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Maria Ferrando   April 7, 2020

Disability and Sexuality: The Phenomenological Breakdown of An Able-Bodied Sexual Culture

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An abstract of
a thesis submitted to the Faculty of Emory College of Arts and Sciences
of Emory University in partial fulfillment
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Bachelor of Arts with Honors

Women's Gender and Sexuality Studies

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Abstract

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Historically, the needs and capacities of people with intellectual and developmental disabilities (IDD) have been constructed through medical models of disability that, originating in eugenic logics, have served to exclude people with IDD from broad society. Particularly in regard to notions of sexuality, people with IDD have experienced barriers to sexual expression (and thus, to sexual culture) because of protectionist notions that falsely define people with IDD as necessarily vulnerable to sexual abuse. Using a phenomenological standpoint, this thesis argues that disability, as well as able-bodiedness, are products of social construction that serve the implicit purpose of bolstering the status and position of able-bodied people as "normal" against people with IDD who are conceived as "abnormal." Deconstructing notions of normality and abnormality strengthens the conditions for meaningful platforms for people with IDD to express themselves as sexual citizens.

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Acknowledgements

This research was only possible through the knowledge and support I have received from a variety of professors, mentors, supervisors, and colleagues at Emory University and beyond.

I extend my sincerest gratitude to:

Dr. Stu Marvel, for serving as my thesis advisor and meeting with me continuously throughout this process to both hold me accountable to my goals and encourage me to develop my ideas into a cohesive and comprehensive piece of writing.

Dr. Jennifer Sarrett, for serving as a member of my thesis committee, and for helping me frame the subject of my research. Dr. Sarrett's comments and expertise have been critical to the development of this thesis, and I thank Dr. Sarrett for the nuance she has provided to my argument.

Dr. Jessica Wahman, for serving as a member of my thesis committee and for helping me better understand how to best use phenomenology to enhance my thesis. Additionally, Dr. Wahman's critical perspective on phenomenology has proved beneficial in thinking through my theory and applications.

Johanna Berglein, for being my supervisor at the Young Adult Institute, Inc (YAI), and for the conversations I have had with the self-advocates YAI supports, which served as the impetus for my research.

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Introduction: A Phenomenological Analysis of Intellectual and Developmental Disabilities

Historically, people with intellectual and developmental disabilities (IDD) have been ostracized from mainstream communities through a variety of social and physical systems. This isolation continues in obscured ways through the language used and the attitudes people have towards people with IDD. In particular, stereotypes of people with IDD as either asexual or, conversely, as sexual menaces have had significant consequences in limiting the rights and agency of people with disabilities. This thesis will examine the issue of sexual inaccessibility for the population of people with IDD through an in-depth analysis of the historical practices that have allowed for harmful systems of care, as well as a discussion of the current obstacles that people with IDD face in engaging within a sexual culture. A phenomenological analysis of these conditions, with an additional lens of disability and crip theory, help to uncover these dynamics between disability and sexuality by problematizing the able-bodied natural attitude that informs how people formulate proper love and sex.

Arguing for the reconfiguration of the sexual autonomy of people with IDD, I plan to disentangle the negative social consciousness surrounding disability and sexuality by examining the Social Darwinist origins of these conceptions, the modern repercussions of this theory within sexual choice and education, and the portrayal of disabled sexuality within media.

Definitions

The process of defining "disability" has historically been contentious. There have been a variety of approaches towards defining disability, and these approaches have included a medical model and a socio-cultural model. Disability is most commonly defined according the to the Americans with Disabilities Amended Acts (2008), which is based on a medical model of disability, which states that, with respect to an individual, disability refers to any "physical or

mental impairment that substantially limits one or more major life activities of such individual"[1].

This approach is often criticized because it imagines people with disabilities as deficient, as well as "incapable and in need of protection and correction" from able-bodied systems of care[2].

The social model of disability, as a response against the medical model of disability, defines disability as impairments "caused by social structures and processes;"[3] positing that disabilities are not internal disadvantages but rather are external constructions formed through social barriers to inclusion. Thus, the social model of disability locates the responsibility of deconstructing these social barriers within society, rather than within people with disabilities[4]. While the social model attempts to elucidate the failures of society in adjusting to the needs of people with disabilities, this model has been criticized because it resorts to "highlighting differences between disabled and non-disabled people" and excludes the individual "experiences of disabled people" by overly centering the experiences of those who are physically disabled[5]. People with learning disabilities, for example, can be excluded from this model because it intrinsically asserts that all disabilities are essentially the same and can all be addressed through the adjustment of externally imposed social barriers.

Both the medical model and the social model of disability fail to address the lived experiences of people with IDD, and the reality that the medical model's definition of disability is the foremost definition in circulation reveals the importance of meaningfully including the voices of people with IDD within social movements for disability rights. This thesis leans closer to the definition of disability introduced through the social model, but it importantly holds that

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[1] (Definition of Disability)
[2] (Ruiz, 2017, p. 92)
[3] (Waldschmidt, 2018, p. 70)
[4] (Owens, 2014, p. 385)
[5] (Owens, 2014, p. 389)

the social structures that create disability are varied and complex, and thus the deconstruction of these social systems must likewise be varied and complex.

Intellectual and developmental disabilities, more specifically, are defined through a medical approach as "disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development"[6]. This definition broadly includes a variety of disabilities, including Down syndrome, Autism Spectrum Disorder (ASD), and cerebral palsy. People with IDD oftentimes also have concomitant impairments that affect them in physical or social ways. While this thesis uses the terminology of IDD to refer to a variety of disabilities, it is important to recognize that the embodied experience of IDD is individual. That is to say, the lived experiences of an autistic person will be (and have historically been) different from the lived experiences of a person with Down syndrome.

Other important terms to this thesis include sexual autonomy, sexual accessibility, and sexual culture. Many people with IDD experience physical and social barriers that affect how they can embody their sexuality, and this can potentially lead people with and without disabilities to have distorted understandings of sexuality as either necessarily heteronormative or innately able-bodied[7]. This thesis uses the term "sexual autonomy" to refer to the freedom to express one's sexuality without external limitations and is most often used to indicate how the sexualities of people with IDD are often heavily regulated by caretakers in order to "protect" them. Sexual accessibility refers to the capacity to learn about or engage in sexual relationships or interactions. Many people with IDD are limited in their exposure to sexuality due to social perceptions that would like to keep people with IDD "ignorant" of sex due the perceived child-like state of people with IDD—thus reducing their opportunities to access meaningful sexual

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[6] (What are Intellectual and Developmental Disabilities?)
[7] (Alexander & Gomez, 2017, p. 116)

educations[8] [9]. Additionally, due to limitations within community homes, access to privacy in order to engage in sexual interactions or behaviors is limited. Finally, this thesis builds upon Tobin Sieber's theory of a "sexual culture," which encapsulates how there are certain perceptions about how sex should be properly performed which inevitably are exclusive and ableist[10]. The perception of sex as private and spontaneous, for example, can exclude the reality that many people with disabilities experience when engaging in sexual encounters as their sexual experiences might require more planning or might only be possible in public health-care environments. Additionally, the sexualities of people with IDD are often only addressed through a perspective oriented towards health. That is, people with IDD are often formulated as a vulnerable population that must be protected from sexuality due to heightened risks of abuse and manipulation, which is coupled by fears surrounding people with IDD contracting STI's and having unwanted pregnancies[11]. This medical-based understanding of sexuality, however, allusively perpetuates the sexual vulnerability of people with IDD by excluding them from accessing sexuality in a safe environment.

Methodology

This thesis utilizes a film and literature review in order to come upon its analysis of how the bodies of people with IDD become charged or imbued with negative emotions that limit their sexual access. Building off of Sara Ahmed's application of phenomenology within feminist studies, wherein she argues that objects-within-the-world are "arrived" upon with certain expectations and stigmas prior to any authentic interactions between the perceiver and the perceived, this analysis reveals how social systems guided by eugenic theory have caused the

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[8] (Hodges, 1997, p. 18)
[9] (Walker-Hirsch, 2007, p. 14)
[10] (Siebers, Sexual Culture for Disabled People, 2012, p. 39)
[11] (Walker-Hirsch, 2007, p. 31)

bodies of people with IDD to become "sticky" with latent emotions that distinguish people with

IDD as "outside" of society[12].

Robert McRuer's concept of compulsory able-bodiedness, an idea that builds upon and

constitutes the conditions of compulsory heterosexuality, has also been incredibly helpful in

defining a "natural attitude" or "life-view" that constructs how beings-in-the-world engage

within society[13]. It will be argued within this thesis that disability serves as the

phenomenological breakdown of the able-bodied natural attitude. This breakdown has the radical

potential to deconstruct any coherent understanding of what it means to be an able-bodied being-

in-the-world, as tightly held concepts of self-sufficiency and of a certain kind sexual culture are

revealed as myths. This disruption of able-bodiedness is discussed further in Chapter Four

through media representations and reviews that reveal the instability of an able-bodied versus

disable-bodied binary.

In order to understand how certain stigmas have been attached to those with IDD, a

historical analysis of how disability was formulated generally is essential. Using scholarly

articles that elucidate the connection between eugenics and institutionalization, this thesis

engages upon a thorough analysis of the history of eugenic theory, and how this system of

knowledge developed the conditions of mass-institutionalization and sterilization globally.

Finally, this thesis utilizes a film review in order to better understand how intellectual and

developmental disability has been portrayed within media, and how these representations have

worked to inform and affirm present social consciousnesses surrounding disabled embodiment.

Films and media are vital to this thesis because they serve as a primary method of interaction

between people with disabilities and non-disabled community members. Due to legacies of

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[12] (Ahmed, 2007, p. 127)
[13] (McRuer, 2002, p. 371)

social isolation caused by the mass institutionalization of people with disabilities, social

consciousnesses of disabilities have been formulated almost exclusively by representations of

disabled characters in media[14]. Additionally, many social movements for disability rights gained

an elevated platform when general audiences were shown the experiences of people with

disabilities on screen[15]. Media analysis is thus crucial to the formulation of disability studies as

media has the potential both to perpetuate harmful stereotypes concerning disabled embodiment

as well as to deconstruct able-bodied norms of the human experience. This thesis relies upon the

voices of people with IDD in order to understand how people with IDD view current

representations of disability in media—elucidating both current obstacles to sexual access, as

well as the possible distortion of intellectual and developmental disabilities within television and

film. This work was primarily accessed through blogs, or through media reviews published

within journals and periodicals.

Chapter Overview

        The first chapter of this thesis aims to define what phenomenology is and how it is

relevant to a discussion about disability and sexuality. This chapter will establish how our

consciousness are directed towards beings within the world in ways that are necessarily altered

and framed through our lived experiences. These experiences imbue things within the world with

certain emotions or biases that are often taken for granted as the truth or nature of those things.

This unconscious judgement of the world constitutes a "natural attitude." A phenomenological

perspective aims to disrupt the idea that the world operates within objective truths; positing

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[14] (Davis L. J., 2006, p. 11)

[15] As evidenced by Geraldo Rivera's documentary on Willowbrook, a state-run institution for people with disabilities, where the conditions and treatment of inmates within institutions was revealed for the first time to general audiences. This documentary led to massive appeals for deinstitutionalization and the rights of people with disabilities (The Closing of Willowbrook, 2021).

instead that our understanding of the world is the product of our subjective experiences[16].

Positioning embodiment as crucial to the formulation of one's experiences has interesting

applications to queer and disability studies, and this first chapter will explore how the bodies of

people with disabilities become "problem-bodies" because of their radical potential to

breakdown the coherency of an able-bodied natural attitude.

The second chapter builds on the potential consequences that arise when subjective

feelings become reconfigured as objective truths. Engaging in a historical analysis of eugenic

theory and the rise of institutionalization, the second chapter of this thesis reveals how social

perceptions of people with disabilities as immoral or depraved were taken for granted as the

nature or truth of all people with disabilities. These views had significant social power and led to

the mass institutionalization and sterilization of people with IDD. People with IDD were imbued

with infantilizing rhetoric that defined them as "perpetual children"[17]—a view that has persisted

today and is the reason why many people with IDD still experience barriers to sexual expression

and accessibility as caretakers unconsciously believe that people with IDD are asexual.

Additionally, because it was believed that people with IDD were socially inept, social views of

people with IDD as "sexual menaces" became popular and contributed to the practice and

proliferation of the forced sterilization of people with disabilities.

The third chapter continues to analyze how certain social perspectives are still observable

within a post-institutionalist society. While deinstitutionalization and the termination of forced

sterilization constitute areas of major progress for the treatment of people with IDD, barriers to

sexual access still exist in more latent, complicated ways. Issues of sexual privacy, over-

medicalization, and exclusive educational systems continue to prohibit a sexual culture for many

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[16] (Kuryla, 2020)
[17] (Thompson & Townson, 2015, p. 52)

people with IDD. This urgency to "protect" people with IDD from sexuality persists through these methods, and indirectly serves to isolate people with IDD from society.

The final chapter of this thesis considers how the exclusion of people with IDD from society and from a sexual culture is perpetuated through media portrayals of disability. These representations have often served to bolster the social positioning of people with disabilities as "outside" of the "natural" sexual culture. This chapter engages with a variety of television shows and movies in order to understand how socially mandated conceptions of heteronormativity and able-bodiedness can either be sustained or deconstructed through the inclusion of disabled characters.

Ultimately, this thesis intends to disrupt what is considered "normal" in terms of embodiment, as notions of normalcy are necessarily imbued with expectations of able-bodiedness. Phenomenology is incredibly useful in drawing out how although disability is socially constructed, differences in ability are often seen as objective realities that necessarily implicate able-bodied people with certain values that privilege their lived experiences as normal and thus superior to the lived experiences of people with disabilities. The thrust of this thesis, therefore, is not to "normalize" disabled embodiment, because the notion of normalization necessitates that there is a normal upon which we can rightfully compare. Rather, this thesis aims to make the "normal" and "abnormal" unintelligible through the deconstruction of imbued values that position non-disabled bodies above disabled bodies.

Chapter 1: Introducing a Phenomenological Understanding of Disabled Embodiment

"Only when the world's taken-for-granted and self-evident condition is interrupted can the world itself appear and be brought into question, that is, its appearance relies on its being brought into question"

-- Lisa Diedrich, *Breaking Down: A Phenomenology of Disability*[18]

Pioneered by philosophers such as Edmund Husserl and Maurice Merleau-Ponty, phenomenology has become a widely used methodology by which to understand the individual's experience of the world. Urging to "go back to the things themselves,"[19] phenomenologists resist approaches to knowledge that claim, with certainty, that truth can be objectively ascertained through positivist science[20]. Phenomenology, instead, engages with how our being-in-the-world is necessarily connected to how we formulate knowledge. Merleau-Ponty, in particular, puts out of question the possibility of a comprehensible, objective reality because, as he asserts, our body is a "unit of meaning" that both shapes and is shaped by our perceptions of objects-within-the-world through the frameworks and contexts we have adopted[21]. Building on the theory of embodiment introduced by Merleau-Ponty, this chapter aims to elucidate how natural attitudes towards what constitutes "proper" embodiment have served to designate disabled ways-of-being as necessarily inferior to able-bodied ways-of-being. This chapter uses a phenomenological standpoint to reveal and displace the unstable binary of able-bodiedness and disable-bodiedness. Engaging with the disabled body both as a condition of possibility and as a site for phenomenological breakdown, this chapter aims to understand the charged reality of what it means to be disabled in a society that privileges able-bodiedness.

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[18] (Diedrich, 2001, p. 211)
[19] (Willis, 2001, p. 3)
[20] (Willis, 2001, p. 2)
[21] (Reynolds, 2016, pp. 419-420)

On Phenomenology and Embodiment

In order to consider the potentiality of phenomenology as an elucidating force upon the condition of being disabled within the world, it is vital to discuss the defining ideas and methodologies present within phenomenological analysis. Investigating the experience of the individual is crucial to the production of knowledge because it reveals the unavoidable reality that our consciousness is inevitably a consciousness-of the world around us. This insight exposes that our being-in-the-world is mediated and granted by other beings-in-the-world through their perception of us. Our existence as a particular being-in-the-world— that is, our self-conception, however, is not simply produced through another's "innocent" gaze. Rather, from the moment of our being perceived, our status as a being-in-the-world is imbued with certain expectations and emotions that are framed through the perceiver's lived experiences. Our lived experiences develop a life-view that produces how we perceive the world. Life-views operate as the culmination of our experiences that grant meaning to our memory, and in turn, our future. All of our interactions within the world become necessarily framed through this life-view, making our understanding of the world wholly connected to our experience as an individual. This fundamentally alters our perception of the world in a way that necessarily reduces its capacity to be "objective." That is to say, our perceptions are intentional—we are directing our consciousness towards the world in a way that is framed by the life-view we have created.

Our perception of the world around us is thus pre-theoretical, or "non-thetic,"[22] insofar as we gain knowledge through our embodied experiences. Consciousness is therefore "taken not as a part of the world, but as the constitutive presupposition for experiencing any world whatsoever"[23]. Our consciousness-of the world is embodied because our perceptions are altered

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[22] (Kuryla, 2020)
[23] (Behnke)

by our physical possibilities. The world essentially "appears" to our bodies as "unfinished and in the making"[24] so that "any spatial thing is always seen from a particular standpoint,"[25] and this is precisely why our consciousness-of the world constitutes what we consider to be the true nature of the world. The world cannot be outside of our embodied consciousness of it, as our interactions within the world are what grants it meaning. Knowledge is, therefore, always perspectival "since it is always related to, and constructed by, the person engaged in knowing"[26].

More specifically, our bodies meaningfully alter our stance within the universe—that is to say, the condition of our body changes the way we perceive things and the way we are perceived by others. Our body is, therefore, not merely an object-in-the-world. The body is, rather, a "lived body" that it is singularly capable of perceiving meaning within its surroundings; in the words of the philosopher Elizabeth Behnke: "the lived body is a lived center of experience, and both its movement capabilities and its distinctive register of sensations play a key role in how we encounter other embodied agents in the shared space of a coherent and ever-explorable world."[27]

An example of how our embodiment is non-thetic, and, thus, creates the conditions upon which meaning can be perceived, is revealed through concepts such as space. As explained by Merleau-Ponty: "far from my body being for me merely a fragment of space, there would be for me no such thing as space if I did not have a body"[28]. Merleau-Ponty suggests that the understanding of space is first gained through one's embodied experience of space, rather than through theoretical or metaphysical understandings of space—highlighting the primary and

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[24] (Kuryla, 2020)
[25] (Behnke)
[26] (Willis, 2001, p. 2)
[27] (Behnke)
[28] (Merleau-Ponty, 2012)

unavoidable quality of embodied experience. This assertion also implies that the corporeal characteristics of one's body affects the manner in which they interact with other beings-in-the-world. In this way, people form "identical relationships with the body" and "the body forms the identity"[29]. Our bodily way-of-being shapes both our understanding of beings-in-the-world and how beings-in-the-world understand us.

This embodied experience can be used to understand how objects and beings become entangled by the life-views and emotions of their perceivers. As explained by the feminist and queer theorist Sara Ahmed, we "arrive 'at' [certain objects] with an expectation of how we will be affected by them, which affects how they affect us, even in the moment they fail to live up to our expectations."[30] Objects or bodies become "charged" or "sticky" because their status as objective beings-in-the-world becomes, prior to any theoretical understanding of them, wrapped up within the subjective manners in which we categorize and perceive them. The life-views that classify certain beings-in-the-world and encases them within our biases are axiomatic insofar as they are "already established in [the] mind by a Piagetian process of assimilation and accommodation"[31]. That is to say, we begin to form the life-views that shape our experiences from the first moment we begin to experience—leading to our life-views being closely connected to the emotions, mannerisms, and prejudices of those around us. Thus, many of our life views are historically produced insofar as they are built upon our assimilation into past systems of power and knowledge.

The life-view that frames our consciousness becomes an automatic means by which the world is mediated. The unreflective manner in which our affect and memory creates the world

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[29] (Davis L. J., 2006, p. 7)
[30] (Ahmed, 2007, p. 127)
[31] (Willis, 2001, p. 1)

around us is defined as the "natural attitude" by phenomenologists. Despite the fact that our standpoint frames our perceptions, there is a lack of recognition that our first-person experience is unique, and that beings-in-the-world are not necessarily imbued with the qualities and values that we have attributed to them. In the words of Behnke:

> In the natural attitude, not only are we typically straightforwardly directed toward objects rather than reflecting on the structures of our own subjective experience, but entities such as 'bodies' (whether these are taken as 'psychophysical realities' or 'embodied persons') are given as ready-made realities within a pregiven world; even the experiencer for whom such entities are given is him/herself taken as one entity among others in the world.[32]

However, it is precisely at the moment that the natural attitude is interrupted, halted, or disturbed that a phenomenological analysis can occur. The recognition that the world is shaped by our embodied experience of it allows us to begin to truly investigate the world and "return" to the objects-of-the-world. That is to say, the truths that have been imbued into objects-in-the-world can no longer be perceived as objective; allowing for us to begin to see objects as they are and not how we have imagined them to be. When we are no longer able to take our world for granted, we can begin to meaningfully understand the conditions for our own experienced reality.

"Problem-bodies"- The Creation and Embodiment of Disability

"The non-normative body – a body that appears as an object of fear and curiosity – is therefore considered an opportunity to think through values, ethics and politics that congregate around such bodies."

-- Goodley, *Dis/entangling Critical Disability Studies*[33]

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[32] (Behnke)
[33] (Goodley, 2017, p. 86)

Embodiment has thus far been established as a fundamental aspect of the phenomenological approach, mainly due to the fact that our embodied experiences create and mediate the world around us. Thus, it follows that the shapes, functions, and abilities of our bodies modulate the horizons of our experiences. The world, however, in its being shaped by the interactions of beings-in-the-world has been constructed for the sake of some bodies more than others. Many phenomenological disability theorists locate the disabled body as the point of disruption that suspends the natural attitude of able-bodiedness and reveals the condition of what it means to be a body-in-the-world. In this way, the disabled body becomes a "problem-body" that unsettles the comfortability of societies that have taken for granted and privileged the non-disabled body. It comes as no surprise, then, that "the word 'problem' shows up throughout disability studies to signify how lived bodies participate in a web of social relations and especially how certain lived bodies strain the threads of that ideologically delicate web."[34]

The disruption of the natural attitude of body and embodied experience itself through the "problem-bodies" of people with disabilities intimates that the condition of disability is necessary for any theoretical understanding of the "normative" condition of non-disability. Able-bodiedness can only be defined in relation to the condition of disabled-bodiedness- that is to say, "to be able-bodied is to be 'free from physical disability.'"[35] To interpret, therefore, able-bodiedness as prior to disability is to fundamentally misunderstand how able-bodiedness becomes a coherent, recognizable quality of being-in-the-world. This displacement also serves to disillusion any sort of clearly defined understanding of disability[36]. This is because identity categories in general are wholly interwoven within their inclusions and exclusions from other

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[34] (Chivers & Markotic, 2010, p. 10)
[35] (McRuer, 2002, p. 371)
[36] (Goodley, 2017, p. 85)

identity categories. Bodies (and therefore, identities), as understood by Merleau-Ponty, are not "natural species" but rather the products of "historical ideas"[37]. Thus, disability cannot be understood as an objective quality of being-in-the-world. Rather, the identity of "disabled" is mediated and socially constructed through both the individual with disability's subjective experience and the external expectations of their perceivers who hold certain beliefs about "what bodies should be or do."[38] This breaking down of familiar binaries has been essential to feminist and critical race theorists. Positioning marginalized populations as the foundations upon which privileged populations define themselves, through their comparison, as a supposedly self-enclosed identity deconstructs the potential of either group being independently coherent. The breakdown of these binaries causes identity categories to lose their rhetorical grip because the objectivity of the characteristics or natures of both the privileged and the marginalized are revealed as socially constructed[39].

This analysis displaces the binary between able-bodiedness and disable-bodiedness as the terms of the binary are revealed to be much more intimately connected than the what the natural attitude of embodiment would disclose. Using a Derridean method of deconstruction, it is clear that because disability is necessarily constitutive of ability, ability can no longer been seen as the pure or self-sufficient primary term within the able-bodied/disable-bodied binary—thus fracturing an able-bodied attitude of the world as "the" natural way-of-being. While this is productive for the work of crip theory and disability studies because it would seem to necessitate "new, inclusive and potentially exciting forms of response"[40] to the "problem-bodies" of the world, the capacity for disability to disrupt the natural attitude has been historically resisted and

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[37] (Butler, 1966, p. 520)
[38] **Invalid source specified.**
[39] (Guess, 2006, p. 649)
[40] (Goodley, 2017, p. 85)

even feared by those who would prefer to continue taking their bodily experience of the world for granted as the "natural" way of being. These historical consequences will be elaborated upon in the following chapter through the discussion of the urgency of Social Darwinism in defining and subordinating "problem-bodies."

Conclusion

This chapter has aimed to establish the phenomenological theory of embodiment and reveal how the breakdown of disability displaces the unstable binary of able-bodiedness and disable-bodiedness. Understanding the imbued nature of identity as a product of historical and subjective temporality, rather than as an objective nature within a body, helps to expose the manner in which the supposed inferiority of being disabled is constructed as a method by which to maintain the assumed superiority of not being disabled.

Chapter 2: Historical Perspectives

Understanding historical practices regarding the treatment of people with intellectual and developmental disabilities (IDD) is crucial to understanding why sexual autonomy has remained largely inaccessible for people with disabilities. Analyzing how disability has been socially constructed is vital for the phenomenological breaking down of any objective understanding of disabled embodiment. This chapter focuses on how the popularity of Social Darwinism throughout the 1800s and early 1900s has influenced the practices and social understandings of disabilities; leading to an unfortunate history of institutionalization, forced sterilization, community inaccessibility, and pervasive stigmas about people with IDD.

Social Darwinism

Beginning in the late 1800s and persisting into early 1900s, Social Darwinism became a popular method to classify and treat people. Eugenics was informed by the intellectually prior views of degeneracy theory, which postulated that humans had a certain amount of energy that could be lost or depleted overtime through "wrong living"[41]. It was believed that the "problems" of people who indulged "wrong living" compounded in successive generations—each generation being progressively worse off. This line of thought led to the notion adopted by eugenicists that certain people should not be allowed to build families. Believing that physical and mental ailments were caused by "bad" genetics, eugenicists emphasized the importance of restricting the capacity for people deemed as "unfit" to procreate. This knowledge-system purported a heavily classist and racist ideology, where the definition of "unfit" could broadly be applied to most marginalized populations. This served as the direct affirmation of the eugenicists (who were most often wealthy white men) believed racial and intellectual superiority. Eugenicists alleged

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[41] (Hodges, 1997, p. 18)

that one's genetics were implicitly connected to their capacity for success, commonly asserting that those with "bad" genetics were destined to an impoverished and immoral life.

Through the use of statistical data, however, eugenicists asserted that populations can be normed[42]. Eugenicists analyzed human characteristics through bell-shaped curves to understand not only what is average but what is extreme. Used as an approach to nonstandard populations, eugenics aims to norm what is defined as abnormal. Those who fall short of the characteristics defined as "normal" are differentiated as more than simply a derivative from the data, but as a deviant from society. Moral implications are applied to those who do not fit the norm, creating an urgency or "obsession" to eliminate "defectives"- a category that included the non-white, poor, "feebleminded," and physically disabled[43].

The definition of what is normal and what is abnormal is central to the production of an able-bodied natural attitude. The bodies of people with disabilities, as well as the bodies of black and indigenous people of color, become "abnormal" objects incapable of embodying the "proper" way-of-being— a way-of-being whose origins lie within eugenicist thought. The definition of disability is thus necessarily understood as socially constructed for the specific aim of placating the embodied experiences of non-disabled white people as the "norm" of human experience generally. Revealing the socially constructed nature of these limitations, this chapter uses a phenomenological standpoint to expose the subjectivity inherent within apparently objective qualities-of-being associated with people with IDD. To even begin to understand people with IDD as "defective," one must automatically assert that there is an "effective" group upon which disabled bodies can be normatively compared. However, given that disability is formative of ability, as discussed in the previous chapter, able-bodiedness cannot be understood

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[42] (Davis L. J., 2006, p. 6)
[43] (Davis L. J., 2006, p. 7)

as the objective condition upon which all other ways-of-being in the world can be compared against. Able-bodiedness and disable-bodiedness are mutually constitutive of one another, thus denying the possibility for either experience to be innately granted social superiority.

This chapter specifically investigates how eugenic ideologies have created the "menace of the feebleminded." Believing that mental disabilities were defects passed generationally between those with intellectual disabilities that inevitably rendered them disposed to immorality and sexual depravity, people with IDD were construed as a threat to society[44]. This, in turn, had consequences for the engagement of people with IDD within sexual relationships, as preventing and denouncing the sexual autonomy of people with IDD was vital to "protecting" the "overall fitness of the population"[45].

The rise of institutionalization

The primary method by which to discourage the proliferation of "defective" subpopulations was through institutionalization and sterilization. Utilizing a medicalized approach, influenced by eugenic movements that profiled human beings as "products of heredity, like stock,"[46] caretakers and family members of people with disabilities were made to understand institutionalization as the only way for a person with disabilities to receive adequate and proper care— despite the fact that abuse and neglect was rampant within institutions.

That being said, the institutionalization of people with IDD originally began as an educational effort, within the early 1800s, pioneered by Edouard Seguin and John Conolly, and supported by American physicians and educators such as Samuel Howe[47]. Believing that people with IDD were a particularly neglected population, Connolly asserted that, given the proper

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[44] (Thompson & Townson, 2015, p. 48)
[45] (Thompson & Townson, 2015, p. 48)
[46] (Rimmerman, 2017, p. 23)
[47] (Trent, 1994, pp. 12-13)

education and access, everyone could show "improvement in educational skills and moral rectitude"[48]. It is important to note that already apparent in this language is the socially constructed idea that "non-normal" bodies were inherently less capable of behaving morally. Schools were created across the United States for people with disabilities— one of their main objectives being to train people with IDD skills to become active members of their community's workforce[49]. The urgency to place people with IDD within schools or institutions was a result of prevailing social narratives that generated fear around people with IDD remaining idle at home. Mainly, it was thought that people with IDD would develop "loathsome habits," such as eating garbage, erratic bodily movements, and licentious behaviors if they were unproductive at home[50]. However, over time the focus on training people with IDD to return to their community's workforces changed to training people with IDD to work within the institution/school itself, thus perpetuating the institutional system through continual expansion[51].

Beginning in the mid 1800s, schools for people with IDD progressively became more like asylums insofar as they required custodial care facilities to care for long-term students. In particular, students with multiple disabilities had difficulty finding employment and returning to their home communities[52]. Pioneers of the educational movement such as Samuel Howe began shifting their views regarding the education and productivity of people with IDD, stating that their primary focus would no longer be preparing people with IDD for the workforce, but caring for and protecting their "humanity"[53]. This paternalistic notion is heavily influenced by eugenicist thought that considers bodies outside of the perceived standard of humanity as

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[48] (Trent, 1994, p. 13)
[49] (Trent, 1994, p. 23)
[50] (Trent, 1994, p. 26)
[51] (Trent, 1994, pp. 23-24)
[52] (Trent, 1994, p. 29)
[53] (Trent, 1994, p. 30)

necessarily deviant and in need of guidance. Economic hardships in the mid to late 1800s also affected the shift in purpose for institutions, as struggling communities and families pressured schools and institutions to remove and care for the people with IDD who were unable to find work. Additionally, industrialization saw an increase in urbanization as people began to flood into factories for work. Families found themselves placing their family member with disabilities in schools because they were no longer at home to support them[54]. Institutions were quickly overwhelmed by the amount of people within their care, and as one superintendent writes "it is about as much as we can accomplish to keep them comfortable and fed and clothed"[55]. Schools for people with IDD overtime began to resemble asylums rather than places for learning— adopting a more medicalized, custodial approach to care and even beginning to refer to pupils as "inmates" rather than students[56]. This resulted in abuse and neglect becoming steadily more common, as staff within institutions were receiving less training, working longer hours, and supervising more people than they feasibly could. Many institutions became involved in scandals revolving around the "mysterious deaths" of inmates and accusations of misconduct by staff and superintendents[57].

Another life-view that has served to define the condition of being for people with IDD is the notion that they are "perpetual children," who, due to their disability, are "permanently arrested" from adulthood[58]. This has had significant effects on the perceived horizons of possibility accessible to people with IDD, as parents of people with IDD were commonly told by medical professionals that institutionalization was the only way to ensure their child's proper

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[54] (Thompson & Townson, 2015, pp. 48-49)
[55] (Trent, 1994, p. 97)
[56] (Trent, 1994, p. 37)
[57] (Trent, 1994, p. 121)
[58] (Thompson & Townson, 2015, p. 52)

care[59]. By 1923, only six states did not have public institutions for "mental defectives"[60]. Additionally, in the United Kingdom, the English Mental Deficiency Act of 1913 allowed for the compulsory institutionalization of "mental defectives" and women "giving birth to an illegitimate child"[61]. The massive increase in institutionalization served the purpose of controlling the "deviant members" of society by completely removing people with IDD from public view[62], therefore erasing people with IDD from social consciousnesses. It also served as a method of sexual control, where the sexualities of inmates within institutions could be constantly monitored and regulated[63].

In regard to how the sexualities of people with disabilities have been perceived within able-bodied discourses of sexual embodiment, an interesting dichotomy emerges where people with disabilities are simultaneously seen as asexual (because of their imagined child-like state) and, conversely, as hypersexual. These contrasting views are held at the same time; often serving the same purpose of excluding people with IDD from "normal" sexual culture[64]. That these views can be simultaneously held contributes to the phenomenological notion that there cannot be an objective truth concerning the sexual nature of people with IDD. The individual experience of a person with IDD concerning their engagement in sexual relationships, therefore, must be the only reliable source for understanding how that particular person with IDD operates as a sexual entity.

That being said, the rise of mass institutionalization affirmed stereotypical life-views for many community members about the natures of people with IDD- situating people with IDD as a

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[59] (Thompson & Townson, 2015, p. 52)
[60] (Thompson & Townson, 2015, p. 49)
[61] (Thompson & Townson, 2015, p. 48)
[62] (Rimmerman, 2017, p. 23)
[63] (Thompson & Townson, 2015, p. 48)
[64] (Siebers, Sexual Culture for Disabled People, 2012, p. 86)

population outside of society, requiring constant supervision, and incapable of successfully engaging in relationships with others. The presumed propensity for people with IDD to be sexual deviants, in particular, was supposedly treated within institutions through various punishments, but most notably through the practice of sterilization.

The Practice of Sterilization

Within institutions, sterilization was a common practice used to reduce the sexual behaviors of inmates, as these were considered "detrimental to the inmates' well-being or offensive to 'social sensibilities'"[65]. Indiana, in 1907, was the first state to approve legislation allowing for the forced sterilization of people within institutions due to the belief that "criminality, mental problems, and pauperism were hereditary"[66]. These views were upheld on a national scale in 1924, when the United States Supreme Court decided in *Buck v. Bell* to allow the forced sterilizations of those with "conditions causing insanity or imbecility"[67]. Notably, Judge Wendell Holmes, within the majority opinion, states "it is better for all the world if, instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind . . . Three generations of imbeciles are enough"[68]. Although laws allowing compulsory sterilization were largely not enforced, around 20,000 people in the United States were sterilized- California being responsible for about half of these sterilizations[69]. Because people with IDD did not meet the norm of society, they were formulated as criminals and deviants, and it is evident that sterilization was used as a necessary means by which to "improve" society. Interestingly,

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[65] (Thompson & Townson, 2015, p. 49)
[66] (Krase, 2014)
[67] (Rimmerman, 2017, p. 22)
[68] (Rimmerman, 2017, p. 23)
[69] (Hubbard, 2006, p. 95)

legislation permitting the compulsory sterilization of people with disabilities still exist within

many states, indicating a lack of care in removing these harmful laws from legal frameworks[70].

Sterilization grew in popularity across the world throughout the early to mid 1900s, and

many countries adopted laws advocating for the sterilization of people with disabilities. Many of

the eugenic techniques developed within the Nazi regime were influenced by the policies

developed within the United States and Great Britain[71]. Germany, in 1933, passed the "Law for

the Prevention of Offspring with Hereditary Diseases," which allowed the compulsory

sterilization of the disabled to avoid "the possible transmission of hereditary diseases." As can be

imagined, the list of hereditary diseases was vague and broad and ranged from mental disabilities

to epilepsy and even to alcoholism. This act called for the sterilization of around 400,000 people

before the end of World War II[72], and actually received praise within the prestigious English

science magazine, *Nature*, stating that the law commands the "appreciative attention of all who

are interested in the controlled and deliberate improvement of human stock"[73]. Social Darwinism

was so fervently embraced during this time that even countries on opposite ends of political and

moral spectrums could find similarities in their policies regarding people with disabilities.

Social narratives about people with IDD also influenced the popularization and

normalization of sterilizing those within institutions. People with IDD were forcefully sterilized

due to the idea that childhood should be pure and innocent, leading caretakers and medical

professionals to conclude that people with IDD should remain perpetually ignorant of sex[74].

Given the stigma that people with IDD are "permanently arrested" in a child-like state, there was

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[70] (Thompson & Townson, 2015, pp. 56-57)
[71] (Hubbard, 2006, p. 94)
[72] (Law for the Prevention of Offspring with Hereditary Diseases (July 14, 1933), n.d.)
[73] (Davis L. J., 2006, p. 10)
[74] (Hodges, 1997, p. 18)

an expectation that people with IDD should be asexual. However, people within institutions

showed interests in sexual relationships and engaged in sexual behavior. These interests were

formulated as immoral and fundamentally wrong by medical professionals who denied the

possibility that people with IDD could desire sexual relationships, and thus punishments like

sterilization were enforced to prevent the seemingly deviant behavior. Sterilizations were also

used to stop people within institutions from masturbating. This was commonly enforced due to

the belief that masturbation caused disease[75] and insanity[76]. Women, and in particular women of

color, were also more likely to be institutionalized and sterilized than men because of pervasive

narratives that alleged "feebleminded" women had an "unbridled sexuality" that caused them to

pose a "sexual threat to respectability and normal family life"[77].

Although the practice of compulsory sterilization lost credibility after the end of World

War II, the sterilization of people with disabilities persisted evasively within institutions. Despite

the fact that sterilizations would soon become strictly voluntary, the choice to be sterilized often

came with significant benefits- such as being released from the institution's care[78]. These

benefits served to coercively encourage people with IDD to "choose" to undergo sterilizations.

As such, people within institutions were provided a superficial illusion of choice regarding

sterilization, and this has persisted today. People with IDD are commonly convinced, by medical

professionals and caretakers, that sterilization is in their best interests. Women with IDD, in

particular, are the subjects of coercive sterilization techniques as they are often told that they

cannot properly care for children due to their disability[79]. In fact, up until the late 1990's,

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[75] (Hodges, 1997, p. 18)
[76] (Hodges, 1997, p. 20)
[77] (Thompson & Townson, 2015, p. 51)
[78] (Thompson & Townson, 2015, p. 50)
[79] (Thompson & Townson, 2015, p. 58)

mothers with IDD could lose their children, without any proof of abuse or neglect, simply due to their disability status[80]. That is to say, women with disabilities, even prior to their interaction with community members, have been imagined as incapable of being proper mothers because of their disability status—emphasizing the influence of negative attitudes towards disability and the barriers these negative life-views have produced in the everyday lives of people with IDD.

These barriers can potentially be dismantled through the phenomenological engagement with mothers who have IDD. In order to expose the falsehood of life-views that define people with disabilities as incapable mothers, the actual embodied experiences of mothers with disabilities must be centered. Although mothering might look different between a mother with disabilities and a non-disabled mother, these differences should primarily amount to variations in practice rather than in perceived natural aptitudes. A phenomenological analysis emphasizes the impossibility in accurately assuming the level of support needed by mothers with disabilities based on some assumed or "given" quality of being that inherently classifies all people with IDD with certain aptitudes (or inaptitude's) towards motherhood. The support needed by mothers with IDD, and mothers in general, should be defined by mother themselves because the individual's lived experience of motherhood is the only reliable source upon which levels of support can be determined.

Community consequences

Beyond the physical consequences of the stigmas surrounding people with IDD, these beliefs impacted the ability of people with IDD to make personal decisions about their sexuality and restricted their access to sexual expression. This is evident insofar as people deemed as "defective" were legally prohibited from marrying [81]. Passing originally in Connecticut in 1895,

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[80] (Thompson & Townson, 2015, p. 58)

[81] (Thompson & Townson, 2015, p. 49)

laws restricting marriage accessibility expanded rapidly across the United States, and in less than 20 years, more than half of the US prohibited people with disabilities from marrying[82]. The capacity to exist within society as equals, rather than as "defectives", was largely denied to people with IDD. Once institutionalization became a norm, people with IDDs were rarely seen within their own communities- especially given that institutions were almost completely rural and thus utterly removed from people's towns or cities[83]. Casted as a "defective class[84]," people with IDD were shunned and isolated from society, and this is especially evident through the "ugly laws" that expanded across the United States. Innately connected to the assumption (informed by eugenics) that people with disabilities are and will consistently be poor, ugly laws prohibited people with noticeable disfigurements or deformities from being within public spaces as a ploy to prevent "unsightly" acts of begging[85]. Laws such as these, and the assumption that institutionalization was the only available path for people with IDD, have led to an enduring legacy of inaccessibility because many modern cities, spaces, and programs have not been developed for people with IDD to exist within. Additionally, ugly laws bolster the historical foundation upon which common life-views concerning the perceived natures of people with IDD as morally deviant and in-human are based.

Only since the 1960's has a global movement for the eradication of large-scale institutions for people with disabilities began to take root, and only 13 states within the US, as of 2015, have succeeded in removing all people with IDD from institutional care into smaller scale community homes[86]. Advocates for deinstitutionalization emphasize that institutional

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[82] (Thompson & Townson, 2015, p. 49)
[83] (Deinstitutionalization: Unfinished Business, 2012)
[84] (Davis L. J., 2006, p. 9)
[85] (Schweik, 2009, p. 23)
[86] (Lulinski & Tanis, 2018, p. 3)

environments restrict the capacity for people to fully express themselves, as people with IDD are far too often deprived of their right to privacy and their choices restricted by medical authorities[87]. A lack of sexual access, created by restrictive policies including the inability to lock one's own door[88], have long left people with IDD without a "sexual culture[89]". That is to say, sexuality has long been situated as abnormal or immoral for people with IDD through histories of institutionalization and sterilizations, and only recently have self-advocates been able to begin to break-away from those long-held attitudes.

Conclusion

The sexual autonomy of people with intellectual and developmental disabilities (IDD) has historically been conceived as deviant and depraved through the practices of institutionalization and sterilization spurred by eugenics. Social Darwinists, believing that those with "bad" genetics should be prevented from procreation, created the conditions for the mass institutionalization and sterilization of people with IDD. People with IDD were removed from their communities and casted as social pariahs, destined to a life of poverty and criminality. These attitudes continue to have consequences in both subtle and blatant ways, as many people with IDD still live within institution-like settings and are victims of coerced sterilizations. Stigmas that people with IDD cannot understand their sexual desires, nor responsibly act as sexual citizens are insinuated through the continued practice of medicalizing and pathologizing the sexual behaviors of people with IDD.

This chapter focused on how eugenics led to the historical practices of institutionalization and sterilization, the unfortunate conditions afforded to people with IDD, and the negative social attitudes created through these systems. Examining how social conceptions of disabilities have

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[87] (Siebers, Sexual Culture for Disabled People, 2012, p. 45)
[88] (Deinstitutionalization: Unfinished Business, 2012)
[89] (Siebers, Sexual Culture for Disabled People, 2012, p. 38)

historically evolved from eugenicists conceptions of "normal" and "abnormal" human embodiment reveals the importance in deconstructing these attitudes through a phenomenological framework that denies the givenness of any identity's position as superior or inferior. The next chapter will discuss more closely the current conditions of people with IDD in regard to both areas of progress and of stagnation—focusing on how the legacies of eugenics and institutionalization have affected how the sexualities of people with disabilities are perceived by care-takers and non-disabled community members.

Chapter 3: Disability Today- Accessibility and Sexuality

While significant progress in the field of human rights for people with IDD has been
made since the 1800s, the legacy brought upon by Social Darwinism, institutionalization, and
sterilization continues to influence the current practices and conditions people with IDD face.
Largely due to the successes of the self-advocacy movement beginning in the 1960s, the human
rights of people with IDD have been globally recognized. However, some of the policies that
have arisen from this progress have latently perpetuated a lack of sexual accessibility for people
with IDD.

This chapter focuses on how the sexuality of people with IDD has progressively become
a larger topic of conversation amongst disability advocates, beginning with an examination of the
self-advocacy movement and the successes and critiques of the globally implemented
"Convention on the Rights of Persons with Disabilities." Following this discussion will be an
analysis of the progress of deinstitutionalization—that is, the removal of people from large-scale
"homes" into community-based living centers. This chapter will also investigate the continued
inaccessibility of sexuality for people with IDD due to issues of sexual privacy, over-
medicalization, and faulty sexual educations. It is important to acknowledge that people with
IDD are a sexually vulnerable population, and this chapter will conclude by analyzing politics of
consent regarding people with IDD- recognizing the ways in which policy formation for consent
can work for and against the interests of people IDD.

The Self-Advocacy Movement and Global Measures for Human Rights

Emerging within the late-1960s in Sweden, the self-advocacy movement is credited as a
major impetus for the implementation of a "social," rather than medical, model of disability.
Prior to the self-advocacy movement, the living-conditions of people with IDD were determined
by eugenicist models of treatment that reduced the perceived humanity of people with disabilities

by categorizing them as "defective"[90]. As discussed in the previous chapter, this led to the justification of extreme abuse in institutions and a lack of personal agency for people with IDD to make decisions regarding their own health and sexuality, amongst other things. A significant theorist that contributed to the self-advocacy movement, Dr. Bengt Nirje, is quoted to have said "To be allowed to be human means to be allowed to fail"—a direct response to medical professionals and care-takers who asserted that people with disabilities could not be trusted to make decisions for themselves[91]. This quote also nods to the fact that people with disabilities have historically been framed as outside of society; highlighting how the natural attitude towards the human condition is formulated as able-bodied.

Abandoning this medical disability model "that portrayed individuals with disabilities as incapable and in need of protection and correction"[92], the self-advocacy movement successfully introduced a social model of disability that understood the manner in which disability was created through "social stigma, stereotypes, and discrimination"[93] that, in turn, restricted the capacity for people with disabilities to fully engage with society. The social model can be used to phenomenologically deconstruct the notion that people with disabilities are inherently less human than non-disabled community members. The conditions that create disability are not found within people with disabilities themselves but within social structures that have been formulated to exclude people with disabilities. Disability was thus redefined as "a limitation that resulted from social oppression and practices of discrimination"[94].This new model proved to be innovative, and other movements, like LGBTQ, racial justice, feminist, and civil rights

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[90] (Davis L. J., 2006, p. 7)
[91] (The Self-Advocacy Movement 1980, 2021)
[92] (Ruiz, 2017, p. 92)
[93] (Ruiz, 2017, p. 93)
[94] (Ruiz, 2017, p. 93)

movements, applied the model to understand their own subject positions. For example, feminists (such as Judith Butler) have used a social model of sex and gender to reveal that, rather than being the product of inherent biological qualities, the categories of gender and sex are more-or-less "performances" that we engage in. This understanding rejects the "masculine/feminine binary structures" that have insisted that gendered behaviors are inherently connected to one's sex. This model has also been useful for feminists to theorize how the category of "female" has been socially constructed (rather than biologically necessitated) as subordinate to the category of "male"[95].

Indicated by the slogan "nothing about us without us," the self-advocacy movement rejects models of treatment that have historically denied the agency of people with disabilities in their own choices and lives[96]. The denial of people with IDD from their meaningful engagement in the structural processes of their lives especially relates to how life-views concerning disability from a non-disabled perspective have historically been taken as objective truth. The opinions and experiences of people with IDD were not understood as necessary to the formulation of legislation for the rights of disabled people because those within power relied upon their preconceived notions of what they believed people with IDD would want and need. This often led to protectionist and paternalist logics within disability discourse, as those with infantilizing views towards disability were given a privileged position in the discourse's formulation. The work of self-advocates has been crucial in breaking down the intellectual and social authority of previous models of disability.

A phenomenological standpoint reveals that legislation for disability rights have historically failed to address the needs of people with disabilities because those typically writing

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[95] (Butler, 1966, pp. 520, 527)
[96] (Ne'eman, 2017, p. 21)

these laws subconsciously hold the ableist view that successfully addressing disability means adjusting social structures so that people with disabilities can better participate in an able-bodied way-of-being. Assuming an able-bodied position as the natural, preferred way-of-being produces social consciousnesses that will always and inevitably denigrate disabled embodiment. Thus, breaking down the qualities and values we have imbued into able-bodied and disable-bodied ways-of-being is crucial to formation of responsive legislation that thoughtfully engages with, rather than erases, disabled ways-of-being.

Fundamentally altering the way in which disability is understood as an external, societal issue rather than an internal problem with the individual, the self-advocacy movement is responsible for much of the progress this chapter will discuss. Some of the major platforms of the self-advocacy movement include the banning of large-scale institutions, the implementation of employment programs, the prohibition of forced sterilization, and the recognition of the sexual autonomy of people with disabilities. To varying degrees of success, these platforms have been globally implemented through the Convention on the Rights of Persons with Disabilities (CRPD), which was adopted by the United Nations in 2006. While there had been earlier conventions, such as the UN Declaration on the Rights of Mentally Retarded Persons in 1971, these conventions held "patronizing and pejorative visions towards people with disabilities"[97]. The CRPD, on the other hand, adopted an approach "that centered on the autonomy, dignity, and equality of persons with disabilities"[98].

However, the CRPD is not free from criticism. Although it makes leaps and bounds of progress from its predecessors, the CRPD still holds somewhat conservative views towards the sexuality of people with disabilities. When concerns about sexuality are presented within the

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[97] (Ruiz, 2017, p. 93)
[98] (Ruiz, 2017, p. 93)

articles of the CRPD, they typically use language that strengthen the "protective trend" of the medical model of disability that asserts, for example, that people with disabilities need to be guarded from sex[99]. The CRPD also falls victim to the over-medicalization of the lives of people with disabilities, as sexual and reproductive rights are almost only mentioned within the convention's article on health[100]. This hyper-fixation on health misunderstands the interests of people with disabilities as needing "protection," despite advocates and civil society members calling for the implementation of global programs to advance the "sexual desire, freedom, and self-determination" of people with disabilities[101]. Thus, it is clear that there is still progress to be made in regard to the social barriers that exclude people with disabilities from sexual expression.

Deinstitutionalization

A major platform for the self-advocacy movement is the elimination of large-scale institutions (deinstitutionalization). As a significant and urgent goal of the CRPD, deinstitutionalization has been implemented to varying degrees of success globally. Deinstitutionalization became a major rallying point for people with disabilities and advocates in the 1960s when multiple class action lawsuits and increased surveillance of institutions revealed the "appalling conditions and the poor treatment"[102] of patients. Exposés such as Geraldo Rivera's "Willowbrook: The Last Disgrace," a televised documentary released in 1972 about a long-term institution for adults with developmental disabilities in New York City, unmasked the inhumane treatment of people with IDD within institutions and gave the public a first-hand perspective on institutional life. Massive reform was demanded by the parent advocacy groups who were able to see, for the first time, the true conditions of their children's supposed "care"[103].

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[99] (Ruiz, 2017, p. 94)
[100] (Ruiz, 2017, p. 96)
[101] (Ruiz, 2017, p. 96)
[102] (Davis, Fox-Grage, & Gehshan, 2000, p. 2)
[103] (The Closing of Willowbrook, 2021)

While the effect of media portrayals on social consciousnesses will be analyzed in depth in the next chapter, it is important to recognize the transformative quality the representation of disability on screen can have upon audiences who most likely have never met or interacted in prolonged, meaningful ways with people with disabilities. It is incredibly easy to hold attitudes towards disabilities that are unfounded or biased towards an able-bodied perspective when one has never been introduced to an alternative perspective. The representation of disability on screen has the radical phenomenological potential to breakdown what general audiences have taken for granted in regard to "proper" forms of human embodiment. Geraldo Rivera's documentary exposed the horrific reality of institutionalization to millions, and thus the perspective that people with disabilities should be treated within institutions (because of historically ingrained eugenicist values) necessarily had to breakdown. The language of eugenics, as this documentary revealed, did not just serve to rhetorically position people with disabilities as lesser than human, but it manifestly created the conditions for people with disabilities to be treated as if they truly were, in an objective and natural sense, lesser than human.

Supreme court cases such as *New York State Association for Retarded Children v. Rockefeller* in 1973 resulted from the advocacy of parents of Willowbrook patients. This case ruled that "people with developmental disabilities should live free from cruel and unusual punishments" and that people with IDD should be "entitled to at least the same living conditions of prisoners"[104]. Clearly, there were still major steps to be taken in regard to understanding people with disabilities as people and not as inmates. The Americans with Disabilities Act (ADA) passed in 1990, and this Act was particularly helpful in cultivating conditions for equality

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[104] (Linnell & Wieck, 2012, p. 51)

for people with disabilities. The ADA provided legal recourse for the discrimination against

people with disabilities in public life— particularly in the areas of employment and public

accessibility[105]. The ADA was quickly used to legislate for a variety of cases concerning the

inequitable conditions people with disabilities faced. For example, in 1999, the ruling of

Olmstead v. Lois Curtis relied upon the ADA in order to mandate the closing of institutions—

requiring that states "make reasonable modifications to their programs to foster the placement of

individuals in the least restrictive setting appropriate for each individual"[106]. The mandate's

language of "least restrictive setting," in particular, helped bolster the urgency of the movement

towards deinstitutionalization. That being said, there are currently no states that are in

compliance with *Olmstead v. Lois Curtis*, calling into question the case's efficiency and success

in implementation[107].

There are a variety of barriers that limit state success in deinstitutionalization. Negative

stereotypes concerning people with disabilities account for one of these barriers, as there is

significant community resistance to the placement or integration of people with IDD into

residential communities[108]. This "not in my backyard" mentality can be attributed to the legacy

of eugenic theories which claimed people with IDD were morally deficient, and to the lack of

interaction between people with IDD and community members due to decades of social isolation

caused by institutionalization[109]. These stereotypes, along with issues of funding, have greatly

hindered the transition from large-scale institutional living to community-based living. As of

2015, 18% of people with IDD still live in settings of seven or more people, and 21,103 people

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[105] (What is the Americans with Disabilities Act (ADA)?)
[106] (Linnell & Wieck, 2012, p. 52)
[107] (Linnell & Wieck, 2012, p. 52)
[108] (Davis, Fox-Grage, & Gehshan, 2000, p. 20)
[109] (Davis, Fox-Grage, & Gehshan, 2000, p. 20)

live in state-operated institutions. It is believed that by the year 2030 the United States will be institution-free—an estimate that is over three decades after wide-spread advocacy for deinstitutionalization following the exposé of Willowbrook[110].

Sexual Rights and Barriers to Care

Although the eradication of large-scale institutions is an incredibly important goal, there are still significant troubles that arise within community-based care centers. Some of these issues include the lack of sufficiently trained support professionals due to high staff turn-over caused by low wages and a lack of professional incentives[111]. Support professionals within community-based homes for people with disabilities are trained quickly because of a constant need for more workers. These trainings can often lack a sufficient focus on how staff should support the sexuality of people with IDD because "pleasure is simply not a priority"[112]. Rather, support professionals are encouraged to focus on developing life skills or adaptive behaviors (like practicing personal hygiene and using public transportation)[113].

This lack of support in matters of sexuality indicates a general issue with how the sexualities of people with IDD are formulated within systems of care. This is despite the fact that sexuality, in general, has become increasingly important within the global sphere, as indicated by the slogan "sexual rights are human rights"[114] The demand for sexual rights emerges from the connection that when one is suppressed sexually, they are oftentimes suppressed in other aspects of their lives as well. Thus, many human rights organizations have begun to consider sexual rights as one of the "prerequisites" for "equality and justice"[115]. This perspective holds true for

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[110] (Lulinski & Tanis, 2018, pp. 1-2)
[111] (Davis, Fox-Grage, & Gehshan, 2000, p. 20)
[112] (Alexander & Gomez, 2017, p. 115)
[113] (Alexander & Gomez, 2017, p. 115)
[114] (Committee on Economic, 2016)
[115] (Sexual Rights Are Human Rights, 2015)

disability advocates as well, as indicated by the following quote: "by silencing and rejecting the sexuality of those who are differently embodied, [people who hold disability stigmas] 'damage the very possibility of human becoming'"[116] for people with IDD. The sexual exclusion of people with IDD works to stealthily identify people with IDD as less than human.

The systems that exclude people with IDD from sexuality are ubiquitous, and the reasons people with IDD are denied sexual autonomy oftentimes relates to paternal motives of "protection". The language of legislation such as the UNCRPD is often oriented towards sheltering people with disabilities from abuse, rather than safeguarding the equal participation of people with disabilities in sexual expression[117]. When people with IDD are denied the opportunity to learn about sexuality, however, the very cycles of violence and abuse that "protective" policies aim to eliminate are perpetuated[118]. Additionally, the fear of people with IDD being sexually exploited has led to the continued (and common) practice of "informed" sterilization [119].

The negative language of protection, which upholds that people with disabilities should be free from abuse and exploitation, misplaces the blame for sexual abuse within people with disabilities and not within the systems that have created the conditions for their sexual vulnerability. A phenomenological lens helps to breakdown the false and harmful belief that people with disabilities are innately prone to sexual misuse because it reveals that the high risk of sexual violence against people with disabilities is "socially created," rather than biologically given[120]. The systems that perpetuate sexual vulnerability include a lack of sufficient sexual

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[116] (Ruiz, 2017, p. 93)
[117] (Addlakha, Price, & Heldari, 2017, p. 7)
[118] (Hollomotz, 2009, p. 110)
[119] (Thompson & Townson, 2015, p. 58)
[120] (Hollomotz, 2009, p. 109)

education for people with IDD and negative stigmas surrounding intellectual disability in general.

In regard to sexual education, students with IDD can find themselves in classrooms that fail to appropriately accommodate their disability and thus they have difficulty in meaningfully processing the material being presented. General or mainstream educators are oftentimes not aware of how to support their students with disabilities, or they lack the training to produce multi-modal, carefully paced teaching plans, and thus discussions about sexuality can fail to sufficiently adapt to the learner's needs[121]. This is coupled by the fact that sexual educations often only address sexuality through heteronormative, able-bodied lenses[122]—therefore positioning disabled or queer embodiments of sexuality as abnormal and unsuitable for public discourse. Referred to as "sexual ableism" by the disability theorist Michael Gill, people with IDD are labelled as "unable to live and act in sexually deliberate ways"[123] because of social consciousnesses that exclude and vilify embodiments of sexuality that lie outside of the perceived norm or natural sexuality. It is thus vital that attitudes which postulate the primacy and superiority of able-bodied sexuality are broken down and transformed so that there is no longer a coherent "norm" of sexuality that becomes the beholden perspective taught within sexual education courses.

The lack of comprehensive sexual education has consequences on the sexual health of people with IDD. Without a circumstantiated amount of sexual understanding, people with IDD, when in situations of abuse, can have difficulty identifying- and thus reporting- sexual misconduct. Additionally, even when people with IDD report sexual abuse, they are often not

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[121] (Walker-Hirsch, 2007, p. 14)
[122] (Andrabi, 2018)
[123] (Gill, 2015, p. 147)

seen as reliable witnesses[124]. Therefore, the implementation of meaningful sexual education programs is necessary to ensure both that people with IDD are aware of their sexual rights and can act upon those rights.

Additionally, recognizing people with IDD as potential sexual beings creates discomfort for caretakers who would prefer to label the people they support as "perpetual children" and thus should be kept "ignorant" of sex. This becomes a significant issue because when caretakers refuse to talk about sexuality with people with IDD, people with IDD "remain unaware of their rights"[125] (including rights to provide or refuse consent)—which, as revealed before, propagates the social conditions which perpetuate sexual violence.

While the conditions for sexuality have improved in community-based homes, as compared to the conditions within institutions, people with IDD still report issues with care-takers restricting their sexual expression. As reported within a study by psychologists Christina Fitzgerald and Paul Withers in 2013, many women with IDD living in group-homes reported that "they were not 'allowed' to have sex with their boyfriends and feared the consequences of getting 'caught'"[126]. Additionally, people with IDD living within group-homes experience barriers to their sexuality as a result of over-medicalization that in turn limits their access to privacy. People with IDD are subjected to increased surveillance in their sexual activities and interests- limiting their capacity to make their own sexual decisions. While there are benefits to this medicalization, as it is important to consider whether people are aware of the consequences of a sexual relationship, over-medicalization convolutes the process of sexuality—a process that society commonly characterizes as passionate spontaneity[127].

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[124] (Walker-Hirsch, 2007, p. 31)
[125] (Alexander & Gomez, 2017, p. 116)
[126] (Alexander & Gomez, 2017, p. 116)
[127] (Siebers, Sexual Culture for Disabled People, 2012, p. 45)

To that end, people with IDD experience challenges in regard to their sexuality because caretakers are hesitant to be liable for any possible breaches in policy. Because the field of sexuality for people with IDD is heavily surveilled and take on a negative "protection from" stance, staff are left believing that "they are not able to support a customer's sexuality, and fearful about the consequences if they do"[128]. This is especially evident in the legislation regarding whether a person with IDD is capable of giving consent. Policies and decisions such as *People v. Easley*[129] require that people with IDD understand the risks and consequences of sexual relationships before they engage in sexual activities, and this is determined through three key elements: "capacity, information, and voluntariness" (all of which are impossible to be precisely quantified)[130]. Despite the drawbacks of ambiguity that the process of determining consent inherently produces, it is important to recognize that this legislation does important work insofar as it ensures that people with IDD have the tools and language to express themselves sexually and understand their responsibilities to others before engaging in any sexual relationships.

People with IDD oftentimes rely upon care-takers to educate them on the tools to succeed in the consent-determination process, but issues of training and staff bias means that many people with IDD struggle to achieve consenting status[131]. On a positive note, however, some agencies and non-profits that support people with IDD, such as the Young Adult Institute of New York, have implemented courses for the people they support in order that they can meet the legal

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[128] (Alexander & Gomez, 2017, p. 117)

[129] *People v. Easley* was argued in 1977 and determined that the "mental capability to form an intelligent opinion" on the subject of sex is a necessary requirement for one to be determined as capable of giving consent." This was determined after Frank Easley was convicted of rape in the third degree for engaging in sexual intercourse with a woman who was determined under law as "mentally defective" (People v. Easley, 1977)

[130] (Walker-Hirsch, 2007, p. 184)

[131] (Walker-Hirsch, 2007, p. 186)

requirements to be consenting[132]. Operations such as YAI's, where sexual consent programs are specifically designed for people with IDD, are creating actionable steps towards recognizing and advocating for the sexual rights of people with disabilities insofar as they create safe, supportive environments in which essential sexual skills can be developed.

Conclusion

When considering social advancements in regard to the treatment of people with disabilities, it is easy to point out obvious positive changes. While the human rights of people with disabilities has become a global prerogative- leading to legislation such as the UN CRPD that advocates for equal opportunities for people with disabilities- there remain certain areas of oversight where the compulsion to separate those with disabilities from those without remains imperious. In particular, the advancement of sexual accessibility for people with IDD continues to be overshadowed by a "protective" urgency that seeks to exclude people with IDD from their own sexual autonomy.

Applying this understanding of the incessant paternalism, which originates from eugenicist, non-disabled perspectives towards disabled embodiment that influence our social consciousnesses concerning the sexuality of people with disabilities, the next chapter will examine how disability is represented and broadcasted to society. More specifically, the next chapter will use a phenomenological analysis to understand the influence the history and creation of disability (both in its eugenic origins and its protective-medical implications) has on how the bodies and experiences of people with disabilities are presented within media.

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[132] (Wang, 2019)

Chapter 4: Disability on Display

"One of the tasks for a developing consciousness of disability issues is the attempt, then, to reverse the hegemony of the normal and to institute alternative ways of thinking about the abnormal."

--Lennard Davis, *The Disability Studies Reader*[133]

Despite issues of invisibility within public spaces, people with disabilities have been visible within media and other forms of artistic expression for as long as recordable history. From the ancient statue of Venus de Milo (who is considered an object of aesthetic beauty by disabled theorists because of her lack of arms which "eschew(s) the uniformity of perfect bodies"[134]) to current characters such as Sam Gardner in the show *Atypical*, figurations of disability have long served as powerful metaphors for the variability of humanity. This representation of disability has been crucial to the formation of social consciousnesses concerning what it means to be disabled, and this chapter reveals how these representations have permeated into a general life-view about how the bodies and capacities of people with disabilities are understood. Using a phenomenological analysis, this chapter analyzes current media representations of intellectual and developmental disabilities to uncover the ways in which disability breaks down the natural attitude of the human condition. This chapter also engages in a discussion concerning how people with IDD become "charged" by able-bodied perceivers with protectionist or infantilizing emotions that result from negatively engrained life-views. The embedded nature of these presuppositions will be revealed through popular media, and specifically through the characters and interactions presented within the shows/movies *Atypical*, *Love on the Spectrum*, and *Keep the Change*.

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[133] (Davis L. J., 2006, p. 15)
[134] (Siebers, Disability Aesthetics, 2006, p. 65)

The overall aim of this chapter is to discuss how positive representations of intellectual and developmental disabilities have the potential to serve a specific role within media as deconstructive forces that reveal the instability of the human condition (which is typically figured as able-bodied)—especially as it relates to how characters or people with IDD within media are portrayed as sexual entities. This analysis will reveal how ingrained histories of eugenic theory, institutionalization, sterilization, and protectionist medical models of disabilities come together to form specific life-views that perpetually frame the condition of sexuality for people with IDD. To this point, this chapter works to deconstruct the stability of the human condition, which is constituted as a result of the historically informed binary between able-bodiedness and disable-bodiedness. Exposing the myths of radical self-sufficiency and sexual cultures through media portrayals of disabilities reveals how compulsory able-bodiedness, a concept developed by the disability theorist Robert McRuer, becomes innate within social consciousnesses, and consequently becomes enveloped in the life-views that "charge" the bodies of people with disabilities.

The Role of Disability Within Media

"The human body is both the subject and object of aesthetic production: the body creates other bodies prized for their ability to change the emotions of their maker"
<div align="right">--Tobin Siebers, Disability Aesthetics[135]</div>

Characters with disabilities have always been present within media and entertainment, but the manner in which they have been presented has been subject to change. Historically, literary narratives have used disability in order to reveal something about the human condition. The configuration of disability as abnormal within media disrupts the able-bodied natural attitude that underscores how society understands what it means to be human. This constitutes what

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[135] (Siebers, Disability Aesthetics, 2006, p. 63)

disability theorists David Mitchell and Sharon Snyder identify as "narrative prosthesis"—a concept that refers to how "disability has been used throughout history as a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight"[136]. As a point of phenomenological breakdown, the condition of being disabled has the edifying power to problematize and destabilize what was previously taken for granted. That is to say, disability within media illuminates how the world is catered towards able-bodiedness; making disable-bodiedness the "unruly resistance"[137] to an imagined, preconditioned horizon of possibilities.

While this understanding of the "narrative prosthesis" within media seems to draw out the productive and thought-provoking quality that disable-bodiedness brings to public consciousnesses, disabled characters are "rarely centrally represented"[138]. Despite the literary power that disability can bring to a narrative, disabled characters often serve as metaphorical and ideological moments of transformation rather than self-contained, engaging characters with their own right. When disabled characters appear in literary narratives, they usually are figured as objects of pity, or conversely, as objects of immorality. These tropes inevitably affect the manner in which disability is forged within social consciousness. For example, most villains within entertainment tend to be "physically abnormal"[139], and this sort of representation simultaneously reflects and creates life-views concerning how disabled bodies should be perceived.

The effect of these representations, which are informed by theories of eugenics that synonymize disable-bodiedness with moral depravity, is amplified because of the lack of community interactions between people with and without disabilities. Figuring those who are

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[136] (Mitchell & Snyder, 2006, p. 206)
[137] (Mitchell & Snyder, 2006, p. 206)
[138] (Davis L. J., 2006, p. 11)
[139] (Davis L. J., 2006, p. 11)

disabled as inherently evil or lewd, although clearly unfounded, undoubtedly added to the urgency of institutionalization as a "solution" to the imagined moral calamity brought upon by the presence of people with disabilities within the world. This isolation, combined with negative media representations, further cemented charged feelings of fear and aversion towards people with disabilities that have continued to subconsciously guide the way in which people with disabilities are approached within society today.

The Sanctioned Stare

Disabled representations on screen are usually the primary way in which society can develop an understanding of disabled embodiment. This is why positive representations in the media are absolutely essential, as these portrayals wield so much discursive power for how disability will broadly be imagined by able-bodied audiences. Media is unique insofar as it permits the prolonged interaction between non-disabled audience and disabled characters on screen. Rosemarie Garland-Thomson, a leader in disability justice and disability theory, develops this idea in her work concerning staring. Staring, Thomson claims, is the "embodied and visual exchange that carries cultural and historical meanings" which ultimately crafts a narrative about what is novel or unexpected[140]. This idea is elucidated through the history of freak shows, where disability was presented as synonymous with monstrosity or abnormality. The curiosity about disabled embodiment, once again, was strengthened by the lack of community engagement with people with disabilities due to the isolation brought upon by institutionalization.

Current representations within media, I argue, can often serve the same purpose as freak shows—that is, to allow people without a familiarity of disability to indulge in their curiosity in

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[140] (Garland-Thomson, 2005)

order to possibly "challenge" or reaffirm their understanding of human embodiment. This dynamic, however, necessarily removes all agency from the "looked upon"[141]. This is because the body that is the subject of the stare is objectified by the person watching, who uses the Other's body solely as a means by which to better understand their own status and position, as represented in aspects of phenomenological theory which emphasize how our consciousness of the world is intentional. Specifically, characters with disabilities are objectified in order to reveal the natural attitude to the audience—rendering disability as a merely a narrative prosthesis that grants non-disabled audiences the ability to reaffirm their life-views or, if done positively, to deconstruct their natural attitude towards proper embodiment. While modern media still can function as a kind of freak show, due to the continued lack of opportunities for meaningful interactions between disabled and non-disabled community members, some representations in media have the potential to challenge long-held beliefs able-bodied audiences hold toward people with IDD. One of these representations will be discussed through the Rachel Israel's *Keep the Change,* which, I believe, successfully deconstructs concepts of normality and abnormality in sexuality and in human embodiment.

A Phenomenological Analysis of Intellectual and Developmental Disability Within Media

Within the field of Disability Studies, understanding disability as simultaneously a condition of possibility and as a site for phenomenological breakdown is, for the most part, explored through physical disability. However, I argue that the bodies of people with intellectual or developmental disabilities have been similarly been imbued with feelings of extreme tension that fundamentally alter their status position. Able-bodied perceivers, through the legacies of eugenicist logics and resulting issues of community accessibility, have ingrained life-views

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[141] (Garland-Thomson, 2005)

towards people with IDD that are replicated and reinforced when they fail to understand the origins of these thoughts as social constructions and not as the "a priori" natures of people with IDD. Thus, even prior to actual interactions between non-disabled people and people with IDD, non-disabled people often hold certain expectations of people with IDD that frame their understandings of disabled embodiments. Saturated by negative emotions, specifically in regard to their engagement with romanticism and sexuality, people with IDD experience a subjectivity that has been externally defined by the paternalistic and anxious notions of others. These life-views will be explored through how characters with intellectual and developmental disabilities are presented within current popular media.

This section will analyze how modern representations of disability within shows and movies such as *Love on the Spectrum* and *Atypical,* while seemingly well-intentioned, ultimately still perpetuate a system of compulsory able-bodiedness that subconsciously reaffirms the ableist attitudes of their audiences. As a comparison, the next section will discuss the movie *Keep the Change*, directed by Rachel Israel, which is singular insofar as the characters radically engage in their sexualities. This film works to deconstruct myths of able-bodiedness and disable-bodiedness through the reimagining of sexual culture—one that is not limited by the natural attitude of able-bodiedness.

Love on the Spectrum
Love on the Spectrum, a popular Netflix reality show, documents the experiences of both couples and individuals with autism as they navigate the world of dating and sexuality. Receiving overwhelmingly positive reviews from general audiences, and with critics describing the show as "a compassionate, human celebration of difference, and of love"[142], *Love on the*

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[142] (Nicholson, 2020)

Spectrum appears to be a positive representation of people with intellectual and developmental disabilities that works to bring awareness and thus promote the accessibility of sexuality for people with autism.

While the show's overarching narrative aims to universalize the human desire to love and be loved in order to assert a "common humanity," the show, at times, falls victim to common tropes that exclude or deride the engagement of people with IDD with their sexuality. The show already begins at a certain deficit because, for the most part, the show only includes a specific demographic of autistic people who are white, verbal, and heterosexual. There are multiple scenes with the show where individuals are subtly infantilized or are expected to conform to an able-bodied sexual culture. While these moments may seem inconspicuous to general audiences (as evidenced by the lack of criticism from able-bodied viewers), they subconsciously reaffirm, as well as constitute, the life-views that have formulated people with IDD as sites of sexual exclusion within a general social consciousness. In one particular scene, a married couple within the show is being interviewed about their relationship, and one interview asks if they had "consummated" their marriage. While seemingly an innocent, possibly humorous, question, the question is inevitably tied up within latent assumptions of otherness that imbue the conditions of people with IDD as necessarily outside of heterosexual and able-bodied interactions. The question alludes to the perception of disability as asexual, because if the subjects of this narrative were able-bodied, there would be no doubt of their sexual involvement with one another. As one critic of the show forthrightly asserts, "autistic people have sex, just like anybody else"[143].

Additionally, the show celebrates the work of therapists such as Jodi Rogers who works as a relationship counselor for people on the spectrum. Jodi Rogers seeks to similarly

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[143] (Luterman, 2020)

universalize the experience of love so that people, regardless of their disability, can be successful in a romantic relationship. However, in her coaching sessions, Rogers encourages her students to engage in romantic behaviors that are typically associated with an able-bodied conception of sexual culture. Rogers teaches her students to "hold out a chair for [their] date, make eye contact, [and not] talk too much about what [they] love"[144] in order for them to appear as neurotypical, and therefore as what she conceives of as romantically desirable. However, these behaviors oftentimes feel unnatural for people with autism, and arguably more importantly, these behaviors might not appear as important for non-neurotypical couples. Rogers inadvertently perpetuates a system of sexual culture that has been specifically formulated by and for able-bodied couples, thus situating this culture as the standard, and the sexual culture of people with IDD as derivative or secondary.

The consequence of these exclusions is that the work the show aims to produce is reduced to the subtle reaffirmation of already present life-views that have constituted autism, and IDD generally, as outside of the norm of sexuality. *Love on the Spectrum*, while claiming to be working against of typical narratives concerning sexuality and disability, ultimately works according to the social consciousness that designate the sexual autonomy and agency of people with IDD as abnormal. *Love on the Spectrum* affirms a symbiotic relationship between compulsory heterosexuality and compulsory able-bodiedness. Overall, this show reflects how people with IDD are charged with emotions that infantilize and ostracize them even prior to their engagement with non-disabled community members.

To conceptualize intellectual and developmental disability in a manner that resists this ostracization first requires that our media forgoes the natural attitude of able-bodiedness. *Love on*

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[144] (Luterman, 2020)

the Spectrum attempts to bring people with autism into the realm of an able-bodied sexual culture by purporting an imagined universal experience of love. Understanding phenomenologically that there is no objective or universalizable truth regarding the experience of love reveals how people's independent subject positions alter how they interact with and share space with other "embodied agents"[145]. Heteronormative, able-bodied love cannot be rendered as coherent or universal, as the narrative of *Love on the Spectrum* might suggest. Ultimately, a phenomenological analysis of this popular television show reveals how a natural attitude of heteronormative able-bodiedness functions to allusively exclude disability, even in its attempt to promote a more inclusive narrative of love and sexuality.

Atypical

As another popular television show on Netflix, *Atypical*, by Robia Rashid, has received overwhelmingly positive reviews, and is currently in the production process of a fourth season. The main protagonist of the story, Sam Gardner, has Autism Spectrum Disorder (ASD), and the audience follows as Sam and his family navigate complicated relationships, friendships, and conflicts. The first season, in particular, focuses on Sam Gardner's search, struggle, and eventual success in finding a sexual-romantic relationship. Despite the acclaim the show has received from both neurotypical and neurodivergent audiences, there are still significant issues in the manner in which the show represents autism.

Most obviously, Sam Gardner comes across as a heavily stereotyped version of what it means to be autistic. As many critics assert, it "often feels like *Atypical's* writers have combed through the literature – the many academic accounts, memoirs and so on – and extracted, intensified and amplified all the most obvious autistic behaviors"[146]. Sam Gardner is the "perfect

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[145] (Behnke)
[146] (Felperin, 2017)

stereotype" of people with autism, and this has the effect of blurring the nuances of the individual experience of autism. The embodiment of autism varies from person to person, but this show gives credence to a general understanding of people with autism as "creepy, insensitive, and just really awkward"[147].

This stereotyped representation becomes even more blatantly problematic when it is discovered that Sam Gardner is played by a neurotypical actor. The portrayal of disability by non-disabled actors has been problematized by communities of people with disabilities because these representations inevitably perpetuate negative and overly simplified ideas about what disabled embodiment entails. Tobin Siebers calls the action of non-disabled actors playing disabled characters a sort of "disability drag" that conveys cliched aspects of disability to audiences that are typically unaware of or lack the opportunity for interactions with actual people with disabilities. While typical drag has the potential to engage in a subversive and characterized critique of gender stereotypes, disability drag often goes unnoticed, where the representations of disability by non-disabled actors is taken as the truth of disabled embodiment in general. As Siebers comments, "the modern cinema often puts the stigma of disability on display, except that films exhibit the stigma not to insiders by insiders, as is the usual case with drag, but to a general public that does not realize it is attending a drag performance"[148].

The example of disability drag in *Atypical* functions to affirm the very stereotypes it rhetorically wishes to problematize. By writing Sam Gardner's character as the "poster-child version of autism"[149], the writers of *Atypical* find themselves relying upon the same tropes that other shows (such as *Big Bang Theory*) convey about autism. These witty-natured, smart,

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[147] (Moss, 2017)
[148] (Siebers, Disability as Masquerade, 2004, p. 17)
[149] (Felperin, 2017)

socially awkward characters represent only a small part of what it looks like to be on the autism spectrum. These representations of autism inevitably purport a singular version of autism in a way that erases the disabled embodiment of people on the spectrum who do not conform to an idealized portrayal. This has very real consequences for the community of people with autism, given the history that the diagnostic criteria to be diagnosed (and thus to receive supports) with autism was long defined by these idealized portrayals of autism—especially as they present in men[150]. When autistic people are not perceived to conform to a universalized (but, in reality, rather narrow) notion of what autism is, they can be denied access to forms of care and support.

Ultimately, while the both *Love on the Spectrum* and *Atypical* have good-intentions and have generally received favorable reviews both from people within and outside the autistic community, these shows lack diversity in their portrayal, comply to able-bodied and heteronormative conceptions of sexuality, and rely upon stereotypes portraying a version of autism that can potentially have real-world consequences for people on the spectrum.

Disabled Embodiment and the Release of Compulsory Able-bodiedness in *Keep the Change*

This section explores in-depth the embodiment of intellectual and developmental disabilities in the 2018 movie *Keep the Change*, directed by Rachel Israel. The movie stars Brandon Polanksy and Samantha Elisofon, both of whom are actors with autism, as they maneuver through their budding romantic and sexual relationship. Interestingly, the movie is inspired by Brandon Polansky's true experiences in his own dating life, as Polansky had asked Rachel Israel on a date 15 years prior and the two soon after developed a close friendship. The main character of the movie, David, is an inspiring movie-maker who is ordered to join a local support group in Manhattan for people with autism after making inappropriate jokes to a police

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[150] (Lisa, 2017)

officer. In this support group, David meets Sarah (played by Samantha Elisofon) and, after some initial awkwardness and incompatibility, the two hit it off and make their relationship official. What I find particularly interesting about this movie is how the experience of disabled embodiment is portrayed, and how the characters both comply and resist heteronormative, able-bodied conceptions of normalcy and sexuality. The audience goes on a journey with the main character as he confronts his internalized ableism through his interactions with others on the spectrum.

David, in the beginning of the movie, denies his status as a disabled person. Clearly influenced by his mother, who claims that she "doesn't like the look"[151] of the people in David's support group, David holds internally ableist views towards himself and refuses to confront the reality of how autism affects him. Attaching his self-worth to his conception of "normalcy," David finds himself constantly struggling to maintain the appearances and expectations he has set for himself. This is particularly evident through David's harmful views towards people without homes in New York City. In several scenes, the audience follows as David either makes rude remarks or verbally assaults those who are experiencing homelessness—and it becomes evident that David subconsciously sees his own position as disabled as similarly on the margin of society. After the audience first witnesses David's failure to appear "normal" whilst on a date with a neurotypical woman, he returns home and berates himself by calling himself a "bum" repeatedly. It is clear that David despises those on the streets because he is afraid that, like those who are homeless, his condition positions him on the outside of society and, consequently, on the outside of normalcy. "Normal," in fact, is a word used throughout the movie, and it appears especially in moments where David is attempting to draw a distinction between what he

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[151] (Israel, 2018)

envisions as normal, which is able-bodied, neurotypical behavior, from what he understands as abnormal, which is frequently the behaviors exhibited by those in his support group.

David initially embraces the ideology of compulsory able-bodiedness, which, as McRuer states, "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?'"[152]. The "me," in this case, is a stand-in for able-bodied, neurotypical people who understand their status as the "natural," preferable state of being. David associates romantic and sexual desirability with able-bodiedness, and this is evident within his relationship with his cousin who is a successful actor. David idealizes his cousin, and this is exacerbated when it is discovered that his cousin is the object of one of David's support group member's sexual fantasies. David seeks validation from his cousin throughout the entire movie because it is evident that David subconsciously believes his cousin to be the pinnacle of sexiness, success, and, thus, normalcy.

Constantly comparing himself and wanting to be accepted by his neurotypical peers (including his cousin), David feels the need to cheapen or dismiss the ways in which his autism is embodied within his actions, words, and feelings. For example, David likens his vocal tics, which are exacerbated when he is stressed or uncomfortable, to allergies. Additionally, the audience sees David's disinterest and even anger at having to attend support sessions with other people with autism. David's fear, in the beginning of the movie, is for people to notice his neuro-divergencye, and his attendance in these support sessions seems to highlight and affirm everything about David that he dislikes about himself.

The turning point in the movie occurs when David and Sarah, a member of David's support group, are given a homework assignment to go to the Brooklyn Bridge. Sarah

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[152] (McRuer, 2002, p. 372)

understands her autism in a radically different way than David. Incredibly confident in herself and in her sexuality, Sarah resists David's subtle (and not so subtle) maneuvers to detach Sarah from her unapologetic embodiment of her disability. Sarah makes the first initial move towards David, and it becomes clear to the audience that, for the first time, David begins to see himself as sexually and romantically desirable. However, David subconsciously qualifies this perceived desirability by how closely he can maintain his façade of being neurotypical.

An important moment for David and Sarah's relationship occurs when David begins to become overly stimulated while on a date at an amusement park. His vocal tics begin to become louder and more disruptive, causing other ride-goers to stare at David with concern. Angry at himself for failing to conform to neurotypical standards, David's tics become progressively more aggressive. However, when David begins to dismiss his outburst on the ride—clearly as a result of his fear that Sarah will no longer see him as attractive or desirable because of his neurodivergence—Sarah, in a touching moment, embraces David. Sarah is the first person in David's life who accepts David in his "abnormalcy," and from this point on, David begins to find himself enjoying both the validation he receives from Sarah, and the community he finds within his support group. That being said, David still subconsciously locates himself as outside and above his autistic peers due to his negative perception of what it means to be disabled within the world.

The climax of the movie occurs when David brings Sarah to meet his cousin for the first time. Sarah, who is always her authentic self, begins to speak openly about their sexual relationship and sing for everyone. David, embarrassed by Sarah's apparent social faux pas, begins to demean Sarah in an effort to gain acceptance from his cousin, whom he idealizes. Sarah, feeling both confused and ashamed, leaves unexpectedly. Shortly after, when reflecting

upon the night, David's mother remarks that it is for the best that Sarah left, saying "she was weird" --to which David responds, in his first confrontation against his mother's ableism, "I liked her because she was weird. I'm weird too"[153]. Representing a shift in David's self-perception, David embraces the fact that the standards he had been holding himself to were not only unattainable but ultimately no longer important to him.

Sarah leaving, and the fear of losing her completely, serves as a moment of phenomenological breakdown for David. Recognizing that the love he shared with Sarah was not formed "in spite of" his disability, David's life-view towards disability is exposed to him and leads him to realize that his previous attitude about autism was not only harmful but false. The able-bodied nature of love that David previously aspired towards is revealed through this moment as merely a myth. David was never desirable to Sarah because of the neurotypical façade he tried so desperately to maintain. That is to say, Sarah's attraction to David was not defined by how close he embodied typical able-bodiedness, but rather was formed through Sarah's attraction to David as himself. She does not turn-away from David when he is unable to control his tics or emotions because she understands desirability outside of the confines of compulsory able-bodiedness. Sarah's being-in-the-world was not limited by the emotions that others associated with her disability, as David's had been. This is why the moment where David confronts his mother about what is "normal" and what is "weird" is so powerful. David essentially trades his comfortable, "normal" world he was accustomed to—where he could deny his disability—for the "weird" world of Sarah; letting go of the life-view that able-bodiedness is necessarily above and superior to disable-bodiedness.

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[153] (Israel, 2018)

It is no wonder that this movie is able to deconstruct and problematize the natural attitude of able-bodiedness, as the movie serves almost as a documentary of Brandon Polanksy's (David's) true experiences in finding love. There is a reality to this movie that feels palpable, and the unapologetic and non-manipulated acting of the characters in the movie adds to its intensity and authenticity. We are able to witness the moment when David chooses to let-go of the life-views that have shaped and informed what he has perceived as the horizons of his possibilities. This movie encourages its audiences, who likely have the same initial perspective towards autism as David, to let go of their ableist notions towards the human condition. This movie radically denies the perspective compulsory able-bodiedness pushes, and positions disability as a condition of possibility (rather than as a condition of impossibility) for true and meaningful love. It is precisely Sarah's embodiment of disability that allows David to release his internalized ableism, and ultimately creates the foundation for their relationship. Overall, *Keep the Change* engages in a wholly different conversation about disability, where disability is not configured as an obstacle to love that is overcome through trainings to appear more able-bodied, but rather is strengthened and amplified by one's radical embodiment of their disability.

Conclusion

This chapter explored how intellectual and developmental disability has been portrayed within media, and the effects these representations have had on the formation of social consciousness towards disability. Overall, the inclusion of disabled characters within media can have the powerful effect of breaking down generally held notions of "natural" embodiment. As this chapter has elucidated, this positive representation is difficult to achieve because of the reality that these portrayals often fall victim to the same paternalistic, infantilizing, and ableist attitudes that they claim to resist. However, when media portrayals are informed by the authentic

experiences of those with IDD, they have the discursive power to deconstruct the mutually

constitutive relationship between compulsory heterosexuality and compulsory able-bodiedness.

Conclusion

This thesis has argued for the breaking down of an able-bodied sexual culture that is exclusive of people with IDD through the phenomenological breakdown of the able-bodied natural attitude. Understanding how sexual inaccessibility is created through ableist social systems deconstructs the notion that people with IDD are inherently less capable of engaging within a sexual culture. The experience of disabled embodiment is thus a site of phenomenological possibility and of disruption because of its radical potential to unsettle social criterions that have taken the privileged non-disabled body as the norm for understanding the human condition. There is no innate or natural experience of sexuality, and thus the fear of sexual proclivity or sexual vulnerability that people with IDD become charged with can no longer be taken as objective truth.

This thesis began with examination of the impact of eugenics on defining disability and the continued impact this ideology has had on social consciousnesses surrounding disability, followed by an analysis of the lack of sexual accessibility for people with IDD due to restrictions in education, environment, and stigma and the effects of this limitation on the engagement of people with IDD in a sexual culture. Finally, this thesis investigated how media portrayals of disabled sexuality have often served to perpetuate negative social consciousnesses that distort the sexuality and embodied experiences of people with disabilities. That being said, representations of disability on screen, when done correctly, have the radical potential to breakdown the understanding of sexuality as inherently able-bodied.

Building off the work of various scholars, such as Sara Ahmed, Robert McRuer, and Tobin Siebers, this thesis uncovered how the bodies of people with IDD have been subjected to the emotions and stigmas of non-disabled populations through unconscious attitudes that have framed people with IDD as outside of society. This exclusion has served as a technology to

prevent the identification of people with IDD as sexual entities, thus reducing their access to humanity. Deconstructing a sexual culture that privileges able-bodiedness is vital because, when people with IDD are ostracized from their sexuality, their horizons of experience are simultaneously reduced.

Through the phenomenological breakdown of an able-bodied sexual culture, it is revealed that the condition of being disabled is not inherently incongruous with being interested in or capable of sexual expression. This has important ramifications on many of the tightly held attitudes non-disabled populations have used to distinguish themselves from people with disabilities. For instance, when people with IDD are seen as sexual entities, it not possible to simultaneously hold the belief that people with IDD are inherently more vulnerable to sexual abuse. The fact that people with IDD are more vulnerable to sexual abuse is not a product of an objective truth. Rather, this condition of vulnerability has been produced through a lack of access to sexual education and sexual privacy-- both of which are the results of the deeply held belief that people with IDD should be innocent of sex-- that have constituted this cyclical process of sexual vulnerability. Recognizing and meaningfully providing resources to people with IDD must necessarily follow from the phenomenological breakdown of an able-bodied conception of sexuality. The responsibility to remediate this situation must therefore be placed within the able-bodied community, which should elevate the voices of people with IDD to express their sexuality and construct interpersonal and community level change.

Ultimately, when life-views concerning disabled embodiment are called into question by the experiences and voices of people with disabilities, and through the realization that many of these emotions have been socially created to privilege able-bodiedness, it becomes imperative

that the origins of these attitudes are similarly called into question in order to deny the

intellectual and social authority that they have unjustifiability and untruthfully been granted.

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