

### ***1.2.1 Affect Theory***

The current literature on disability and sex addresses how healthcare professionals and caretakers can ignore disabled people's desire to have a fulfilling and pleasurable sex life. This thesis adds to the scholarship on queer disabled people's sexuality and pleasure by exploring the conscious and unconscious feelings, emotions, and affects they describe when discussing sex. Affect theory, or what Ann Cvetkovich calls the affective turn in her Introduction to *Depression: A Public Feeling*, is "inspired by the Deleuzian theories of affect as force, intensity, or the capacity to move or be moved" (Cvetkovich 4). It is important to note the difference between affect, which is "precognitive sensory experience" and emotions and feelings, which involve

“cultural constructs and conscious processes that emerge from them, such as anger, fear, and joy” (Cvetkovich 4). Cvetkovich explains further that she is using the term affect in a more general way to encompass “affect, emotion, and feeling and that includes impulses, desires, and feelings that get historically constructed in a range of ways” (Cvetkovich 4). Disabled people can face exclusion both socially and structurally due to inaccessible areas and activities. Social exclusion can be fueled by emotions, like pity, disgust, and fear, as well as fuel emotions, such as shame, sadness, and self-hatred.

Emotions are also connected to inclusion. Disabled people may find inclusion with each other or in accessible able-bodied spaces, like in their personal and sexual relationships, community gatherings, and activism. This inclusion fuels and is fueled by happiness, passion, love, and pleasure. The notions of the norm and equal rights inform structural exclusion and who can surpass it. Considering this desire to conform to the norm that Davis cites as a reason able-bodied people pity disabled people, the language of equal rights and the way it paints disabled people as abnormal contributes to medical and social discourse on disabled people as desexualized and infantilized. Disabled people resist the consequences of abnormality through agency to develop a pleasurable and creative sexual practice. To identify and name which affects surface when disabled people face exclusion and inclusion to sex, it is necessary to understand why disabled people are so prone to the concept of affective “stickiness.”

A concept in affect theory that is important to understanding the possibilities for work on affect and disability is Sara Ahmed’s notion of stickiness. The pity or disgust that ableist people feel toward disabled people, which contributes to their mistreatment and exclusion from many aspects of society, is linked to how stereotypes and negative meanings become attached to them as a sticky sign. The sign used in many of her examples is the slur Paki, which is used in the UK

for Pakistani people or often any Middle Eastern person. A relevant example for this thesis could be the term cripple, retard, or just the term disabled. Consider stickiness as what happens to the surface of an object/sign over time, what Ahmed calls “past histories of contact” and not literally the object’s surface (Ahmed 90). Stickiness can bind other meanings and signs together through repetition. The history of the use of the term Paki, in a negative way, reinforces the term’s status as sticky, connecting not only other immigrants and Middle Eastern people to the term over time, but also connecting negative meanings such as dirty, immigrant, and outsider to the sign in an unspoken way (Ahmed 92). The unspokenness of the other meanings is crucial, as “it is the concealment of such associations that allows such signs to accumulate value” (Ahmed 92). Ahmed argues that disgust is performed when someone is named as a sticky sign, like Paki or cripple, and that disgust “both lags behind the object from which it recoils, and generates the object in the very event of recoiling” (Ahmed 93). Ahmed explains how the performance of disgust creates the disgusting object as it names it and must rely on the pre-existing norms that the disgusting sign is violating (Ahmed 93). Ahmed makes clear that the performativity of disgust goes beyond sticking disgust to the sign; it also is “an attempt to expel something whose proximity is felt to be threatening and contaminating” (Ahmed 94). Others who witness the performance of disgust against the sign repeat it, leading to a collective casting out of the named sign. The disgusted bind together, situating the named sign in opposition to them, as abnormal (Ahmed 94). Disgust implies less-than-human, abnormal, and bad (Ahmed 97). This association conversely situates what is human, normal, and good as non-disabled, white, straight, male. Therefore, Ahmed maintains that feminized and racialized subjects will always be stickier than their white counterparts (Ahmed 92). The same stickiness applies to disabled people, to whom negative signs are attached, through, for example, the discourse on productivity and efficiency



that paints disabled people as a burden to society, the need for exclusion of disabled children from able-bodied children in school that others them, and Westernized standards of beauty that signify what types of bodies are beautiful or ugly. Because of their marginalization, these signs stick to the bodies of disabled people despite advancements in civil rights laws regarding disabled people, as the laws cannot address the stickiness of a sign, or its past histories of contact. The past histories of contact of doctors' disregarding disabled people's sex lives sticks to them as asexual; of only seeing able-bodies represented in porn, tv, and film sticks to them as incapable of having sex; and of disabled people being denied agency and choice by the state when it comes to funding, marriage, and care sticks to them as infantile and childish. Affect, like the feeling of disgust, is not just inside of a person; it has the power to move through someone, travel to others, and stick to someone else, making other affects move through them, travel to others, and stick again to someone else. Affect is relational, and that is why it is important to consider the ways affect moves through people to others when discussing queer disabled sex. Sex is an intimate part of many people's lives and relates to their sense of self and their relationship to others. Through sex, queer disabled people consciously and unconsciously resist medical and social discourses on disabled sex.

### *1.2.2 Personal Narratives of Queer Disabled Sex*

I am tracing affect and emotions from first-person narratives as I recognize that healthcare professionals dominate the discourse on disability, and I trust that queer disabled people are the best to look toward to understand what their sex lives are like. The feelings they experience in relation to sex come through in the words they use and the way they tell their stories through poems, essays, zines, or into a microphone on recording. Self-produced podcasts, zines, and writing offer a casual, perhaps even friendly, environment and may create more

vulnerability and emotional expression. I have three sources: Andrew Gurza's podcast *Disability After Dark*, a collection of zines called *The Ring of Fire Anthology* by E. T. Russian, and the poems and essays of Leah Lakshmi Piepzna-Samarasinha. By utilizing a variety of source formats, this thesis is able to explore an expansive level of personal narratives which includes both self-produced and traditionally published works.

Podcasts are a useful avenue for finding personal narratives of disabled queer sex. There are several podcasts hosted by queer disabled people, and the intimacy found within having a private conversation or just sitting in front of the microphone to record can allow for vulnerable and honest conversations about queer sex. Using search terms individually and together, such as disability, disabled, queer, sex, and LGBTQ, has helped me select the podcast *Disability After Dark*. Throughout several of the over 200 episodes of *Disability After Dark*, Andrew Gurza, a white queer man with cerebral palsy living in Toronto, details recent sexual hookups he has had, interviews sex workers he has been a client of, and even talks about his experiences starring in a porn. Gurza's frank discussions are full of discussions of the feelings brought on by disabled sex, something he has intended to focus on since the very first episode of the podcast. For my analysis I chose four episodes of Gurza's podcast. Gurza is alone in two of the episodes, recounting recent hookups, and the other two episodes are interviews that he does with two different non-disabled long-term sexual partners. I have transcribed, closely read, and analyzed these interviews for affective experiences that show how Gurza and his partner relate to one another and what affects move through and between them when they have sex and when they reflect on it. These affective experiences are defined as moments that Gurza or his partners describe feelings and emotions that affect or are affected by the sexual experiences being discussed.

I also analyzed a collection of zines called *The Ring of Fire Anthology* by E. T. Russian. Russian is a white, queer woman who became a double amputee in a train accident. Shortly after her accident, she began to produce punk zine content that called for a disability revolution, detailed her sex life and experiences with Bondage and Discipline, Dominance and Submission, Sadism and Masochism, (BDSM), and told fantasy stories of anarchist cripples engaging in BDSM after bombing the White House. Russian's work offers a look into the ways that BDSM can produce different affects and relationships among the people involved that my other narratives do not address. Analyzing a zine offers a distinctive example of a personal narrative as zines are self-produced content not regulated by a publisher, and the authority on the zine's topic is the creator. Considering the power of disability life writing to disability studies and the DIY nature of disabled sex, a self-produced zine is a powerful avenue to understand disabled sex. I have analyzed several excerpts from the anthology where Russian is writing about her sex life, her own struggles with shame about her disabled body, and her journey with eroticizing her disabled body.

Finally, through poems and essays about sex as well as a conversation with E.T. Russian about cross-crip sexual experiences, I have analyzed some of the work of disability justice activist and artist Leah Lakshmi Piepzna-Samarasinha, a South Asian American queer woman who deals with a chronic pain disability and writes about pleasuring herself and others, how PTSD from sexual trauma affects her, and how disabled people connect and share intimate, unique moments of recognition through sex. In Piepzna-Samarasinha's work, I have utilized several excerpts from poems and essays in addition to a transcript of a recorded conversation between her and E.T. Russian to analyze how her chronic pain influences her sex life and how she discusses why she prefers sex with another disabled partner than with a non-disabled partner.

I have read all the objects of analysis for negative feelings relating to the discourses on disabled sex I have mentioned throughout this proposal and for positive and negative feelings relating to avenues of resistance through sex. This reading involved the transcription of any textual or auditory narratives, and an annotating of all transcripts and written work. In the following chapters I have connected the affects identified to the discourses I argue are affecting and being affected by my narrators and the queer disabled sex they are having.

### *1.2.3 Discourse Analysis*

In order to understand and evaluate the ways in which disabled people are affected by the way society constructs them as disabled people, it is important to understand discourse analysis and some of the literature on the creation of discourse. In Sara Mills' chapter, "Discursive Structures," discourses are described as "highly regulated groupings of utterances or statements with internal rules which are specific to discourse itself" (Mills 43). In this thesis, attention to discourse allows for study not only of what is being said about disabled people and what they are saying about themselves, but also of whose voices are valued and what types of things can be said about disabled people. Mills describes how speakers that cite taboo topics such as sex or the voices of the insane are not valued in discourse and their utterances are made impossible, unsayable, and unthinkable according to the rules of discourse. Healthcare professionals who have a strictly medical view of disabled people have more value in the discourse on disability than disabled people themselves. If they view disabled people as wrong bodies in need of a medical cure or refuse to view disabled people as people interested in sex, then these negative stigmas connect to them as sticky subjects and affix labels such as asexual and abnormal to them. Social and medical discourses on disability do intersect, leading doctors to make medical decisions that further contribute to discourse on disabled sex as impossible, wrong, or abnormal.

These associations perpetuate a feeling of disgust toward the disabled body and limit emotions about disabled people's sex lives to pity if they are assumed to be unable to have sex or lead to a performance of disgust which asks others to be a community of witnesses to the casting out of disabled bodies from sex.

Researchers in critical disability studies have sought to understand the connection of discourses of disability to affect. In "Feeling Disability: Theories of affect and critical disability studies," Dan Goodley, Kirsty Liddiard, and Katherine Runswick-Cole were brought to affect theory through an ongoing research project about children with life-limiting/life-threatening impairments (LL/LTIs). In order to "combat dangerous discourses" on what a fulfilling and productive life is in a neoliberal society, they researched the "lifeworld" of children instead of clinical topics (Goodley et al. 198). These dangerous discourses on quality of life also appear in Allison Kafer's book *Feminist, Queer, Crip*. Kafer describes how the future imagined for her as a disabled woman "casts disability as pitiable misfortune" (Kafer 2). The researchers' desire to turn to affect theory to combat these discourses comes from a "firm conviction" that researchers should be mindful of the way that the theories they use conceptualize their subjects (Goodley et al. 206). Affect theory is a valuable place to look as it privileges what is happening in the emotive and relational world of these children who are often excluded and viewed as contrary to neoliberal ideas of efficiency and independence. These children are affected by their experiences as LL/LTIs and their growing awareness of being labeled to others as LL/LTIs. Although this research is not yet complete, the authors argue that looking into their emotive and relational world can be bring new insight into how these children feel about their labels, how they resist the definition of a "sick kid," and how they process parts of their daily life. These children are not

just internally feeling emotions in their everyday life, but affects are moving through them and to others, affecting the way they view the world and others.

Affect and discourse are crucial to the topic of queer disabled sex for many reasons. As discussed earlier, queer disabled people are sticky signs, and because of the discourses on disability and sex, certain labels such as asexual, infantile, and undesirable stick to disabled people. Disabled people have feelings about the labels being stuck to them, and they have feelings about resisting those labels. Feelings from others can help make these labels real, such as Ahmed's example of disgust creating negative associations for disabled people as well as Davis' idea that the idea of the medicalized norm requires able-bodied people to pity the disabled in order to reaffirm their own normality. When disabled people resist through sex the labels put onto them through discourse, they are motivated by feelings such as shame and disgust and have other positive feelings as a result of those acts of resistance.

In this thesis, I analyzed the transcripts and texts of my selected personal narratives at several levels. I analyze my chosen texts for affective experiences, or narratives where my disabled narrators are talking about sex and specifically name emotions they experience in relation to the sex they are having. I have looked at words that queer disabled people use when talking about their sexual experiences. I also theorized connections between what they are describing in relation to their sex lives and what they are feeling by annotating for affects and feelings named through certain emotion words such as happiness, joy, relief, frustration, anger, disgust, and shame. I also analyzed ways that affect is relational through moments between partners and between narrators and their audiences to understand how queer disabled sex can produce and shift affects and discourse. In this thesis I have connected feelings described by my narrators to the discourses on disabled sex discussed in this literature review. These connections

are found in their narratives of how certain labels made them feel, such as asexual, abnormal, childish, or undeserving of sex as well as their narratives of resisting those labels by creating fulfilling sex lives and representing them in discourse.

### **1.3 Conclusion**

Disability affects millions within the US, and since the 1970s, disability rights activists have fought for equality for disabled people through access to institutions and state-funded care for citizens. This framework has been a major part of the disability rights movement, which shares a white, male single-issue focus with the field of disability studies. In order to broaden the field of disability studies, more intersectional work needs to be done. The equal rights framework obscures the intersectional nature of oppression and further marginalizes disabled people who do not fit neatly into the state-mandated definitions of disabled. The violence of this framework extends to the lives of non-disabled people, as it dictates a norm that we all must work toward and spend money to achieve. In order to resist the equal rights framework as a primary way to improve the lives of disabled people, we must also investigate the parts of disabled people's lives that don't fit neatly into state-approved areas of intervention. Sex is a valuable avenue to resist the state and the discourses on disability which work to exclude disabled people. Discourses on disability can also be expanded by talking about sex and making unspeakable taboo topics speakable. To think of sex strictly in a reproductive and clinical way is anti-queer and anti-feminist, as it adds to a discourse around sex that denies pleasure entirely. Equally important, clinical and reproductive discourse denies access to sex for those who are not able to or interested in giving birth or are not able to produce genetically valuable bodies for the state. By narrowing the discussion around sex to the experiences of queer people, this research highlights the unique ways that queer disabled people, who are sexually and physically abnormal in an

able-bodied and heteronormative society, resist intersecting oppressions and analyzes queer relationships and community as sites of growth, care, and new possibilities. My focus on the DIY sexual culture of queer disabled people reveals avenues to resisting harmful discourses about sex and how resistance feels. Sex, disability, and queerness are affectively rich experiences and topics, where negative affects such as shame, loneliness, and anger and positive affects such as pride, belonging, and love exist.

Through my thesis, I show how through queer disabled sex affect and discourse inform each other and how queer disabled people craft fulfilling sex lives for themselves using their own creativity and agency. The second chapter of this thesis, “Shining a Bright Light on Sex and Disability,” engages with Gurza’s work on his podcast, *Disability After Dark* and explores the presence of what Gurza calls the “Third Bedfellow of Internalized Ableism.” The chapter depicts how Gurza’s sexual experiences have helped him to overcome feelings of inferiority about his disabled body that are influenced by ableism and normative gay masculinity. The third chapter of this thesis analyzes Russian and Piepzna-Samarasinha together and identifies a cross-crip praxis of love as a powerful force to combat the shame experienced by both narrators and explores both narrators’ feelings about the process of eroticizing their disability. Through my analysis of these personal narratives of queer disabled sex, I conclude that sex and pleasure hold valuable power in combatting the shame associated with non-normative bodies, which is applicable to all people, regardless of the type of marginalization they experience. This thesis also concludes that the DIY sexual culture crafted by queer disabled people is a useful template for pushing the boundaries of what sex and pleasure can be and should influence how we all think about and experience our sexuality.



## 2 SHINING A BRIGHT LIGHT ON SEX AND DISABILITY

Andrew Gurza, a white queer man with cerebral palsy from Toronto, covers topics on his podcast *Disability after Dark* (2018 to present) that range from accessible sex tips, interviews with other sex educators, history of disability and sex, to personal narratives of his own sexual experiences. With over 200 episodes currently available, Gurza's format varies, with some episodes consisting of Gurza talking into the mic alone about his recent hookups or past experiences and others centering interviews with disabled content creators and even able-bodied people about how they think their life might change if they became disabled. He records from his bedroom, and writes, records, and edits the episodes by himself. The frankness and openness that Gurza shares with his audience about his sex life is paired with his understanding of sexual ableism from his work as a sex educator, which makes Gurza's podcast a valuable resource for anyone looking to learn about queer disabled sex and the way it interacts with internalized ableism. Whether Gurza is talking about moments that can be uncomfortable or strange or discussing the pleasure and positive connections he makes through sex, he maintains his relationship to the audience as one that he describes as "crippy and comfortable" ("Episode 98" 00:05:55).

Gurza often says in his podcasts that disabled sex is the best sex you are not yet having, and he acknowledges that his intentions are to expand the discourses on disability and sex: "I've always said, I want to shine a bright light on how disability and sexuality really truly feels and sometimes it can feel kind of wonky" ("Episode 125" 00:01:57-00:02:04). Gurza is aware of the sheer lack of media about disability and sex and has contributed greatly to that deficit with over 200 episodes of *Disability after Dark* available. This chapter explores three main affective experiences that came to the forefront through a close reading of four of Gurza's podcast

episodes: the appearance of what he calls the “Third Bedfellow” of internalized ableism, the pleasure derived from rejecting that unwanted bedfellow, and the alternative sexual culture that Gurza has created. Affective experiences are parts of Gurza’s personal narrative where he names and discusses moments or events that produce named feelings or displays of emotions. The feelings produced by these affective experiences include unease, anger, satisfaction, and confidence. Some of these experiences constitute not only the DIY sexuality that is discussed in this research but also the alternative sexual culture that Tobin Siebers in “A Sexual Culture for Disabled People” cites as a unique place where new possibilities for sex and pleasure become possible. Sexual culture is a term that Siebers uses in contrast to sex life that “references the experience of sex itself” (Siebers 39). The use of the term sexual culture is necessary when discussing disabled sex:

On the one hand, the stigma of disability may interfere with having sex. On the other hand, the sexual activities of disabled people do not necessarily follow normative assumptions about what a sex life is. Neither fact means that people with disabilities do not exist as sexual beings. One of the chief stereotypes oppressing disabled people is the myth that they do not experience sexual feelings or that they do not have or want to have sex--in short, that they do not have a sexual culture. (Siebers 39)

This chapter focuses on some of Gurza’s personal narratives of his sexual culture, which Gurza explores in addition to disabled sexual culture at large through his podcast.

## **2.1 The Third Bedfellow That is Internalized Ableism: Unease, Frustration, Anger**

While Gurza details sexual experiences that are full of positive feelings, he does not shy away from the negative feelings that arise in his queer disabled sex life. These negative feelings,

such as discomfort, frustration, and anger, come from what Gurza calls the “Third Bedfellow” in the episode “I had GREAT SEX TWICE... and then I got Mad”:

...both tonight and last time I had a Third Bedfellow join us and my internalized ableism was that bedfellow. It kicked in hard. Things just started to feel weird. I started to feel uncomfortable and uneasy in the bed. I didn't feel sexy. I didn't feel good. I didn't feel bad, but I didn't feel great either. I felt really uneasy and I was really aware of the fact in this moment with this guy that I was disabled. (“Episode 125” 00:11:13-00:11:43)

Thinking back to Ahmed's concept of stickiness, this bedfellow represents the stereotypes and negative meanings that have been attached to disabled people through past histories of contact. In those moments, Gurza centered his disability in his sense of self and could only think of the negative stigmas attached to that sign that marked him as a burden sexually, as not sexually attractive, and as less of a man. The Third Bedfellow has entered the room, representing Gurza's powerful personification of the complicated and oppressive experience of internalized ableism. Then, instead of a separate party expelling Gurza from the sexual culture, Gurza casts himself out and inflicts disgust on himself. As Ahmed says, the performance of disgust relies on pre-existing norms that the disgusting sign is violating (Ahmed 93). Gurza is not simply disappointed that he could not get his partner to orgasm; he is experiencing and thinking through all of the ways that his disabled sex life is different and worse due to his disability. As Ahmed argues, the performance of disgust in response to a sticky sign works to cast out the sticky sign as abnormal and wrong. Gurza experiences an expelling of the self as he describes dissociating when this happens: “It feels like you're sitting there watching yourself have sex and watching your disabled body do this sexual thing, but you can't really do anything about it and knowing that you can't do much feels really strange. It's an out-of-body experience steeped in ableism”

(“Episode 125” 00:13:27-00:13:48). Watching himself have sex, Gurza has cast his disabled body away from him, disgusted at the trouble he is having during sex. The Third Bedfellow has entered the bedroom pushing Gurza out into a dissociative state where he is stuck in a place of self-disgust and ableist inadequacy. Through disassociating and leaving his own body, Gurza has taken on the dominant ableist view of himself that results from compulsory able-bodiedness that Robert McRuer discusses in “Compulsory Able-Bodiedness and Queer/Disabled Existence”: “A system of compulsory able-bodiedness repeatedly demands that people with disabilities embody for others an affirmative answer to the unspoken question, Yes, but in the end, wouldn’t you rather be more like me?” (McRuer 304). In this moment, viewing himself with disgust from above, Gurza would rather be able-bodied, or at least have a differently disabled body, one that allows him the arm strength and dexterity to give a hand job to his partner.

Despite how much Gurza is being affected by the self-disgust he is experiencing, he does try to resist and push on. Gurza describes harnessing the anger created by his inability to perform sexually in the same ways as other gay men:

I’ve seen guys jerk themselves off in certain ways and I’ve seen it in porn, and I’ve seen it in real life and I just can’t do that. In this weird moment with this guy tonight, as great as it was, I felt emasculated because I knew that I couldn’t get him off that way. I just knew I couldn’t. It’s kind of funny because the angrier I got about it the more I tried to use that anger to create friction with us and I tried to squeeze his dick a certain way. I tried to stroke it a certain way with the anger. I tried to use the anger to create a fast motion and I just couldn’t do it. My body just said no. (“Episode 125” 00:23:06-00:23:48)

The discourse created by past histories of contact with pornography that shows gay men able to perform in a specific way sexually sticks notions of weakness and emasculation to Gurza, whose marginalization as a disabled queer man makes him prone to these negative associations. In this example, pornography is named as a source from which Gurza's perceptions of masculine sexuality and his identification with being unable to model masculinity are produced. Tom Shakespeare's "The Sexual Politics of Disabled Masculinity" theorizes why disability and masculinity are positioned in opposition to one another. Considering the well-theorized point that "male identity rests on separation from, and superiority to, 'the other'" (58), Shakespeare argues, "[i]n some ways, disabled men are never 'real men': they do not have access to physical strength or social status in the conventional way" (60). Gurza's inability here to use his physical strength to create enough friction to give a viable hand job complicates his identity as a "real man," and he became even more frustrated and angry as he tried to push past his inability to give a hand job. This is an example of reliance, or the first of three dominant strategies employed by disabled men trying to reconcile their disability and masculinity:

reliance, which entailed men internalizing traditional meanings of masculinity and attempting to continue to meet those expectations... Those who followed the second strategy encountered the most problems, due to their inability to meet social standards of masculinity. Often this resulted in anger, frustration, and depression. (Shakespeare 59)

When the hegemonic ideals of masculinity are internalized by disabled men, like Gurza is doing here, they do not find relief from the negative feelings of being the Other but instead fall deeper into frustration with their inability to be a "real man."

The all-consuming and unstoppable nature of the emotions brought on by this unwanted bedfellow stand in sharp contrast to the way that Gurza talks about being consumed by pleasure

or overcome with euphoric feelings of power during other hook ups that are explored in the following section of this chapter. Gurza makes a point to acknowledge that no amount of familiarity with the bedfellow or the lies it perpetuates can stop it:

It pissed me off because this stuff doesn't strike you until it strikes you. It just comes up out of nowhere. You can be having a totally fine moment, and this is stuff that I've been dealing with for 20 some odd years and I always kind of think about it but when I'm with somebody that I really like, I put it in the back of my mind and I just go to town. But tonight, for some reason, it was right there, front and center, and the last time too.

("Episode 125" 00:24:10-00:24:33)

While this unwanted bedfellow left Gurza feeling angry and uncomfortable, Gurza is aware that he is able to keep the bedfellow of internalized ableism away most of the time by focusing on the pleasure he is giving and receiving from someone he has a strong connection to. Gurza is grappling with not only the presence of the bedfellow but also his own understandings of how and why it is there. The bedfellow is able to appear out of nowhere despite always being in the back of Gurza's mind, waiting to sneak up on Gurza during sex and wrap him up in a toxic state of disassociated self-disgust.

## **2.2 Kicking out the Third Bedfellow: Power and Pleasure from Defying Sexual Ableist Stereotypes**

Throughout all four of Gurza's episodes analyzed for this chapter, Gurza expressed that the pleasure he felt during sex was specifically tied to the resistance of ableist stereotypes. Gurza talks about how in times where he couldn't perform certain sex acts and he could have fallen into the trap of internalized ableist self-disgust, he gave his partner pleasure and received praise for it:

While I can't thrust my cock, I've learned through analingus how to thrust my tongue really well and this is truly my favorite position to be in with a partner because I get to discover each and every time how much power I actually have in fucking with my tongue. When I give a good rim job I love when my partner moans. I love hearing that moan because again, it tells me that I've given pleasure and that's an important sound for me because I'm always worried I'm not giving enough pleasure. ("Episode 98" 00:36:23-00:36:58)

By performing an accessible sex act such as rimming, Gurza does more than provide pleasure to his partner; he also resists the ableist notions that he cannot give someone sexual satisfaction. The feelings of pleasure his partner expresses through sound move through Gurza, making him feel powerful and happy. This type of connection that comes from Gurza successfully giving pleasure to his partner with his disabled body and the effect it has on quelling Gurza's internalized ableism is uniquely available through sex. The pleasure is enhanced for Gurza as this sexual connection does more than just feel good: it feels like defying the discourses on disabled sex that work to exclude him from sexuality entirely.

The visual aspects of sex also serve to enhance the pleasure Gurza feels as he defies the negative stigmas about disabled sex. His partner's pleasure again serves a vital role:

I always love when a guy is bouncing on my cock, especially as a disabled person. To see this happening, to like watch somebody bouncing on your dick is really awesome. Seeing my lover insert my cock inside of themselves and have that moment of pleasure on their face where insertion is happening is just priceless. Because, again, it tells me that I can give somebody pleasure and it breaks down the falsehood that I'm not about to provide you pleasure and proves that I can. And knowing that I'm giving someone pleasure that

way, the look on their face that my crippled cock did that, is just the best look ever.

(“Episode 98” 00:37:41-00:38:24)

The pleasure that his partner experiences, and the positive feelings of pride and sexual power that Gurza feels as a result, are intensified by their relation to stereotypes about disabled sex. Gurza has something to prove to his partners and to himself: he can access a pleasurable sex life, but it just requires a bit of effort and creativity. Once he can prove that, as evidenced by the look of pleasure on his partner’s face, the pleasure Gurza feels having sex grows stronger. By soaking in the power he feels by pleasing his partner with his “crippled cock” and not in spite of it, Gurza ties his identity as a queer cripple to his sexual power.

Gurza also talks about how the way a partner makes a point to praise him for his sexual performance can work against ableist misgivings that Gurza might feel about his sexuality. When one of his partners calls him a “good boy,” Gurza says,

It also fed my internalized ableism and it calmed that right down. Because as disabled people, everywhere we look we are bombarded with all the ways we are wrong or problematic, and as I’ve shown throughout doing this podcast, this can happen in the bedroom too. These ideas that we are wrong, and we are not okay and sexual ableism happens at almost every turn. And we never hear that we are doing something good.

(“Episode 98” 00:39:09-00:39:35)

The transactional nature of sex, where the pleasure experienced between Gurza and his partner produces affects, feelings, and emotions that move through and between them calmed Gurza and worked to combat the negative discourses about disability that Gurza and other disabled people face. While making his partner feel pleasure, Gurza receives the much-needed assurance and approval that his partner is giving to him through the phrase, “good boy” which pushes away



Gurza's feelings of internalized ableism. Sex here engages with internalized ableism in a productive way, where pleasure is enhanced due to its contrast to the discourses on disabled sexuality as problematic. Sexual experiences that feel good for almost everyone, such as receiving praise from a partner, become more powerful when that praise works to counteract the sexual ableism that Gurza addresses often on his podcast.

### **2.3 Alternative Sexual Culture and What Becomes Possible: Confidence and Connection**

The existence of a DIY sexuality where creativity and agency are used to craft fulfilling sex lives, or an alternative sexual culture like Tobin Siebers theorizes, appears throughout Gurza's work. One of the identifying factors of disabled sexual culture that Siebers writes about is how sex is changed temporally for disabled people:

Because disabled people require advanced planning to have sex, their sexual activity tends to be embedded in thinking about the day, not partitioned as a separate event...Moreover, the myth that sex must be spontaneous to be authentic does not always make sense for people who live with little privacy or whose sexual opportunities depend on making arrangements with personal attendants. (Siebers 49)

For Gurza, the anticipation of a hookup that has been planned a few weeks out is paired with his need for a care attendant to help clean him:

I knew that the attendant knew why they were there to help me, and as I've said before, having them know that they are there to help me get ready for me to suck some dick makes it all the more exciting. Because I'm like, "Yeah! Look at that attendant, I am going to blow this person and you're going to help me get ready. So, thanks for that." There's a power in being able to say to your staff member, "help me with this please." It's part of the anticipation of the event for me as a

disabled person having sex and it just felt really nice to have a staff member understand that sex is part of my life and sex is part of my routine in a way. They can help me feel confident to have sex by making sure that I'm clean and prepped and ready and that part of the whole ritual is nice too. ("Episode 98" 00:15:07-00:15:55)

The possibilities for what sex can include extends past the foreplay to orgasm range and includes the feelings of anticipation and excitement that are standard for sex that must be planned in advance and requires the help of a staff member. Not only does Gurza describe getting to enjoy these feelings of excitement during the day, but he also takes satisfaction and feelings of power from having a staff member come to help him prepare for a hookup. Not only is the staff member doing something practical for Gurza to prepare for sex, but their witnessing of the existence of his sex life pushes against those discourses of disabled people as asexual and makes Gurza feel confident. The public acknowledgement by a staff member of something ostensibly private, like sex, is not shameful for Gurza but instills confidence in him.

In addition to figuring out other ways to give pleasure such as analingus instead of hand jobs, this DIY sexuality for Gurza also involves the inclusion of mobility equipment into his sex life, both for him and his partners. When a sexual partner helps Gurza into his hoist, which is used to transfer him from his motorized wheelchair into his bed, Gurza points out how different this feels from when a staff member helps him into bed using the hoist:

These moments are typically not usually sexy as I mentioned before. They are often predicated on care and needing care, but this time was different. With this

particular lover every time it is a little bit different, and he puts each strap of my sling on the hoist with such a careful perfection and precision that it's really, I've never been turned on by being strapped into my hoist ever, but this had me going for sure. ("Episode 98" 00:28:41-00:29:11)

Something that Gurza experiences at least twice a day, being brought in and out of bed by the hoist, takes on new meaning when it is done by an experienced and careful partner. Instead of the hoist being a sexual mood killer, something Gurza does mention occasionally in other episodes, the hoist and the act of being strapped into it excites Gurza sexually. Gurza's sexual experiences with the hoist include more than how the hoist enables him to get into bed, but how the hoist also helps his able-bodied partners be more physically comfortable during sex, allowing for extended penetrative play. In a conversation between Gurza and Jon Shield, a friend and sex worker he works with, they discuss the hoist:

Jon Shield: The hoist was a little bit of a challenge, but also kind of fun because not only did we get to lift you up into it, but I believe I was using it to support myself while I was riding you too?

Andrew Gurza: Correct, and that's a thing we do regularly now when we have sex which I really enjoy because those pieces of equipment are not usually talked about in sex play. ("Episode 170" 00:14:41-00:15:05)

The creativity that Gurza employed by encouraging his partner to utilize mobility equipment to make sex more comfortable for both of them makes the sex they have more pleasurable and unique to Gurza's disability. Without his disability, that equipment

would not be readily available, and Shield may not have experienced what becomes possible when utilizing this type of equipment.

Gurza often contrasts his sex life with his experiences with staff members and in clinical settings. Here, he talks about how he appreciates the tactile nature of his hookups with one regular sex partner, named Raj:

What I like about sex with you is there's a lot of grabbing. There is a lot of tactile pressure and I think for me as a disabled person I don't get that pressure a lot. People touch me out of necessity and out of fear...I think what's really powerful about that is that like you could grab me, but I can also grab you whereas in so many instances a personal care attendant of mine is grabbing me in a rough way... they can grab me with strength but technically if I did the same to them, it would be like, "Woah. you just violated so many rules." ("Episode 117" 00:21:57-00:28:30)

Due to the understandable boundaries between care attendants and Gurza, his experience with tactile pressure is limited and one-sided. Gurza expresses a need for reciprocal touch, to be able to push back against his partner in a way that feels good and feels strong. To move from mostly being touched out of necessity and fear to being touched out of passion and desire is incredibly powerful.

Another way that Siebers marks the sexual culture of disabled people is alternative erogenous zones: "when touching is involved, the places being touched may not be recognizable to other people as erogenous zones" (Siebers 49). Gurza talks about his own alternative erogenous zones when referencing parts of his body that he has desexualized because of their regular contact with care attendants: "He's putting his hands all up

between my legs, touching my inner thighs, all these places that I honestly kind of forgot about as sexual places” (“Episode 125” 00:10:18-00:10:21). These parts of the body not only represent the ways much of Gurza’s experience with touch is limited to care work but also constitute different erogenous zones. Sex allows him to reexperience touch and multiple parts of his body in a pleasurable way.

Gurza and his partners often speak of the alternative sexual culture that Gurza invites his sexual partners into and how it contrasts to typical white gay male sexual culture. The two partners interviewed in the episodes for this chapter are sex workers with whom Gurza has long-standing relationships. Due to these sex workers’ emphasis on touch-based therapy combined with Gurza’s experiences as a disabled man, what they get out of sessions together goes against particular stereotypes of what sex between queer men can and should be. Instead of privileging a facet of gay male sexual culture that emphasizes casual hook-ups and penetrative sex, Gurza values the deeper level of connection that he is able to experience with his long-term sexual partners. This facet of gay male sexual culture is what Gurza calls masc for masc, or the segment of gay male sexuality that requires both partners to embody and perform rigid masculinity. Gurza spoke to Raj about the connection they share:

It’s nice that for you the favorite part is the connection. Because of our masc for masc culture, the way queer men are socialized to be with each other we never hear this stuff. We never hear about how it was. It’s just, “Oh yeah, I sucked your dick and that was cool but whatever.” So, it’s nice to like hear that the time we spend together, especially for me as a disabled person who never hears this stuff and is told constantly by gay men that I’m needy, that I’m too much, that I’m too

intense. It's nice to hear that for you as a nondisabled person being with me that is does hold some importance to you. ("Episode 117" 00:38:20-00:38:59)

Masc for masc culture, as Gurza puts it, sees sex as a nonchalant activity between two people with the possibility for pleasure and emotional connection stifled ("Oh yeah, I sucked your dick and that was cool but whatever"). However, in his relationship with Raj, Gurza is encouraged to tap into the side of himself that seeks connection, reassurance, and patience from his partners. More so, Raj and Gurza share this appreciation, as Gurza is acknowledging that he is grateful that Raj's favorite thing about their relationship is the deeper emotional connection they share through sex. Gurza, as discussed earlier, is more prone to affective stickiness than the average gay man. Because of this, he has faced exclusion within the gay male sexual community for not meeting their standards of a viable sexual partner and so has Raj, who is Indian. However, through Gurza's work with trusted and experienced sex workers, he not only can access a sex life but also can form valued and multilayered connections with his partners that provide both of them with a sexual experience that defies the type of gay male hookups that Gurza and Raj are excluded from. Instead of just sitting in his exclusion from one type of gay male sexual connection, Gurza has taken time and agency to craft the kind of connection he wants, one that includes every part of his disabled body and allows him to share with a partner the level of emotional connection that some other gay men might not be interested in. For Gurza, having a close relationship to his partners is integral to their sexual compatibility:

There have been so many moments where you've been on top of me and we're supposed to be having hot sex. And we both look at each other and just start falling over laughing. There have been so many times and I enjoy that because

especially in gay male spaces there's this presumption that it has to look a certain way and be a certain way. When you see it in porn, and you see those things in porn, it's often not fun. And I like that when we spend time together, we can play with that and I think that's really important. ("Episode 170" 00:20:44-00:21:14)

By already accepting their exclusion from mainstream gay male sexual culture, Gurza and his partners open themselves up to moments of laughter and intimacy that would be discouraged or not even possible in other gay male spaces. Intimacy and playfulness are valued, allowing Gurza and his partners to experience a relaxed and fun sexual experience, one that is not bogged down by expectations of sexual performance or physical capabilities.

Gurza's personal narratives describe disabled sex as breaking away from traditional sexual mechanics, similar to Sieber's description of alternative sexual culture. Siebers writes about how disabled sex is not limited to predictable sex acts: "Rather, disabled sexuality has an ebb and flow that spreads it out among other activities, and its physiognomy does not necessarily mimic conventional responses of arousal, penetration, or orgasm" (Siebers 49). This ebb and flow reflects the ways that disabled sex expands the possibilities of sex and pleasure as it cannot be defined by traditional expectations of sexuality. Gurza's able-bodied partners like Raj discuss how the unpredictable and unlimited nature of his sex with Gurza makes it more enjoyable for him,

Raj: That's what I don't like is when it's broken down into mechanics, ya know, when it's just like. . .

Andrew: Making out, blowjob, rimming, then fuck?

Raj: Yeah, exactly, like that whole thing. When you just allow it, when you just feel each other's bodies and the energy between you two, the connection, and just let that happen, the most like beautiful things happen, and the thing is like for me it's so funny because most of the time it's not fucking.

Andrew: Full disclosure, you and I haven't really fucked. But it doesn't matter because each time it feels like we did. ("Episode 117" 00:39:54-00:40:31).

Instead of his disability strictly being a hindrance, it forces new avenues for connection and pleasure that leave both partners satisfied. By decentering the typical model of gay penetrative sex and privileging whatever feels right and happens in the moment, these two are able to connect on a deeper level. When Gurza later in this interview talks about cumming with Raj, he mirrors what Siebers says about disabled people needing to not judge their own sexuality against normative sexuality:

I think for me, a part of why cumming was initially, in my sexual experiences, so important is because that would connect me to a level of normalcy, if I just cum like everybody else. Then, my sex will be more normal and now I'm kind of reaching this weird point in my sex life where it's like I don't want to be normal. If I cum? Great. It'll be part of how I'm weird. I want to play with that as part of my disabled identity and have it be okay. ("Episode 117" 00:42:23-00:42:54)

Gurza initially perceived his sexual abilities as inferior because of negative associations about his disabled body. However, he stopped emphasizing ejaculation as a way to achieve normalcy and began accepting his sexual abilities by genuinely wanting to play with the ways that his sex life is different. Here, Gurza is practicing what Shakespeare identifies as the third dominant strategy that disabled men use to reconcile their



masculinity and disability, “rejection, which was about creating alternative masculine identities and subcultures...The third group went further in letting go of conventional gender identity and rejecting the ideology of masculinity” (Shakespeare 59). By moving past accepting and into appreciating his weirdness, he opens up new possibilities for sex and pleasure for himself and the people he has sex with. Gurza does this by “playing with” the way his disabled body cannot always achieve an orgasm during sex. He is leaning into this difference as a part of his unconventional gender identity and reporting a feeling of self-acceptance that stands in sharp contrast to the anger and frustration he experienced when he tried to push himself to give a hand job that represented a masculine sexuality. Gurza is refusing to give the affirmative answer to the question of “wouldn’t you rather be more like me” that McRuer says compulsory able-bodiedness demands disabled people respond to (McRuer 304). Instead, Gurza responds to both compulsory able-bodiedness and normative gay masculinity with a commitment to playing with his self-proclaimed weirdness and sexual difference.

## **2.4 Conclusion**

Through analyzing three types of affective experiences: the appearance of the Third Bedfellow of internalized ableism, the kicking out of the Third Bedfellow, and Gurza’s discussions of his alternative sexual culture, this chapter has explored the relationship between queer disabled sex and larger systems of oppression such as compulsory able-bodiedness and normative gay masculinity. Gurza’s relationship to the Third Bedfellow shows a complicated push-and-pull that at times causes Gurza to become caught up in a state of self-disgust that lifts him out of his present sexual experience and at other times shows Gurza powerfully overcoming thoughts of internalized ableism through his own alternative crip pleasure. This complicated

relationship with internalized ableism is tied to perceptions of masculinity that Gurza has encountered in porn and other dominant discourses and Gurza's journey from attempting to rely on masculine ideals to rejecting them in favor of his own alternative gender identity.

Gurza's alternative sexual culture as a queer disabled man makes possible two examples of relational affective exchange between him and his partners. First, Gurza experiences feelings of power and confidence through witnessing his partner's moans of pleasure and their proclaiming him a "good boy." Through the act of witnessing the pleasure his partners experience from Gurza's own "crippled cock," Gurza is able to be seen and see himself as a sexual subject. No longer excluded from sexuality, Gurza becomes a sexual actor at the sight of his partner's pleasure, defying the dominant ableist view the Third Bedfellow pushes Gurza to see himself through. Second is the freedom between Gurza and his partners to explore gay male sexual connection that privileges intimacy and playfulness as a result of their exclusion from gay male spaces that value penetrative sex in casual hook-up settings. Gurza's willingness to play with the parts of his disabled identity that do not meet traditional masculine ideals works to create a safe sexual space for him and his partners to explore new possibilities for pleasure and emotional connection that may not be likely within other sexual spaces such as hook-up culture.

Gurza's experiences, when analyzed through other disability studies scholars, show that disabled sexuality gains power against oppressive discourses such as compulsory able-bodiedness and normative gay masculinity when it is used to reject or overcome those discourses instead of trying to negotiate a space within them. Gurza's sexual experiences also show the immense weight of internalized ableism, with Gurza often worrying that his sexual ability will not be enough to satisfy his able-bodied partners.

While transformative possibilities for sex are still present with able-bodied partners, as this chapter has explored, what becomes possible when both people in a sexual relationship are disabled? What becomes possible when a commitment is made to only have sex with other disabled people? In the next chapter, through the work of E.T. Russian and Leah Lakshmi Piepzna-Samarasinha, this thesis will explore the familiar feelings of shame surrounding disability and sex, but also new possibilities for a cross-crip praxis of lust that situates queer sex between disabled people as a privileged production site for pleasure and connection.

### 3 THE LUST OF RECOGNITION

While the previous chapter explored narratives of queer disabled sex between a queer disabled man and his able-bodied partners, this chapter focuses on sexual experiences that Leah Lakshmi Piepzna-Samarasinha calls, “cross-crip solidarity through fucking,” or sex between disabled partners (*Care Work* 120). Through close reading of a conversation between the narrators, Leah Lakshmi Piepzna-Samarasinha and E.T. Russian, as well as some of their individual creative work, this chapter explores what becomes possible for sex and pleasure through crip lust, which Piepzna-Samarasinha defines as “Loving and having really good sex in a very broadly defined way with another disabled or chronically ill person where you’re lusting towards each other in a sexual fashion” (*Care Work* 115). These texts also address self-pleasure as a form of pain management and the eroticization of disability and mobility devices.

I begin with a conversation with E.T. Russian printed in Piepzna-Samarasinha’s book *Care Work: Dreaming Disability Justice*, called “Crip Sex Moments and the Lust of Recognition.” Russian and Piepzna-Samarasinha are longtime friends and creative collaborators whose work addresses their personal experiences with sex and disability. Through this conversation, I examine descriptions of how cross-crip sex feels and what becomes possible for sex and pleasure when both partners are disabled. The second text I analyze includes some excerpts from another book by Piepzna-Samarasinha, *Body Map*, published in 2015, which is a collection of poems. One poem is titled “Crip Sex Moments 1-10” and was written as a follow-up to the conversation with E.T. Russian mentioned above. Other poems in the book address topics such as using masturbation to manage pain and queer disabled people engaging with BDSM. Unlike Gurza, who chooses able-bodied sex workers to be his sexual partners, Piepzna-Samarasinha is adamant throughout her work that she does not want to date someone who is not

disabled. My final text for this chapter is excerpts from E.T. Russian's, *The Ring of Fire Anthology*, which is a collection of zines that Russian produced from 1997 to 1999. These zines were created about a year after Russian became a double amputee while train hopping. Russian says about her experience *writing Ring of Fire* that,

When I first wrote *Ring of Fire*, I was working out so much about my disability and my sexuality and gender. Looking back on what I wrote about my body and about ableism, I think in a lot of ways I was writing to an audience of people without disabilities. Trying to explain to them what I was going through, so they could gain a deeper understanding. Really, I think I was trying to explain it to myself and it just happened to be helpful to other people who were also new to disability as a concept. (Russian 9)

The *Ring of Fire* zines consist of black and white photocopied pages made of a collage of handwritten poems and prose, comic strips of fantasized acts of crip rebellion like burning down the White House, personal ads looking for sex clipped from newspapers, and even art depicting disabled people in lingerie or having sex. The chosen excerpts *from Ring of Fire* engage with eroticization of mobility devices, the negotiation of disability and desirability, shame, and BDSM.

Through these two narrators, this chapter explores the alternative sexual culture crafted through cross-crip sex, which is driven by what I call a cross-crip praxis of lust. By analyzing these texts for the description of sexual experiences that include reflections on the narrators' and their partners' feelings, I uncover how through a cross-crip praxis of lust these narrators refuse the shame and constraints that the social and medical models of disability theorize. In "Rethinking Disability: The Social Model of Disability and Chronic Disease," Sara Goering describes the social model of disability:

In addition to pointing to the tangible environmental and structural changes that could be made to be more inclusive for people of differing body types, the social model of disability focuses attention on the attitudinal obstacles faced by people with non-standard bodies. Other people's expectations about quality of life, ability to work, etc. for a person with disability not only affect the ways in which physical structures and institutional norms are made and sustained (based on presumptions about inability to perform), but also can *create* additional disability by making it harder for such individuals to feel good about themselves. (Goering 135)

Both narrators explore feelings of shame about their disabled bodies in their work, which comes from the acknowledgment that their bodies are different and a fear that they will be rejected from social and romantic life because of it. However, through cross-crip sex, both authors experience "the lust of recognition" or the powerful feelings of desire that Piepzna-Samarasinha and Russian describe feeling when engaging in sexual relationships with other disabled people. These cross-crip sexual partnerships reveal the presence of what Piepzna-Samarasinha calls "crip knowledge," which is a level of understanding of the need to negotiate each other's nonnormative bodies and to use creativity to make the giving and receiving of pleasure possible. This crip knowledge is crucial in the creation of the cross-crip praxis of lust that this thesis explores as a way to counteract the shame toward and rejection of disability that the social model of disability is concerned with. Through the experiences of this chapter's narrators, we also see cross-crip sex requiring an eroticization of one's own disability, which has benefits in the narrator's sexual experiences with other partners and their own practices of self-pleasure through masturbation.

Through these narrators' experiences of sex and pleasure, we also see productive possibilities for alleviating disability issues identified through the medical model of disability. While the social model of disability is concerned with how the social world is disabling for those with non-normative bodies, Goering points to what is disabling for non-normative bodies according to medical model of disability:

We should not, however, lose sight of the fact that people living with impairments experiences negative effects tied more directly to their bodily conditions. People with impairments that involve, for example, fatigue, pain, depression, or chronic illness may want both to overcome social barriers and discrimination that oppress all people with disabilities, *and* to voice their desire to remove or address the troubling accommodations of their impairments, through medical or other means. (Goering 135)

The physical presence of pain and discomfort from disability that the authors and their disabled lovers experience is alleviated through masturbation and sexual pleasure, as explored in their work. Therefore, this thesis argues that a cross-crip praxis of lust is a powerful force that not only empowers disabled people to reject the shame they experience about their disabled bodies, but also helps mitigate the pain experienced as a result of their disabilities.

### **3.1 The Lust of Recognition and a Cross-Crip Praxis of Lust**

One of the most prominent feelings that Piepzna-Samarasinha names when discussing her sexual experiences with other disabled people is a feeling of relief: "I don't want to ever have sex with anyone but another chronically ill or disabled person again. I'm just like, oh god, it's such a relief" (*Care Work* 115). Piepzna-Samarasinha explains that this relief comes from her partners' ability to nonchalantly understand and respect her body's changing needs and limitations. She calls this understanding that her partner must "negotiate my body in different

ways” a form of crip knowledge (*Care Work* 118). Piepzna-Samarasinha identifies crip knowledge as an important and not taken-for-granted ingredient in the making of great sex,

And how that crip knowledge was so tied to that person’s awareness about consent, in the middle of being a big pervert who’s into a lot of pretty intense SM. I mean, it was amazing. It was really, really, really amazing. I felt so lucky. I was so lucky. (*Care Work* 118)

The baseline understanding that both partners must negotiate their disabled bodies in order to have sex, or crip knowledge, opens the door to the kind of communication that is required for great sex, especially kinky sex. This understanding is unique to cross-crip sexual relationships as the relationship begins with each person having this crip knowledge gained through their own lived experience as opposed to one partner having to do the work of educating their able-bodied partner on why their body needs to be negotiated in different ways during sex and how. Piepzna-Samarasinha’s feelings of relief and gratitude for her partner’s crip knowledge show the powerful potential of cross-crip fucking compared to sex with an able-bodied person. This crip knowledge, when paired with kinky sex, becomes even more powerful to Piepzna-Samarasinha. Emma Sheppard, in “Chronic Pain as Fluid, BDSM as Control,” writes that when kink and chronic pain intersect, new possibilities for agency and control become possible:

What this meant is that in using pain within their play, participants were able to engage emotionally with their pain, and with their bodily selves, in a controlled space, and in ways in which they were in control, rather than relying on the judgement of medics or caregivers. This is because in kink, they had the ability to decide how they received pain, and to call a stop to any activity—as well as the knowledge that the pain is temporary.



Kink play is also a space where they are able to be uncontrolled in their emotional response—to give voice to their experience. (Sheppard)

Chronic pain and disability can rarely be controlled, and for Piepzna-Samarasinha, flare-ups can happen at any time. However, through kinky play with a crip-smart partner, she is given a sense of control over her pain, pleasure, and sexuality.

This lust of recognition and the power it produces is similar to discussions within trans communities about t4t, or trans for trans, which is a “politicized and eroticized separatism” (Malatino, 654). In “Future Fatigue: Trans Intimacies and Trans Presents (or How to Survive the Interregnum),” Hil Malatino writes:

T4t emerges from a recognition that trans subjects, too, might benefit from a severing of ties to cissexist modes of interpolating trans bodies (as failures, fakes, inorganic, inauthentic), and, moreover, that such strategic separatism might be one of the most direct routes toward cultivating self-love, self-regard, and self-care... (Malatino 654)

This severing of ties to modes of interpolating bodies as negative is what Piepzna-Samarasinha describes happening when she has sex with other disabled people. Disabled people, whose bodies are often stigmatized as broken or a burden, can experience a break from that stigmatization through disabled partners who possess the crip knowledge that Piepzna-Samarasinha finds so valuable. Piepzna-Samarasinha talks about the healing component of the lust of the recognition:

The lust of recognition! Yes! I think it’s like any identity stuff. I mean, the first time I fucked someone else who was South Asian, I was like--I mean, I know it’s corny to talk about “going home,” but I felt that. And there was something really healing about that. (*Care Work* 118)

Although Russian is white and does not discuss experiencing the lust of recognition on any axis other than disability, Piepzna-Samarasinha, who is of South Asian and European descent, makes the comparison between the healing she experienced through cross-crip sex and the first time she had sex with someone who shared her ethnicity. Malatino also identifies the healing power of the lust of recognition: “The hope is that, in community with one another, insulated--however temporarily--from cissexist modes of perception, some significant healing might be possible” (Malatino 654). The healing from ableist modes of perception that label Piepzna-Samarasinha’s disabled body as something too complicated or problematic to be desired is why she emphasizes her commitment to having disabled sexual partners. These ableist modes of perception fuel feelings of shame about their disabled bodies that both Piepzna-Samarasinha and Russian find relief from through cross-crip sex later in this chapter.

Russian and Piepzna-Samarasinha also discuss the lust of recognition as an erotic feeling of desire for disabled partners that extends beyond the healing and mutual understanding that can come with cross-crip sex. Russian talks about being attracted to someone’s disabled body and not in spite of it:

I realize that I’m attracted to the fact that they’re walking with a cane and they’re cute. And then, there’s this process I go through: *Am I fetishizing their cane?* I’ve been writing about this on and off the last couple of years. Is it a fetish? Or is it that I recognize myself in the cane? And then there’s that lust of recognition. There’s something really charged for me, where I just crush out. It’s hot. I feel drawn--like a magnet--to the person. They have to be an awesome person that’s cute in other ways--it’s not just the cane--but there’s something. It’s like this extra electric charge that’s there for me and it’s very real. (*Care Work* 118)

Russian acknowledges that this attraction holds an extra electric charge and becomes more powerful because she can see herself in that other person's disability. Through being aroused by another attractive disabled body and the mobility equipment it needs, Russian is not only experiencing an attraction to another layer of this prospective partner's identity, but is acknowledging the erotics of her own disabled body, something that is explored later in this chapter. Russian's attraction to this person is intensified as she fantasizes that this person may also have the crip knowledge that constitutes great disabled sex. By seeing her own crip body reflected in this person, she hopes that this possible partner would not reflect ableist modes of perception and shame Russian for her own similarly impaired body. This shared experience of disability creates new possibilities for and higher levels of sexual pleasure and mutual attraction.

Finally, both Piepzna-Samarasinha and Malatino address how the lust of recognition and t4t engage with difference. Malatino writes,

T4t is inevitably a difficult practice of love across difference in the name of coalition and survival, and it thus can't presuppose or predicate such love on identitarian or subjective sameness. Too often, "trans folk/people/communities" gets deployed as an abstract and overcoded monolith, coming to signify for diversely stratified communities. When used monolithically, trans coheres in ways that minimize colonial and racial differences and operates as implicitly white and settler, presuming a form of trans belonging sutured through the experience of "trans" as a single-axis form of minoritization. A t4t praxis of love enables and elicits more finely grained attention to differences between and among trans folk, with all the dissonance and difficulty engaging such differences entails.

(Malatino 656-657)

Here, t4t is not about homogenizing trans folks, but is concerned with multiple positionalities across trans identities. This t4t praxis of love does not ignore but is concerned with whatever difficulties arise from engaging those differences while being committed to trans for trans love. This attention to difference is also present in Piepzna-Samarasinha's discussion of cross-crip sex:

One thing that we're trying to do with this project of writing "Crip Sex Moments" is like... I don't know. I kind of think of it as like: the good, the bad, the ugly, and the real. You know?... Maybe you're fucking someone who has your exact disability; maybe they have a different one. But even though you don't have the same experience, you're giving each other love and appreciation and you're like, "Wow you're really fucking hot and I'm gonna figure out how to make you feel pleasure in your body and I'm gonna respect your body and you're gonna do the same thing, awesome." (*Care Work* 120)

This cross-crip praxis of lust requires a mutual respect and desire to problem-solve how to give one another pleasure despite the differences between bodies and how they work. An interesting feature of both Malatino and Piepzna-Samarasinha's praxes is that while they hinge on a single axis of identity, trans or crip, the attention to difference makes space for an appreciation of the intersections of difference across race, gender, sexuality, and class and the possibilities and challenges that can arise. This commitment to creatively figuring out the different avenues to pleasure rejects ableist discourses that disabled bodies cannot or should not receive sexual pleasure. Instead of waiting for able-bodied people to reject ableism, this cross-crip praxis of lust is agentic and takes matters into its own hands by privileging sexual experiences between disabled people. A cross-crip praxis of lust is crucial to the DIY sexuality that is evident throughout the personal narratives in this thesis.

### 3.2 Crip Sex Moments: Shame

In order to fully appreciate the positive outcomes of the cross-crip sex that both authors explore, it is important to analyze their experiences of shame regarding their disability and sex. In Sara Ahmed's *The Cultural Politics of Emotion*, she writes that, "Shame can be described as an intense and painful sensation that is bound up with how the self feels about itself, a self-feeling that is felt by and on the body" (Ahmed 103). Both Piepzna-Samarasinha and Russian discuss the shame that they feel about their disabled body and what it causes them to do and feel. In Piepzna-Samarasinha's collection of poems, *Body Map*, she explores the experience of shame and disabled sex in two poems, "crip sex moments 1-10" and "crip sex moments." The latter poem tells the story of Piepzna-Samarasinha's love affair with another activist who also dealt with chronic pain; however, neither of them had begun to identify as disabled and they both struggled with feelings of shame:

When I met you, when I saw you across the cafeteria at the writers of colour retreat and knew you would be in my life for a long, long time, I didn't know you were disabled. I barely knew I was. We both knew, knew it every day waking and sleeping, behind our eyelids every day of our life, but it's not like we told anybody, or they knew how to listen. You told me haltingly about your body the second or third time we fucked. Were you worried I would reject you? (*Body Map* 51)

These feelings of shame that Piepzna-Samarasinha and her partner felt about their pain not only affected their own adoption of a disabled identity but informed how they hid their pain from the people around them. In *Care Work*, Piepzna-Samarasinha writes about the prevalence of silence surrounding disability among Queer Trans Black and Indigenous People of Color (QTBIPOC) that disability justice is concerned with combatting:

...I, like many other QTBIPOC I knew, thought of disability as something that you weren't allowed to talk or write about in QTBIPOC culture... There was a huge echoing silence in POC and/or queer activist communities. I had a few friends who whispered to each other about our chronic illnesses – but the most we could say was “It sucks, right?”

We had no idea we could be part of a community, a history, a movement. (*Care Work* 18)

Hiding one's disability was an unspoken rule in the QTBIPOC community that not only prevented cross-crip solidarity within the activist community but also worked to obscure the lineage of disabled activists past and present doing activist work.

Attempting to hide or conceal oneself is a crucial aspect of the feeling of shame:

The subject may seek to hide from that other; she or he may turn away from the other's gaze or drop the head in a sensation more acute and intense than embarrassment. In other words, shame feels like an exposure – another sees what I have done that is bad and hence shameful -- but it also involves an attempt to hide, a hiding that requires the subject turn away from the other and toward itself. (Ahmed 103)

Although the sexual relationship between Piepzna-Samarasinha and her partner opened the door to a refusal of shame through communication about their shared pain, Piepzna-Samarasinha identifies that it came haltingly, and with a fear of rejection. Shame is experienced when we fear negative judgement from others whose opinions matter to us (Ahmed 105). For her partner, their desire to be loved by and approved of by Piepzna-Samarasinha intensified their feelings of shame. That fear and feeling of shame is also driven by the discourses that construct disabled people as a burden, with the presence of their pain or different bodies as problems that their partners will have to deal with, which can be seen in Piepzna-Samarasinha's acknowledgment that the people around them would not know how to listen. The struggle with how the social

world does not accommodate disabled bodies is what the social model of disability is concerned with. The shame that Piepzna-Samarasinha describes her and her partner feeling about their disabilities reveals their fear that the wrongness of their disability speaks to their wrongness as a person. The act of assigning the badness of an action to the self is another relevant feature of shame, as Ahmed writes: “In shame, more than my action is at stake: *the badness of an action is transferred to me*, such that I feel myself to be bad and to have been ‘found’ or ‘found out’ as bad by others” (Ahmed 105). Understandably, when faced with the possibility of being found out as disabled, and the ableist judgements of being a burden that comes along with it, Piepzna-Samarasinha and her partner chose to hide their disability from those around them. However, this shameful negation of their own disabled identity works to prevent the type of transformative, pleasurable connections that can be made through disabled sex that was discussed in the previous text.

Once the hurdle of shame is overcome, and Piepzna-Samarasinha and her lovers openly address pain and disability, the possibilities for sexual pleasure expand and she describes a reciprocal feeling of acceptance of one another’s needs. This excerpt is from “crip sex moments 1-10,” so it is unclear if Piepzna-Samarasinha is referring to the same disabled lover or not:

I am thirty-four and when I start fucking you and the other one, I decide I don’t want to date anyone who’s not a crip ever again. Same as when the end of white boys happened, I sink gratefully into the pleasure of never having to explain. My sickness, unpredictable tides of fevers and sore hips, microtrembling butterfly hands and legs, need a strict sleep schedule, Siberian ginseng, yoga once a week that is medicine not lululemon luxury. Of moaning and cajoling and coercing, yes, there, fuck me, oh yes sudden breaking into oh fuck! My hip! No, no! Being absolutely normal. I sink into knowing that you will never

laugh shame me for being too tired to make it to the club, and I will never shame you for the pain that tops you every day all day. (*Body Map* 42)

Piepzna-Samarasinha has rejected a discourse of silence and shame about her pain and her unpredictable body, moving to feeling liberated by never needing to explain herself to her disabled lover, similar to the relief she felt when she stopped having romantic and sexual relationships with white men. For Piepzna-Samarasinha, the crip knowledge that bodies need to be negotiated differently to make pleasure possible through cross-crip sex allows for an exchange of relief and release between her and her partner. Cross-crip sex frees her from the shame surrounding her disabled body and allows her to experience vulnerability and pleasure with her partner.

Russian also describes her experiences with being ashamed of her disabled body and worrying about how disability would change her sex life. In the moments after becoming a double amputee she pondered,

In other words, I have to plan out every move I make which takes out some of the spontaneity of sex, and makes me embarrassed sometimes too. Sometimes I get self-conscious...I remember laying in the hospital bed after the amputations were done wondering if people find me sexually attractive anymore because I was now "crippled."

(Russian 21-22)

Russian's experience of having disability suddenly and severely thrust upon her immediately led her to question her sexual worth. Russian's feelings of self-consciousness toward her body and her assumed impossibility of being considered sexy reflects that she is identifying herself as different and unable to conform to the mainstream ideals of what is sexually attractive. This privileging of a mainstream ideal is another key feature of shame. Ahmed writes,



Shame can reintegrate subjects (Braithewaite 1989) in their moment of failure to live up to a social ideal. Such an argument suggests that the failure to live up to an ideal is a way of taking up that ideal and confirming its necessity; despite the negation of shame experiences, my shame confirms my love, and my commitment to such ideals in the first place. (Ahmed 106)

By acknowledging that her newly disabled body does not fit the ideals of being sexually attractive, Russian is affirming the existence of an ideal sexual body type and an ideal level of mobility required for sex. At this stage of her life, only days after losing her legs, Russian is grappling with this new reality of being excluded from sexuality or at least excluded from mainstream ideals of what is sexually attractive and has not yet done the work of negating the necessity of a mainstream ideal of sexual attractiveness. However, as this chapter will explore later, Russian's play with the erotics of her disabled body through *Ring of Fire* show how queer disabled sex can be used to combat those feelings of shame that hinder pleasure and connection.

### **3.3 Crip Sex Moments: Managing Pain with Pleasure**

Both Piepzna-Samarasinha and Russian write at length about masturbation and self-pleasure, and Piepzna-Samarasinha specifically writes about masturbation as a form of pain management for the chronic pain she experiences from her fibromyalgia. While freedom from shame about her disabled body can be achieved through cross-crip sex, the presence of physical pain in her everyday life remains problematic. However, sex can also be productive to alleviate that pain. Piepzna-Samarasinha writes about shifting the concept of "work" away from capitalist notions of a typical occupation to the self-pleasure she uses to counteract her chronic pain in the poem, "everyone thinks you're so lazy. don't let them":

this is your work:

slam the alarm over and over again.

then grab your Hitachi.

this will melt the shards of ice hardened in joints...

this is your commute:

to bless the daily act of breathing

as work as necessary as nine-to-five. (*Body Map* 37)

To others who do not understand the daily presence of pain in her life, her daily routine of using a vibrator to pleasure herself into a state of relaxation could seem frivolous or luxurious.

However, the practice of self-pleasure to mitigate her pain and keep her alive, “to bless the daily act of breathing,” is just as valuable as capitalist notions of being a productive working citizen.

Piepzna-Samarasinha’s use of masturbation as pain management also disrupts limitations on how long sex should last or what it should entail:

When I flare, I go in my bed and I fuck myself so hard. I close all the doors and I make myself come, over and over again. Sometimes I jerk off, read library books and look at Facebook at the same time. My cock in my pussy and my vibrator on my clit stays there forever. Sometimes I just hover there in that place with no coming for hours, and there is no pain, just me being the slut that kept me alive. (*Body Map* 49)

Again, Piepzna-Samarasinha credits her commitment to radical self-pleasure with keeping her alive. Her reclaiming of the term slut, one used to shame women who engage in anything more than minimal amounts of appropriate pleasure, shows the value and pride that Piepzna-Samarasinha finds through her sexual pleasure. The length and frequency of her practice of self-pleasure, hovering in that place on the edge for hours, also disrupts the notion of an average sex life.

While a major part of Piepzna-Samarasinha's use of pleasure to manage pain is self-medicating, she also writes about how her sexual partners have the ability to give her relief from the pain she experiences. She writes about the release of the weight of physical and emotional pain through sex:

I don't have to work to come. And I cry when I do cause it's like all the pain, all the not-enough, all the worked to death worn-through tired cripp body, is coming out of my pussy onto her hands when she gives me what I have needed for so long. Later, she texts me, "I could tell you needed to be fucked so bad and I was so happy to be able to give that to you." And then there was the moment on Skype where she said, "Only the hottest girls have fibromyalgia" and I threw back my head and laughed and laughed and fell in love.

*(Body Map 77-78).*

Sex and specifically, her lover's cripp knowledge of how to intuitively meet Piepzna-Samarasinha's needs have the power to relieve the physical experience of pain from her disability and the weight of ableist notions that she is not-enough. Just as Piepzna-Samarasinha described in the conversation with E.T. Russian earlier in this chapter, kink plays a valuable role when combined with cripp knowledge in creating powerful and pleasurable sexual experiences. Emma Sheppard also explores the experience of chronic pain among people who also partake in BDSM sexual activity in "Chronic Pain as Fluid, BDSM as Control." Sheppard writes about the participants in her research who engage in kink play: "One of the pleasures of kink was the time and space to engage with pain, as well as an audience willing to witness pain" (Sheppard). Piepzna-Samarasinha's partner is witnessing her disabled body experience pain and bringing pleasure to it in a way that acknowledges and honors her disabled body, instead of ignoring it.

Piepzna-Samarasinha also touches on the experience of her disabled lovers negotiating their own pleasure and pain:

The pain tops you every day, all day so you top all the time. You top at work at the dungeon and with your lovers. You don't let anyone touch you. When I ask you how the yoga for people with scoliosis class went you said, "it was difficult." When I ask why you say, "it's difficult basically any time I try to be inside my body." (*Body Map* 42)

Her disabled lover engages with pain differently here. While Piepzna-Samarasinha writes about being on the receiving end of pleasure and pain, this particular lover needs to give pleasure and pain. Dominating in every facet of their sexual life allows them to regain a sense of control that in other experiences of being in their bodies, such as the yoga class, feels challenging and uncomfortable. The idea of being in your own body can be taken for granted when your body is not a source of pain and discomfort. While Piepzna-Samarasinha's partner struggles to be in their own disabled body, they are creating alternatives to being present in themselves by asserting dominance in sexual encounters and giving others the pleasure and release that they can't achieve for themselves.

### **3.4 Eroticizing Disability**

The final way that Russian and Piepzna-Samarasinha's work engages with disability and sex is in the eroticization of disabled bodies and mobility devices such as prosthetics and canes. Other disability studies scholars have explored the complexities of eroticizing disability, specifically Alison Kafer in "Desire and Disgust: My Ambivalent Adventures in Devoteeism." After detailing some of her experiences and reactions to communities of heterosexual men who claim a devotee identity to women who are amputees, she poses some questions:

Instead, I want to imagine a sexuality that is rich and robust not in spite of impairment, and not fetishistically because of impairment, but in relationship to it. How have disabled people crafted sexual identities and practices that take our impairments into account, not in order to overcome them, but to capitalize on them? How might impairments enhance sexual encounters, opening up new possibilities and experiences? (Kafer 346)

Rejecting the presence of a fetishizing able-bodied devotee's reaction to a disabled body, what other ways have disabled people eroticized their own impairments? How can capitalizing on one's impairments expand the possibilities for what is sexy and how to feel pleasure?

Through the chronology of the issues of *Ring of Fire*, Russian shows a progression of eroticizing her impairment. Beginning with her attraction to a woman in her amputee support group, she writes:

Amputee girl

You make me wet

I wanna lay with you and

Bite your bitten lip

Spread lubricant all over

The stumps of your legs

And cum

When I see you wheeling yourself down the

hallways of the hospital

I look at your hands on the wheels

And I imagine

Sucking each and every finger of them

like they were our feet (Russian 27).

By exploring her attraction to a fellow amputee in the months after becoming one, Russian not only expresses an attraction to this other person, but an identification with them. The lust of recognition in wanting to suck the amputee girl's fingers like they were *our* feet suggests that Russian is aroused by what she sees about her own disabled body in this other person. This is an instance where representation can have productive power towards liberation from ableist ideas about who can be sexually attractive as it was crucial for Russian to lust after another amputee as she grappled with her own sexual identity in this newly disabled body.

This sexual self-identification does more than bring sexual pleasure; Russian also writes about the liberatory experience of eroticizing her disability. Frustrated with her flesh-colored compression socks that she must wear at all times, Russian adapted them:

So, this week, when I finally figured out a way to eroticize them I was way excited. I liberated myself a red and black vinyl bustier with a built-in garter-belt and realized that my ugly tan socks are just the thing to hook onto my garters. Yay!!!! I've felt soooo much better ever since I figured that one out. I hated feeling like being an amputee holds me back, and that was how those ugly tan socks made me feel. (Russian 41)

Much like the cross-crip praxis of lust demands a commitment to using creativity to figure out how to pleasure another disabled partner, Russian felt relief and empowerment by committing to figuring out how to eroticize her own disabled body and the clinical clothing she must wear. Here, by using creativity and agency to customize her compression socks, Russian is having fun finding ways to eroticize her disability and feel sexy, something she worried about in the days after her amputations would not be possible.

Later in the *Ring of Fire* series, Russian explores how her experience of getting used to walking on prosthetic legs allowed her to relate to the use of another type of prosthetic, a strap on dildo:

I was finally getting to fuck someone with a dick. It had been my dream for so long, and now that it was happening I couldn't feel a thing!!!! It was just like when I learned to walk. I couldn't feel the ground as I was walking. Like both my feet were asleep but I have to walk on them anyways. Fucking with a dildo was just like that. My body was inside of him but I couldn't feel it. (Russian 95)

Russian feels that her prosthetic legs and the dildo are both a part of her body, despite the fact that they can both be removed at any time. Russian's departure from valuing the "natural body" is seen through her excitement that her artificial legs and cock allowed her to use her body in new ways that spoke to her internal dreams and sexual desires. Although her legs and her cock have felt strange and foreign at times, both devices allow her to change her form, increasing her mobility in several ways. Her prosthetics change her mobility, giving her more freedom of movement in her daily life because she does not have legs, and the dildo changes her sexual mobility allowing her to fuck her partner in ways she always wanted, but were not possible because she was not born with a penis. Russian is able to enjoy this sexual encounter despite not feeling sensation through the dildo because the experience of being inside her partner comes from a powerful place of desire to take up a masculine sexuality. Russian wrote in the introduction to the *Ring of Fire* anthology that she was exploring her disability and her sexuality and gender all at the same time, which is represented in her experience adjusting to using the prosthetic legs and a strap on. While Russian knows that using a dildo to fuck someone feels

different than if she had a penis, the prosthetics are still a valuable tool allowing her to take on a new role in the exploration of her gender and sexuality.

Piepzna-Samarasinha also writes about the eroticization of mobility devices, specifically a cane:

You wrote that your cane was the sexiest adaptive device ever, it made my nipples tighten. I posted on your wall, “My cane is brown and curvy and strong like me. Maybe our canes could go on a date?” You posted back, “I’d like that very much.” And it was on. (*Body Map* 55).

Through the lust of recognition, Piepzna-Samarasinha’s already preset initial attraction to this person is intensified by their identification with a disabled sexuality. She then identifies herself with her mobility device in a flirtatious way by comparing the strong, brown curves of the cane to her own body. Although unattached to her natural body, the cane is an important part of her physical form and her sexuality. Not only does Piepzna-Samarasinha see her cane as an extension of herself as a brown disabled woman, but asks her prospective partner to do the same, to share an appreciation of both their disabled bodies in the cross-crip sex they may have. Just as Kafer asks, Piepzna-Samarasinha is capitalizing on her own impairment and using it to create new possibilities for sexual desire between her and this prospective partner.

### **3.5 Conclusion**

By analyzing some of the personal narratives of queer disabled sex written by Leah Lakshmi Piepzna-Samarasinha and E.T. Russian, this chapter has explored facets of their disabled sexual cultures and the role that cross-crip sexual relationships plays in their lives. Through their stated commitments to having sexual relationships with other disabled people, they create new possibilities for the transformative power of sex and pleasure. My identification



of a cross-crip praxis of lust similar to the t4t praxis of love that Malatino discussed shows the important role that cross-crip sex can have in unlocking sexual pleasure and in liberating disabled people from feelings of shame about their disabled body that are driven by ableist modes of perception that cross-crip sex rejects. Crip knowledge paired with the commitment to using creativity and agency to make each other feel sexual pleasure is crucial to a cross-crip praxis of lust and are identified by both of my narrators as important factors in their journeys toward assuming a disabled/crip identity. The lust of recognition that has the power to free these narrators from shame-inducing sexual encounters also aids in an eroticizing of their own disabled bodies as they build sexual relationships with other disabled people.

While cross-crip sex has the power to mitigate the shame of disability that is understood through the social model of disability, this chapter also explored how using sexual pleasure, for the self and with others, to alleviate the pain of disability, can be valuable in addressing disabled needs understood through the medical model. Disability is a broad term for a variety of different conditions and impairments that affect this chapter's narrators and their partners in a myriad of ways. Cross-crip sex is a unifying practice, where an attention to difference allows for a multitude of challenges that disabled people face to be addressed in a variety of creative and playful ways.

## 4 CONCLUSION

Despite discourses formed through medical professionals, the law, and media that exclude disabled people from sexuality by constructing them as either hyper- or a-sexual, infantile, or sexually unattractive, disabled people utilize creativity and agency to craft their own DIY sexual cultures. While disabled people can and are contributing to discourses on disabled sexuality by talking about, making art about, and doing theoretical work about disabled sexuality, it is important to analyze the role of negative discourses on perceptions of disabled sexuality and what happens when disabled people craft a sexual culture. Specifically, when adopting a disability justice framework, which, among other tenets, includes sexuality as an important factor in improving the lives of disabled people, what becomes possible for how sex and pleasure is understood for us all?

Ultimately, these interactions with discourses has led this thesis to explore three questions regarding the personal narratives of queer disabled people about their sexual experiences:

- (1) How do queer disabled people talk about sex?
- (2) How do they describe the ways sex affects their perceptions of the self and the body?
- (3) How do they describe the ways sex affects their perceptions of their relationships to others?

In order to explore these questions, this thesis has employed close reading into the affective experiences of three narrators: Andrew Gurza, Leah-Lakshmi Piepzna-Samarasinha, and E.T. Russian. In all of these narrators' experiences, we see a utilization of both creativity and agency to build meaningful and pleasurable sexual relationships that defy discourses on disabled sexuality as problematic or nonexistent. By closely reading their personal narratives of queer

disabled sex for affect and emotion, this thesis has explored the role that internalized ableism and shame have on hindering the enjoyment of sexual experiences, as well as the role that disabled sex has in liberating these narrators from some of the shame around their disability. This thesis has also explored how a commitment to a cross-crip praxis of lust has powerful, transformative potential for sex and pleasure.

By analyzing Gurza's retelling of his sexual experiences with able-bodied partners as well as conversations between Gurza and his sexual partners, I have explored his personification of internalized ableism as the Third Bedfellow. This unwanted participant in Gurza's sexual experiences had the power to lift Gurza out of his body, to a place where he adopted a dominant ableist view of his own sexual self-worth, which led to feelings of unease and self-disgust. In these moments, Gurza exhibited a reliance on notions of traditional masculinity and experienced frustration and anger that his disabled body could not perform certain sex acts. Gurza's battle with this Third Bedfellow also swung in another direction, as he narrated experiences where he kicked the Third Bedfellow out of the bedroom. In moments where Gurza was witnessing himself provide sexual pleasure to his partners, and where his partners witnessed and praised Gurza's ability to please them by calling him a "good boy," we see the power that sexual pleasure has in aiding Gurza in rejecting ableist notions that he is not a viable sexual partner. Finally, through Gurza's personal narrative, this thesis explored Gurza's journey with his own masculinity through sex, as Gurza concludes he wants to play with the ways he is weird, such as his inability to consistently orgasm during sexual encounters, and he adopts a practice of leaning into his own difference, rejecting traditional masculine ideals in favor of crafting his own gender identity.

Through Gurza, this thesis has explored the radical power of having a witness to one's own sexual abilities in thwarting feelings of discomfort and self-disgust that internalized ableism caused Gurza to feel during sex. However, through the work of Piepzna-Samarasinha and Russian, this thesis has also explored what becomes possible for sex and pleasure through analyzing the affective experiences of two narrators who express a commitment to seeking sexual partners who are also disabled. This thesis has identified a cross-crip praxis of lust, that through what Piepzna-Samarasinha calls crip knowledge, shows disabled people having the shared understanding of the need to negotiate the body's changing needs, which is crucial to the communication and understanding required to craft pleasurable, safe, and even kinky sex. Cross-crip sex, as explored in these narrators' personal narratives, holds powerful potential for addressing the needs of disabled people from both a social and medical perspective. The same negative discourses that construct disabled sexuality as problematic also work to construct disabled people as a burden or broken. This negative construction of disabled people as problematic brings about feelings of shame, that at times, have led these narrators to hide their disability from others in an effort not to allow the perceived wrongness of their disability to reflect their wrongness as a person. However, through a cross-crip praxis of lust, specifically the lust of recognition, the narrators discussed a change in their perceptions of their own disabled bodies. For Russian, lusting after another amputee allowed her to explore the erotics of her own disabled body. Even if their sexual partner is differently disabled from them, cross-crip sex enabled both narrators to reject ableist modes of perception that seek to classify only certain types of bodies as sexually viable, thus opening the door to a better sexual experience for everyone involved.

Cross-crip sex does more than provide avenues for combatting feelings of shame influenced by negative discourses on disability; it also reveals the role that sexual pleasure has in managing the physiological challenges of disability, such as chronic pain. Piepzna-Samarasinha's personal narratives show that she considers her role as the slut keeping herself alive as a part of her work, disrupting capitalist notions of a valuable work life, something she neither is able nor wants to adopt due to her chronic pain.

By analyzing all three of these narrators' experiences, this thesis has explored the powerful role of shame as it relates to disabled sexuality. Whether it be as a Third Bedfellow that demands Gurza inflict disgust upon himself or as a force that makes both Piepzna-Samarasinha and Russian question whether being disabled and sexual are mutually exclusive, all three narrators talk about shame when they discuss their sexual experiences. Something uniquely different about these narrators' experiences of shame involves their choice of sexual partners. While Gurza says he is at times able to overcome feelings of internalized ableism, the Third Bedfellow is always in the back of his mind. Would this relationship to the Third Bedfellow change if he adopted a cross-crip praxis of lust? Does he need to? Or is his adoption of intimacy and longevity with his sexual partners enough? I ask this question because each time Piepzna-Samarasinha discusses cross-crip sex, she describes a total liberation from shame about herself as a sexual actor and a relief in never needing to explain her body again. I don't intend to argue that Gurza's sexual experiences are somehow limited because of his choice of able-bodied sex workers as sexual partners, but I hope to see through the continuation of his podcast if he shares experiences of cross-crip sex in the future.

This thesis has explored what analyzing affect in personal narratives of queer disabled sex can reveal about the sexual lives of three queer disabled personal narrators. But what can this

knowledge unearth about sex and pleasure for everyone? Most importantly, this thesis has emphasized the powerful role that shame has in limiting experiences of sexual pleasure. Regardless of whatever normative discourses are fueling the shame we experience, the need to hide parts of ourselves to those we have sexual relationships with can cause pain and quite literally take us out of the act itself, into a headspace of self-disgust and anger. Yet, through sex, we can also experience a liberation from shame, one that can lead us to reject shame about ourselves in other areas of our life, such as when Piepzna-Samarasinha began to take on a disabled identity and speak openly about her chronic pain in other areas of her life and art unrelated to sex. I argue this increase in self-acceptance is because we can gain confidence and an appreciation for our own bodies through our sexual relationships, as we see in the experiences of all three narrators, such as Gurza's rejection of a constraining traditional masculinity in favor of exploring what makes him different.

The alternative sexual culture crafted by these narrators also shows the importance of exploding mainstream definitions of sex and pleasure. In order to maximize pleasure and the transformative possibilities for sex regarding shame and self-perception, sex can and should be separated from mainstream, able-bodied, heteronormative definitions that constrain sex to certain timeframes, specific acts, and limited erogenous zones. These definitions, which already do harm in working to exclude certain people from having what is considered valuable sex, also limit our own creative thinking about what constitutes sex, limiting our exploration of pleasure for ourselves and others.

Further research into the topic of queer disabled sex is still needed, and I believe that the sexual experiences of queer neurodiverse disabled people would be a valuable path of inquiry. I hope to expand my current research and shift from the personal narratives of physically disabled

people to neurodiverse queer individuals and women. Neurodiverse children of color and white girls are poorly researched and often denied diagnosis and resources. Ageism worsens this disparity, as neurodiverse adults do not receive the same attention as children. My own Attention Deficit and Hyperactivity Disorder (ADHD) and navigating sensory processing, executive disfunction, emotional regulation, and dopamine levels as it pertains to sex, influences my interest in inquiry into this topic. Also, more scholarly exploration of a correlation between neurodiverse people and queer and trans identities could be useful as these discussions have been proliferating in neurodiverse and autistic online communities.

Through this thesis, it is clear that sex and pleasure hold immense power. For these personal narrators, whether it be cross-crip sex or sex with an understanding and patient partner, a praxis of lust and understanding opens the door for pleasurable experiences of connection and acceptance that shape these narrators lives and experiences. Our sexual experiences do not exist inside of a vacuum, but instead require us to engage with our differences, in ways that ask us to confront the dominant discourses that work to make us feel inferior and wrong. Hopefully, this thesis has helped provide some answers to the question, what can sex do? Sex can and will force us to reveal and confront the deepest parts of ourselves we are told to be ashamed of. Sex can also create space to be seen and see others wholly, as long as we are willing to creatively commit to a shared experience of pleasure. I encourage us to consider how a praxis of lust can strengthen the relationships we form around sex and pleasure in order to increase the presence of the transformative power that great sex can have in our lives.

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