“I Wouldn’t Want to Be Anyone Else”:

Disabled Girlhood and Post-ADA Structures of Feeling

by

Anastasia Todd

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Graduate Supervisory Committee:

Heather Switzer, Co-Chair
Mary Margaret Fonow, Co-Chair
Julia Himberg

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ABSTRACT

Spotlighting the figure of the exceptional disabled girl as she circulates in the contemporary mediascape, this dissertation traces how this figure shapes the contours of a post-Americans with Disabilities Act structure of feeling. I contend that the figure of the exceptional disabled girl operates as a reparative future girl. As a reparative figure, she is deployed as a sign of the triumph of U.S. benevolence, as well as a stand-in for the continuing fantasy and potential of the promise of the American dream, or the good life. Affectively managing the fraying of the good life through a shoring up of ablenationalism, the figure of the exceptional disabled girl rehabilitates the nation from a place of ignorance to understanding, from a place of nervous anxiety to one of hopeful promise, and from a precarious present to a not-so-bleak-looking future.

Placing feminist cultural studies theories of affect in conversation with feminist disability studies and girlhood studies, this dissertation maps evocations of disabled girlhood. It traces how certain affective states as an intersubjective glue stick to specific disabled girls' bodies and how these intersubjective attachments generate an emergent affective atmosphere that attempts to repair the fraying fantasy of the good life. Utilizing affect as methodology and object of analysis, this dissertation interrogates ambivalent visual artifacts: ranging from the "real" figure of the disabled girl through YouTubers, Charisse Living with Cerebral Palsy and Rikki Poynter, to a fictional disabled girl in *Degrassi: Next Class;* spanning from physically disabled beauty pageant contestants to autistic girls learning how to dance; and, finally, looking to a black disabled girl in her life and death, Jerika Bolen. I contend that through their roles as disability educators, shared objects of happiness and optimism, and pedagogues of death, exceptional disabled

girls have been deployed as guides on a new roadmap to ideal, affective post-ADA citizenhood.

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Chapter 1

Introduction:

The Post-ADA Disabled Girl

“Fantasy is an opening and a defense.”

– Lauren Berlant (2011)

“Cowardice, are you serious? / Apologies for freedom? / I can’t handle this! / When freedom rings / answer the call / on your feet / stand up tall! / Freedom’s on your shoulders / USA!”

– The USA Freedom Kids

“A lot of times people get scared of their freedom, especially politics and all, and you know, they apologize for it. We’re trying to turn that around. We’re trying to make people celebrate their freedom,” thirteen-year-old Sarah, who is blind, articulates in an interview about the musical girl group she is a part of, The USA Freedom Kids (“Donald Trump’s USA Freedom Kids” 2016). The USA Freedom Kids became a viral sensation after they performed their hit song, “Freedom’s Call,” at a Donald Trump presidential rally in Pensacola, Florida. The song was originally written about General George Patton, but was changed to be about Donald Trump, as manager Jeff Popick was inspired by Trump’s presidential candidacy speech. Within one week, their performance was watched over 30 million times on YouTube. The performance incited polarizing affective states within the national imaginary. Although *The Young Turks* argue that it is “really uncomfortable to watch," a commenter on a YouTube recording of the performance, John B. writes, "What amazes me is just how many people have been brainwashed to hate their own people, culture, and traditions. What's wrong with being patriotic?" Disgust, hope, zeal, and despair were all generated by the bodies of adolescent girls decked out in lace-up, white wedge boots, and red, white, and blue satin dresses. Although this phenomenon could be written off as pop cultural ephemera, or a metonym for the bizarre state of the 2016 presidential election, it has stuck with me. Popick explains, "No matter who is elected, there needs to be a force of freedom, and if it has to be these cute little girls, then so be it."

Following the upload on YouTube, *Vice* and *The Young Turks*, two self-proclaimed "progressive" media outlets, produced content on YouTube that took a closer look at The USA Freedom Kids phenomenon. The *Vice* video was an extensive interview with the girls and Popick. Although only three of The USA Freedom Kids performed at the rally, the group is actually comprised of five girls from the ages of eight to thirteen. One of those girls who did not perform at the rally is Sarah, and as Popick explains, "Sarah has been blind almost since birth. I think it's her sense of hearing that is so acute that she's always on key, always on point. It's amazing what she can do, and we just love having Sarah as part of the group." Sarah adds that she, too, loves being part of the group: "This is just absolutely incredible, and I am just so glad that, you know, that music has been a very important part of my life, and I am glad that I am with my group, and I'm glad that I get to show people who I am."

Although Sarah did not perform at the Trump rally, her contribution to The USA Freedom Kids is spotlighted in the interview with *Vice*. Her disabled girl[1] body is integral to the girl group, or, as Popick explains, to the production of a *force* of U.S. freedom. It is this hypervisible figure of the disabled girl as it is habitually tethered to national fantasies of the good life and the affectivity that she incites that I am interested in. In this case, "freedom" could be read as a metonym for the good life, which is in crisis. How does Sarah affectively assuage this crisis? If, as Driscoll (2008) emphasizes the modern girl "emerged as an index of the problem of the present," then what does it mean, at our historical present, that the disabled girl emerges (15)? How does she move us, as a nation, amidst the fraying of the welfare state and the fragile promise of the good life? If 2015 marked the twenty-fifth anniversary of the Americans with Disability Act (ADA), then what is the function of the hypervisible figure of the disabled girl, as she emerges in the shadow of the un-admitted failure of the ADA? Ultimately, this dissertation is interested in this tension between the fantasy and the fray and how it is affectively managed through the exceptional disabled girl. This management occurs, I argue, by way of a transformation of certain affective attachments in an attempt to repair the fraying good life through a shoring up of ablenationalism.

Figurations of the exceptional disabled girl, similar to Sarah, populate this dissertation. Ranging from the "real" figure of the disabled girl YouTuber, Charisse

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[1] Throughout this dissertation I have explicitly made the choice to use "disabled girl" rather than "girl with a disability." James Overboe (1999) and other scholars and activists of disability argue that, "the term 'person with disability' demonstrates and is underscored by a 'normative' resemblance that we can attain if we achieve the status of being deemed 'people first' (with the term's emphasis on independence and extreme liberal individualism) in the eyes of an ableist centered society" (24). 'person with disability' demonstrates and is underscored by a 'normative' resemblance that we can attain if we achieve the status of being deemed 'people first' (with the term's emphasis on independence and extreme liberal individualism) in the eyes of an ableist centered society" (24).

Living with Cerebral Palsy and Rikki Poynter, to a fictional disabled girl in *Degrassi: Next Class;* spanning from physically disabled beauty pageant contestants to autistic girls learning how to dance; and, finally looking to a black disabled girl in her life and death, Jerika Bolen, I trace how these figurations function reparatively. I contend that through their role as disability educators, shared objects of happiness and optimism, and pedagogues of death, disabled girls have been deployed as guides on a new roadmap to ideal, affective post-ADA citizenhood. Placing feminist cultural studies theories of affect in conversation with girlhood studies and critical disability studies, this dissertation maps these evocations of disabled girlhood, how certain affective states as "an intersubjective glue" stick to specific disabled girls' bodies, and how these intersubjective attachments generate an emergent affective atmosphere that attempts to repair the fraying fantasy of the good life.

The figuration of the exceptional disabled girl emerges under a particularly insidious spotlight cast by the contemporary post-ADA production of disability, which can be characterized through the tension of these material failures and the framework of ablenationalism, or exceptional neoliberal inclusion efforts. Post-ADA, here, functions ironically, in a similar way to claims of "post-feminism." Post-feminism is most productively conceptualized as a sensibility, felt through an entanglement of feminist and anti-feminist discourses. It is an insidious recuperation of specific forms of liberal feminism that function to sustain and shore up advanced capitalism. Angela McRobbie (2004) suggests that post-feminist discourses: "actively draw on and evoke feminism as that which can be taken into account in order to suggest that equality has been achieved, in order to install a whole repertoire of meanings which emphasize that it is no longer needed, a spent force" (4). Similarly, I deploy post-ADA as a sensibility that can be conceptualized by an entanglement of discourses and affective states that work to enfold disability and neutralize it in the process of enfolding. In a post-ADA America, disability politics and activism are rendered irrelevant, disability rights have been achieved, and the hypervisible figuration of the disabled girl serves as a testament to this final frontier of American benevolence. This dissertation complicates this fantastical narrative and its attendant structure of feeling.

This project is comprised of three case studies. Each case study, or chapter, maps how different figurations of the exceptional disabled girl operate. The first chapter maps how figurations of disabled girl YouTubers operate as disability educators; the second chapter maps how figurations of time-rich disabled pageant girls and time-bankrupt autistic young women in HBO documentaries operate as shared objects of happiness and optimism; and the third chapter maps how figurations of fictional and real disabled girls, as the are faced with the reality of premature dying, operate as pedagogues of death. Like Sarah, all of these figurations of disabled girls *stuck* with me. The case studies are comprised of gathered visual artifacts that stuck with me because I felt deeply ambivalent about each of them. This dissertation utilizes affect as both methodology as well as object of analysis, and more specifically, the ensuing analysis of these visual artifacts was guided by my feelings of ambivalence toward them.

Further, these visual disabled girlhood artifacts, more than just a collection of ambivalent artifacts, are emblematic of the convergence culture that we live in. Convergence culture can be characterized as a mixed media ecology where "diverse kinds of media producers" and consumers "influence each other in often unpredictable ways” (Jenkins 2014, 280). Convergence culture marks a perceived expansion of participatory possibilities and communicative possibilities within the mediascape. As this dissertation evinces, the logics of ablenationalism work seamlessly with the attendant fantasies of this participatory promise, and call certain exceptional disabled girls forward, casting a luminous spotlight on those disabled girls—real and representational—that can productively work to shore up this fantastical feeling of a post-ADA America.

To lay the groundwork for the case studies that follow, I bring together Nancy Lesko, Rosemarie Garland-Thomson and Julie Elman to illustrate the ways in which the disabled girl emerges in our historical post-ADA moment. I specifically focus on Elman’s theorization of rehabilitation as it grounds my own analysis of function of the figure of the exceptional disabled girl. I then place the disabled girl in the context of post-ADA America, and in doing so begin to generate a nascent outline of her importance to what I term an emergent post-ADA structure of feeling. I end the chapter with situating my project amongst the small but burgeoning discourse on disabled girlhood, and then I follow this with a brief discussion of methodological considerations and an outline of the ensuing chapters.

The Disabled Girl

At the Turn of the Century

The categories of youth and disability have both had particularly vexed relationships to the nation-state (Garland-Thompson 1997; Elman 2012; Russell 2012 Elman 2014). Historically, the category of adolescence has functioned as a repository for national anxieties regarding ‘progress’ and citizenship. As Nancy Lesko (2001) argues in

Act Your Age: A Cultural Construction of Adolescence, at the turn of the century, the spheres of medicine, culture, and policy became invested in adolescence as a space for intervention. Both the discursive figuration of "the adolescent" as well as adolescents were subject to techniques of management to ensure national progress, which was contingent on the production of proper citizens. For example, school was one such site where collective anxieties of modernity were played out on the bodies of youth through the deployment of gendered discourses of education. G. Stanley Hall, "the father of adolescence," argued that boys' schooling should "emphasize the development of strength and virility," whereas girls' schooling was largely preparation for motherhood and marriage (Lesko 2001, 56). The focus on gendered education was one way to ensure that boys and girls were shaped in certain ways for a proper, white supremacist, heteronormative national order in a time characterized by anxieties due to shifting economic, political, and social hierarchies in the United States. Not only did techniques of adolescent management ensure a proper national order, but they also worked to ensure a proper world order, which was and still is characterized by the hierarchical superiority of the First World in relation to the Third World.[2]

These techniques of management were informed by fears of failure and degeneration—the peril of the adolescent proto-citizen who is at risk of not becoming a

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[2] Lesko (2001) argues that specifically, in nineteenth century sociological discourse "the concept of progress was inseparable from that of decline, and the fate of societies was similarly linked to that of individuals" (25). This binary of progress/decline, in the early nineteenth century, is linked to the *recapitulation theory*, which is rooted in European/American white supremacist assumptions of civilizational progress. Recapitulation theory states that each individual child's growth recapitulated the development of humankind. In other words, modern concepts of childhood and adolescence are built upon this "threefold parallelism across animals, savages, and children: children were like savages, savages were like animals, and animals were like children" (Lesko 2001, 33). Within this framework, adolescence became a social space in which a divide between the rational, autonomous, white bourgeois men and the primitive Other was "visualized, embodied, measured, and affirmed" (Lesko 2001 35).

properly cultivated citizen, or one who adheres to the economic and cultural values of U.S. capitalism (Elman 2014, 2). Lesko argues that the making of the modern 'developing' adolescent was co-constitutive of the effecting of a new society. The societal structure that emerges at the turn of the century is one defined by "new rationalities of government," or as Michel Foucault argues, governmentality (Lesko 2001, 58). Thus the creation of adolescence as a stage of development, or becoming, is intimately linked to modern forms of "power and knowledge" concerned with managing a social body, or populations. These techniques of governing focus on the management of risk and the promotion of health and welfare, thus modern adolescence, constructed as a stage of growth and proper cultivation (haunted by the specter of crisis), is intimately tied to new forms of power.

Likewise, disability as a modern construction also emerges and functions in new ways at the turn of the century. For example, Rosemarie Garland-Thomson (1997) in *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* traces the ways in which the disabled figure largely operates as the stigmatized other whose role is to shore up the idealized American self, who by virtue of American liberal individualism, is imbued with autonomy, self-reliance, and independence. One productive site that Garland-Thomson explores is the turn of the century American freak show. She looks at the way which the freak show reduced bodies to pure representation and how that allowed the freak to be fixed as the "figure of otherness upon which spectators could displace anxieties and uncertainties about their own identities" (Garland Thomson 1997, 61). In an era of rapid economic reorganization defined by industrialization and social transformation, the freak show was an institution that allowed normative American embodiment to be defined in relation to race, gender, and class hierarchies that were manifested through "spectacularized" bodily non-normativity. For example the enfreakment of Sartje Baartman, or the "Hottentot Venus," was inextricably linked to the co-constitution of the bodily formations of disability, race, and gender. Thus Garland lays the groundwork for the critical exploration of the ways in which disability, like modern adolescence, was produced as a governable category as a method to manage certain bodies that were deemed "at-risk" for contaminating healthy populations (and in the case of the modern adolescent, he or she was at-risk of self-contamination unless properly cultivated).

The "Modern Teenager" and Rehabilitative Citizenship

Julie Passanante Elman (2014) argues that constructions of modern adolescence, specifically as a stage of crisis ending in (hopeful) resolution (as a properly cultivated citizen and adult), are inextricably linked to disability. In *Chronic Youth: Disability, Sexuality, and U.S. Media Cultures of Rehabilitation* she argues that although the categories of "teen" and "disability" may appear to be disparate categories, "within and around these bodies, rehabilitation coalesced into a culture" (Elman 2014, 14). Through examining new media, television, popular novels, and public policy, Elman contends that following of a set of historic, economic, and social turns that occurred during the 1970s and 1980s, the teenager emerged as a discursive formation that functioned to shore up heteronormative, compulsory able-bodied logics. She forwards that representations of modern, neoliberal, youth both produce of and are produced by rehabilitative logics. Rehabilitation

> yokes capitalist values (“efficiency,” good management,” and “solvency”) to individual health […] and it describes relationships that are simultaneously cultural, bodily, and economic: an entanglement of healthy bodies and healthy economies, once threatened and then restored (Elman 2014, 14).

To rehabilitate “means to restore to a former capacity,” and at its core, rehabilitation is a “self-making project involving perpetual self-discipline and self-surveillance” (Elman 2014, 14). Yearning nostalgically for a past of imagined wholeness, and striving for a future that can recover this imagined wholeness by way of self-making, rehabilitative logics are an amalgamation of bodies, capacities, norms of personal and economic productive labor, and medical knowledge. Elman suggests that rehabilitative logics emerge out of a broad “turn inward.”

As cultural studies scholars document, a broad cultural “turn inward” occurred in the 1970s, dovetailing with neoliberal economic, social, and cultural ideologies[3]. One of the ways that this cultural turn inward manifested was through the self-help industry’s rise to prominence. The two core values of neoliberalism, privatization and personal responsibility, were essential to the emergence of this industry. Pop psychology literature on self-improvement, “twelve step” culture, self-help seminars, and personal life coaching mobilized personal empowerment rhetoric co-opted from the identity movements of the 1960s, converting “dissident rhetoric into a profitable industry” (Elman 2014, 17). Elman (2014) notes that the logic of the self-help industry relied on narratives of personal growth and “achieving [one’s] full potential” through overcoming obstacles, which effectively intertwined rhetorics of disability and adolescence (17).

This intertwining can be seen clearly in the ways in which media industries and policy makers, in a time of instability characterized by a backlash in regard to the value

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[3] See Reiff (1966), *Triump of the Therapeautic* and McGee (2005), *Self Help Inc.*

of popular culture as "educational" as well as in regard to youth activism of the 1960s, mobilized discourses of disability in order to position adolescence as a treatable condition. Elman (2014) argues that "coming of age" was recast "as a gradual process of rehabilitation, one that proactively involved teenagers in their own decision making and self-fashioning through the work of pedagogical popular culture" (8). Good citizenship became defined through this logic of rehabilitation—not just for youth—but for everyone.[4]

Thus good citizenship was reframed as necessitating a turn inward: processes of self-management, growth, and personal reflection became part in parcel of what it means to be a productive citizen. This was and is a necessarily an ableist project; in order to achieve the promise of citizenship, in order to become a good citizen, one must be in a constant process of rehabilitation. Elman (2014) argues, "rehabilitation rests on ableist notions of embodiment involving the language and activity of 'return'—a return to a state of able-bodied normalcy or stability—through 'personal effort'" (17). This rehabilitative logic positions all bodies as forever incomplete and in need of work—not only the "pathologized bodies of the disabled" (Elman 2014, 17).

For example, in "'Nothing Feels Real': Teen Sick-Lit, Sadness, and the Condition of Adolescence," she looks at the emergence of the genre of "teen sick-lit" in the 1980s, which functioned to effectively (and affectively) manage teenagers as a specific response to the legacies of youth activism in the 1960s and 1970s. She argues that the post-Fordist

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[4] For a discussion of how rehabilitation became the reigning logic in terms of the discourse of disability (as opposed to the previous logic of pathology), see David Serlin's (2006) chapter "Disability, Masculinity, and the Prosthetics of War, 1945-2005." He discusses how WW1 marks the emergence of logics of rehabilitation as a method to enfold disabled veterans back into the labor market through technologies such as prosthetics. This logic hinges on enfolding those deemed "worthy" of rehabilitation back into reigning capitalist structures, so it is always, already an exclusionary logic.

economy "commodified emotion and relied intimately on disability for a production of sadness" (Elman 2012, 179). In looking at the genre of sick-lit, defined by stories of adolescents negotiating disability or sickness, Elman (2012) utilizes Deborah Gould's term *emotional habitus* to describe "social groupings' collective (and only partly conscious) emotional dispositions or inclinations toward certain feelings" (178). An emotional habitus defines certain emotions as desirable or preferable, while disciplining others: "it delimits what is emotionally possible at a given moment" (Elman 2012, 178). Thus she argues that "teen sick lit" functioning through a narrative of heterosexual coupling as a method to "overcome" disability, compelled readers to imagine their own bodies as "body projects" that are in constant need of self-surveillance and "rehabilitation" in order to develop into ideal proto-citizens. This genre of adolescent literature is motivated by an economic and cultural logic wherein emotion became commodified "as new forms of affective labor gained cultural and economic currency" (Elman 2012, 188).[5] The figuration of disability that was proffered in various media, including teen-sick lit, functioned to instruct teenage proto-citizens the importance of cultivating emotions the *right* way, or what Elman characterizes as a properly "managed heart." Thus the impetus was for real young adults to emotionally orient themselves in a *correct* way such that they could become successful, productive affective citizens. Specifically, the figuration of the disabled teen functioned through inciting sadness, an appropriate sadness, which was relieved and transformed into happiness as the disabled

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[5] Jason Read (2003) in "The Real Subsumption of Subjectivity by Capital" argues that the contemporary capitalist mode of production can be defined by the centrality of immaterial labor. Maurizio Lazzarato defines immaterial labor as "activities that are not normally recognized as work—in other words, the kinds of activities involved in defining and fixing cultural and artistic standards, fashions, tastes, consumer norms, and more strategically, public opinion" (qtd. in Read 2003, 127). Immaterial labor subsumes affective labor, or forms of labor that circulates feelings and states of being (Read 2003, 128).

figure was rehabilitated through a heterosexual relationship, thus aiding in the production of properly empathetic proto-citizens. The figuration also served to signify an “other” to which an unstable, yet normative adolescence could be set against, as well as contained and managed through. The teen audience was instructed to model this teleology of sadness to happiness through rehabilitative work in their own lives—working on their abnormally deemed bodies or minds (but not disabled) as a method to transform into a productive, empathetic proto-citizen.

As she notes, rehabilitation “has become attached to the notions of liberal individualism and good citizenship that scaffold our commonsense ideas about democracy and citizenship” (Elman 2014, 14). *Chronic Youth* is interested in how rehabilitation has become tethered to what it means to be a good citizen, and Elman (2014) suggests that rehabilitative citizenship has “figured around three key areas of intervention” (20). First, at once intertwines histories of disability and adolescence through the characterization of adolescence as a disabling condition and coming of age as a process of “overcoming” (Elman 2014, 21). Second, it shores up the co-constitution of systems of compulsory able-bodiedness and compulsory heterosexuality through sexual containment by way of fostering “healthy” heterosexual development. Finally, it constructs perpetual self-surveillance as essential to the health of the population as well as the individual. Ultimately, the logics of rehabilitative citizenship come to bear on crisis ridden youth, who function as the “figures for the (mis)management of the perpetual crisis that is neoliberal capitalism” (Elman 2014, 27).

The (Disabled) Future Girl

Elman's theorization of rehabilitative logics is integral to this project. Following Elman, I extend and broaden her theorizations of rehabilitative logic and rehabilitative citizenship by bringing it to bear on contemporary figurations of disabled girlhood. Rehabilitation in this project functions similarly to what Elman has theorized, but as chapter two will illustrate, I am interested in how rehabilitation is affectively incited specifically through the figuration of the disabled girl. Elman argues that "crisis ridden youth" function as figures that index the crisis of neoliberal capitalism, and I concur. However, this dissertation performs a feminist disability studies intervention, and I specifically parse out how exceptional disabled girls function as figures that index our ongoing moment of "the crisis of neoliberal capitalism," but as it is manifested and managed through the fantasy of a post-ADA America. I argue that the figuration of the exceptional disabled girl has come to function as a reparative figure. Tethering rehabilitative logic to national fantasies of benevolence, the exceptional disabled girl is at once a symbol of and a rescue from the fraying good life. This production grounds an emergent post-ADA structure of feeling. In order to perform a fine tuned analysis in each of the ensuing case study chapters, it is necessary to first place the exceptional disabled girl in the context of a nascent outline of what I term a post-ADA structure of feeling.

At the turn of the twenty-first century, many scholars of girlhood document a shift wherein, "young women [have become] constructed as a vanguard of new subjectivity" (Harris 2004, 1). These girls, "future girls," are applauded, and in turn, upheld as examples of the "desire, determination, and confidence to take charge of […] life, seize chances, and achieve […] goals" (Harris 2004, 1). McRobbie (2009) clarifies that because of their emergence as "highly efficient assemblage[s] of productivity," young women are positioned as the privileged subjects of neoliberal capitalism (59). Shifting economic and labor conditions, the privileging of the exploitative gendered flexible subject, in combination with the gains of feminism, have created, somewhat tenuously, new possibilities for certain young women. Working alongside this material shift is a symbolic one: the girl has accumulated new cultural currency by way of exceptionalist rhetoric. McRobbie (2009) mobilizes the Deleuzian term "luminosity" to describe the ways in which girls have been "put under a spotlight" (254) vis-à-vis their imagined potential productivity. Thus girls have become luminous—interpellated into the cultural imaginary as a "metaphor for social mobility and social change" (Ringrose 2007, 472). However, this project of luminization is a technology of regulation and management.

These girls are "supposed to offer clues about the best way to cope with," what Harris (2004) characterizes as "late modern times […] characterized by dislocation, flux, and globalization, and demand citizens who are flexible and self-realizing" (1-2). Further, "late modern times" can be characterized by the shift from state support to privatization, de-industrialization, and the preeminence of finance capitalism. Randy Martin (2007) in *An Empire of Indifference* argues that finance capitalism "has produced distinctions between 'risk-taking investors' and populations 'at-risk,' and between the self-managed and the unmanageable, which work to accumulate both moral and physical capital (30). He forwards the ideal figure of the "risk-taking investor," who is a "modification of the earlier ideal neoliberal subject of the consumer citizen" (Martin 2007, 30). The risk-taking investor "becomes a new model citizen who takes care of their own futures, manages their own affairs, and participates in the management of surplus populations" (Martin 2007, 30). Thus, the "future girl" manages her own future: she is a good investor and a good investment.

This dissertation contends that the exceptional disabled girl functions as a reparative future girl. The figuration of the exceptional disabled girl is indeed deployed to "offer clues about the best ways to cope with" late modern times, but she exceeds Harris' theorization of a future girl because of the ways in which she functions to tether rehabilitative logic to national fantasies of benevolence. She teaches us how to manage our future, as it is tied to fantasies of national benevolence, which characterized by teleologies of progress (as they are manifested in narratives of neoliberal multiculturalism). She teaches us how to become a productive citizen through her expertise in navigating her "forever incomplete" and crisis ridden disabled body. As we are all in need of work, she can guide us in our individual projects of self-making, self-management of risk, and attempts to return to a "former capacity" or restore stability as we all weather advanced capitalism, or the fraying good life, and its attendant crises.

The Post-ADA Structure of Feeling

2015 marked the twenty-fifth anniversary of the Americans with Disabilities Act (ADA). In a blog post celebrating the anniversary of the landmark piece of legislation, the U.S. Department of Justice writes,

> The power and promise of the ADA lies in its ability to empower individuals with disabilities to dream bigger, and to enable them to pursue their own visions of the American dream. […] Though our country has certainly come a long way towards achieving equal opportunity, full participation, independent living, and economic self-sufficiency for people with disabilities over the 25 years since the ADA was

> enacted, the department recognizes that our work is not yet done. […] We will not stop until every child with a disability can dream the same dreams as children without disabilities—and follow those dreams to reality. Until every person with a disability can pursue a life of work, family, community and civic participation. And until the dignity and value of every person is recognized without question. The department will not rest until, to paraphrase President H.W. Bush's powerful words at the ADA signing ceremony, every last shameful wall of exclusion for persons with disabilities finally comes tumbling down (Gupta 2015).

However, as many scholars of disability argue, despite the ADA's positioning by politicians as the "emancipation proclamation" for disabled folks, disability continues to significantly shape unequal distribution of resources (Maroto and Pettinicchio 2015; Mitchell and Synder 2015; Tremain 2015). "Employment disparities for disabled folks have grown" over the twenty-five year period since the ADA was signed into law, and "interpretations of the law have created major hurdles for disabled plaintiffs and, in many ways, rendered the ADA ineffective in changing employer attitude and practices" (Maroto and Pettincchio 2015, n.p.). Despite the material ineffectualness of the ADA, increasing cuts to Medicare and Medicaid that affect access to healthcare, rapid waves of gentrification that affect access to affordable housing, and increasing dependence on low wage flexible labor, the fantasy and promise of the "American dream," as the blog post points to, persists. The American dream, as this blog articulates, could also be called the good life, which promises "upward mobility, job security, political and social equality, and lively, durable intimacy" (Berlant 2011, 3). This fantasy of the American dream, or the good life, is clearly fraying. Fraying "implies something slow, delicate, processual, something happening on its own time" (Berlant 2011, 196).

Further, as the following chapters illustrate, the disabled girl emerges under a particularly insidious spotlight cast by the contemporary post-ADA production of disability, which can be characterized through the tension of these material failures and the framework of ablenationalism, or exceptional neoliberal inclusion efforts. Mitchell and Snyder (2015) argue that ablenationalism manifests through "open rhetorical claims of a new era of inclusion for people with disabilities issued by the state […] Disabled people now perform their representational work as a symbol of expansive neoliberal inclusion efforts" (116). These new practices of neoliberal disability tolerance, for example, diversity training, representation in advertising campaigns, creation of specific 'disability markets,'[6]"obscure as much as they reveal" (Mitchell and Snyder 2015, 4). Within these terms of ablenationalism, disabled folks have increasingly come to represent new forms of embodied value for the nation-state, thus certain disabled populations have been positioned less as "parasitic" to the nation's resources. In this way, certain disabled folks are recapacitated into what Titchkosky (2003) terms, the "able-disabled." Within this logic, disability is a "static thing" rather than a relationality, which is fluid and contextual (Fritsch 2013, 142). As a thing, "disability can be known, contained, marketed, consumed, profited from and solutions can be found" (Fritsch 2013, 142). The contemporary production of the disabled body as Sothern (2007) concludes, "must also be thought of as a space of the contradictions of neoliberalism—it is at once privileged as a site of inclusion, but that inclusion is also the promise of its exclusion" (146).

As such, this study builds on Berlant's theorizations of precarity, the "politico-affective" condition of the present moment that is engendered by the material reality of the fraying of the good life. Like Berlant, I am interested in tracking an emergent

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[6] Adaptive clothing is an excellent example of the creation of specific disability markets. Buck & Buck, Silverts, and Tommy Hilfiger's collaboration with Runway of Dreams are all examples of specific brands who have developed clothing that is specifically marketed to disabled folks.

affective atmosphere, or shared historical sense, that is emerging. Berlant (2011) argues that “the present is perceived, first, affectively: the present is what makes itself present to us before it becomes anything else, such as an orchestrated collective event or an epoch on which we can look back” (4). Thus the present is a “mediated affect” whose “very parameters are also always up for debate” (Berlant 2011, 4).

Mediated affect can also be discussed in terms of Raymond Williams’ theorization of “structures of feeling.” Devika Sharma and Frederik Tygstrup’s (2015) *Structures of Feeling* return to William’s theorizations and argue, “his work seems to prefigure the conspicuous contemporary interest in affect” (2). Much contemporary work in affect studies “broadly correspond” with Williams’ nascent and dense articulation of structure of feeling, and to bring contemporary affect studies to bear on Williams’ work is to create a productive friction that allows us to really interrogate the “complex phenomenon of the lived presence” (Sharma and Tygstrup 2015, 1-2).

In his writing on the Bloomsbury group, Williams charts the different components that go into a formation of a group “to which members can adhere to and feel attachment” (Sharma and Tygstrup 2015, 1). To understand the group as a cultural and social phenomenon, one must take into consideration not only “ideas, events, and their effects, but also, more ambitiously all of the less tangible qualities that eventually make up the specific social and intellectual atmosphere of the group” (Sharma and Tygstrup 2015, 1). Williams’ attention to ‘style,’ or the implication that one must be attentive to “the sense of lived lives underpinning the cultural record,” the “elusive stratum of reality, evanescent in its manifestations,” is what he characterizes as “structures of feeling” (Sharma and Tygstrup 2015, 1) The lived presence, or “particular quality of social experience and relationship, historically distinct from other particular qualities, which gives the sense of the generation or a period" (Williams 1978, 131). The "experience," "sense," and "quality" that Williams is referring to suggests that to get at this shared historical sense that Berlant articulates, one must compliment an analysis of a social, historical, economic, or material layer with an affective one.

"Affectivity seems to have become an ever more important part of social life today," argue Sharma and Tygstrup (2015, 3). Production, consumption, and participation in our contemporary moment are all systematically organized, structured around, and driven by affect. For example, at the beginning of the chapter I discuss The Freedom Girls in the context of the 2016 election, which is exemplary of how the affective dimension of politics has come to dominant how we understand and experience politics and elections. Another example is how within the service sector, the most dominant labor force in the U.S., emotions, affective orientations, and emotional performances have market value—there is a premium placed on customer service, which consists of appearing welcoming and friendly. An affective layer of analysis, then, affords us the opportunity to really investigate the intricate workings of power as the structure the present.

This dissertation is interested in tracking the emergence of a post-ADA structure of feeling, or an emergent affective atmosphere, whose contours are shaped by the figure of the exceptional disabled girl. Feeling gestures both toward "a distinction from more formal concepts of 'world-view' or 'ideology,'" toward experiences, values, and meanings as they are actively lived and felt, as well as something "intentionally imprecise," an "ambiguity between feelings as embodied sensations and feelings as psychic or cognitive experiences" (Sharma and Tygstrup 2015, 23; Cvetkovich 2012, 4). Structure implies a set of internal relations that are held in tension (Sharma and Tygstrup 2015). As such, methodologically, structure of feeling "is a cultural hypothesis" derived from attempts to track and understand an emerging shared historical sense, and how that underpins "the way we live now," as it is generated by way of mediated affectivity, or an assemblage of embodied sensations, feelings, emotions, experiences (Sharma and Tygstrup 2015, 16-24). My approach shares a certain phenomenological awareness that bodies are not autonomous from the world and that their movement is "always through their relations in the world" (Coleman 2009, 1). This project considers affect as the intersubjective glue that creates, holds, and transverses relations between bodies: it has the "capability to both transform as well as exceed social subjection," it is both "mobile and ordinary," and it "concerns what happens to us, and what we do about what happens to us" (Hemmings 2015, 148-149; Sharma and Tygstrup 2015, 14). In short, affect is that which moves us.

Attending to an emergent post-ADA structure of feeling allows for new ways to track how, for example, the U.S. Justice Department's blog on the twenty-fifth anniversary operates in conviviality with the seemingly disparate phenomenon of The USA Freedom Kids. It implores interrogation of *Vice*'s spotlighting of Sarah, at the fantastical intersection of narratives of U.S. freedom and the "progress" of disability post-ADA.

Situating this Project

The nexus of disability and girlhood is a broad area of study that has been considered within the fields of education (Asch and Fine 1988; Bauer 2001; Erevelles and Mutua 2005; Ferri and Connor 2009; Cowley 2013), psychology (Barese 2002; Bell et al. 2005; Rice et al. 2008;), sociology (Shandra and Chowdhury 2012), nursing (Berman et al. 1999), and public policy (Jewell 2007). "Disabled girl," in many of these conventional studies, is taken as a static category of analysis that is rigidly defined by a medicalized framework. Many of these studies, although disabled girls are indeed the subjects of analysis, are conducted for the purposes of the parents, policy makers, or other institutionalized figures who are somewhat problematically tasked with managing or making decisions on behalf of disabled girls. Potentiality, risk, and vulnerability undergird the conventional discourse on the disabled girl.

For example, Jewell (2007) conducts an analysis of the ethical implications of the sterilization of intellectually disabled young girls and concludes that in recent, controversial cases of sterilization, analogies to eugenics are misplaced and appeals to the rights and autonomy of the disabled girl is problematic. He proposes that an ethical analysis of sterilization would favor the decision making capacities of the parents because the disabled girl does not have the capacity to consent, or not consent:

> After all, another competent individual might consider she will benefit if she seeks sterilization for herself, and so has good reason to do so. To deny those benefits to someone on the grounds of their disability is as much of a denial of their rights as to enforce an unwanted intervention (Jewell 2007, 60).

In Jewell's study, notwithstanding the extremely problematic assumptions about consent and the "choice" of sterilization, the intellectually disabled girl is understood purely through her disability. He does not take into consideration the ways in which disabled girlhood is figured through gender, race, class, sexuality, etc.

Like Jewell (2007), many other researchers discuss disabled girlhood in terms of sexuality, and it is the disabled girls' potential reproductive or non-reproductive capacities that loom largely between the lines in the studies. The disabled girl in Berman et al. (1999) and Shandra and Chowdhury's (2012) research on sexual knowledge and behavior is implicitly heterosexual and is explicitly at risk for engaging in "less positive sexual interactions" (516). Disability, defined as a "limiting condition," increases the likelihood that "one will have sexual intercourse with a stranger versus a steady dating partner" (Shandra and Chowdhury 2012, 528). Disabled girls are also uniformed or misinformed about sexuality, and how their disability can affect their "sexual or reproductive function" (Berman et al. 1999, 193). In these studies, the lack of knowledge places the disabled girl at risk for unwanted pregnancy as well as sexual abuse.

In education research, there are similar narratives of risk. Both physically and intellectually disabled girls are more likely to receive less education than their able-bodied counterparts, and they are less likely to "become women with any college education" (Bauer 2001). Disabled girls are also framed throughout education research, similar to other fields, as future women. Disabled girls, as future disabled women, may not "reach their potential" because of lack of education services (Asch and Fine 1988). In these studies, disabled girls are at risk for not "reaching their potential," wherein potential is defined within a framework of a linear academic track. This presupposes that if the disabled girl receives services while she is young, she will attend college and then attain a job, thus reaching her potential. Again, these narratives take up "the disabled girl" as a rigid category of analysis, one that does not take into consideration how race, class, citizenship, and sexuality position disabled girls differently within an educational setting. Further, she remains a voiceless figure in these conventional studies and is prefigured as already failing unless an institutional figure can intervene and guide her away from her naturalized deficiency, or disability, to a successful approximation of educational normalcy and success.

Ultimately, the disabled girl that has emerged within the past 30 years and circulates in conventional academic discourse is at risk of failing to meet developmental markers, she is socially isolated, she is vulnerable, and she must be understood in order for her parents, teachers, doctors, or other institutional figures to manage and make decisions for her. Framed negatively or within a deficit framework, her disability is positioned as an individual problem that is always limiting and inherent to her body. She is framed in terms of her potentiality—to become successful in academic terms and reproductive terms is dependent on looking forward to her future as a disabled woman. I am not suggesting that these conventional studies are unnecessary, and I do believe that it is imperative that researchers study disabled girls as a population that does need unique support in the shadow of the welfare state; however, I do think that these studies beg us to consider how and why the disabled girl has become an object of analysis in the past 30 years. How disabled girlhood is leveraged in these studies is not separate from, but co-constitutes, the figure of the disabled girl in the contemporary mediascape.

Traces of these narratives and the affects that are generated by way of these conventional academic studies stick to and follow the figure of the disabled girl in my study. As the following chapters illustrate, the figure of the exceptional disabled girl derives her luminosity by her very repudiation of some of these prevailing disability discourses. This is one of the ways in which post-ADA logics operates insidiously. For example, in chapter two I interrogate the ways in which the luminosity of two disabled girl YouTubers is engendered by way of their capacities for rehabilitating able-bodied folks into tolerant neoliberal citizens. Similarly, in chapter three I suggest that disabled girls that participate in a pageant for disabled girls are made luminous through their status as happy objects. In both cases, the disabled girls' luminosity is contingent upon a narrative and affective conversion: from a deficient and risky body to one that is full of promise and potentiality.

As this introduction has forwarded, I am interested in these narrative and affective conversions, and how the figure of the disabled girl has emerged, as inspired by Driscoll, "as the index of the problems of the present." As such, I situate my study among a very small but growing body of knowledge that takes a critical feminist disability studies approach to disabled girlhood. As Erevelles and Mutua (2005) argue in their chapter "I am a Woman Now! Writing Cartographies of Girlhood from the Critical Standpoint of Disability," "disabled girlhood challenges heteronormativity […] and simultaneously disrupts and flirts with patriarchal norms of 'girling' (254). Similarly, the *Girlhood Studies* special issue, Disability and Girlhood: Transnational Perspectives, largely grapples with how girls and disabled folks have been constructed as vulnerable populations. The disabled girl, at the intersection, "invokes the contradictory combination of peril and promise" (Erevelles and Nguyen 2016, 4). Scholars of feminist disability recognize the ways in which disabled girls are "perceived as lacking autonomy and agency" because they are assumed to be inferior to able-bodied girls who can comply with “the criteria of so-called normative girlhood” (Jennings qtd. in Erevelles and Nguyen 2016, 8). Scholars of feminist disability studies recognize that both “disability” and “girlhood” are not ahistorical, static, and rigid biological categories; but rather, they are constituted by and through systems and relations of power.

Ultimately, it is clear that the disabled girls’ body is a site where multiple narratives, relations of power, and affective states collide. Like many critical feminist disability studies scholars, this project understands the disabled (girls’) body as “an embodiment that is not singular but multiple, not bounded but fluid” (McGuire 2016, 18; Garland Thomson 1997; Shildrick and Price 1998; Corker and French 1999; Smith and Hutchinson 2004; Titchkosky 2007; Tremain 2008; Erevelles 2011; Hall 2011; Chen 2012; Kafer 2013). At once, ideological, material, and affective, the disabled girls’ body is also a relation—it is made and remade as it encounters other bodies and other bodies are made and remade as they encounter the disabled girls’ body. This understanding of disabled girl and disabled girlhood affords me the opportunity to investigate how and why the hypervisible figure of the exceptional disabled girl has emerged post-ADA, and it implores investigation of the *function* of this figuration. If a disabled girls’ body is a relation that is encountered, then how does it move us?

Methodological Considerations

This specific iteration of the project began to take shape after my encounter with HBO’s *Miss You Can Do It.* Similar to what I have articulated about Sarah and The USA Freedom Kids, something about the documentary *stuck* with me. After watching the documentary countless times, I found myself dwelling in a state of ambivalence. This affective state was immensely productive, as I found myself unable to make quick or stock critiques of the film. The ambivalence forced me to reckon with the contradictions inherent in the film, and it also provoked me to sit with my own ambivalent feelings about the way that the figuration of the disabled girl was deployed. As I worked to refine my artifacts for this project, I always came back to the ones that, similar to *Miss You Can Do It*, stuck with me. These ambivalent artifacts, films, news stories, YouTube videos, and television episodes left me feeling unsure, one way or another, of how I felt about them. In viewing these ambivalent artifacts, I felt moments of elation and disruption—when the disabled girls and their witty and nuanced way of being-in-the-world took center stage—but I also felt moments of distress and capture—when the disabled girls were insidiously, sometimes violently, deployed for the obvious purpose of shoring up ableism. Encountering this productive tension, which toggled between elation and distress, disruption and capture, guided me in both the delimiting and analyzing of the artifacts. Plainly, I felt that there was *something more* about the figuration of the disabled girl than I could immediately get at in each of the artifacts that I gathered for this project. This something more, or what I have articulated as ambivalence, is both the guide for analysis as well as the "stuff" of my analysis. As I discuss at length in my methodology appendix, affect operates as both a guide as well as an object of analysis in the ensuing chapters, which affords me the opportunity to really get at the complex, and contradictory ways that the figuration of the disabled girl moves us as she emerges in post-ADA America.

Chapter Overview

The first chapter, "'I Am Crying…This Really Touched My Heart:' Disabled Intimacy and the Thick Materiality of the Virtual (Girlhood)," focuses on two disabled YouTubers: Charisse Living with Cerebral Palsy and Rikki Poynter. I suggest that these YouTubers' vlogs function as intimate publics, or spaces of technologically mediated intimacy, where I understand intimacy in terms of a necessary encounter for certain affective states to "bloom" (McGlotten 2013, 9). I utilize Adi Kuntsman's (2012) theorization of cybertouch to investigate how viewers are *moved* by Charisse and Poynters' vlogs and contend that these videos function, in phenomenological terms, as devices of able-bodied rehabilitation. Ultimately, for many, to belong to these disabled girls' virtual intimate publics is to be rehabilitated or affectively reoriented into a tolerant neoliberal citizen. This act of affective reorientation relies on imagining a future-oriented version of tolerance, which effectively depoliticizes disability. Ultimately, I argue, these virtual disabled intimate publics are co-opted as a sign of neoliberal inclusionism.

My third chapter, "'I'm Wanting You to See This as a Chance:' Promise, Futurity, and Not the Bad Life in *Miss You Can Do It* and *How to Dance in Ohio,"* examines two recent HBO documentaries about disabled girlhood. I analyze *Miss You Can Do It*, a 2013 documentary that follows contestants and their families in a pageant for disabled girls in conjunction with *How to Dance in Ohio*, a 2015 documentary that chronicles three autistic girls and their families for the three months leading up to a spring formal for autistic young people. Staging an encounter between biopolitics and affect, I analyze how the figure of the disabled girl in these two documentaries works to asymmetrically incorporate certain exceptional disabled girls into the national imaginary. For the time-rich, young disabled girls in *Miss You Can Do It*, I suggest that they are made valuable to the nation-state through their transformation into happy objects for consumption. This transformation hinges on a narrative of U.S. disability exceptionalism, which is illustrated in the documentary through a celebratory yet tragic tale of an American family's adoption of a Ukrainian disabled adoptee. However, for the time-bankrupt, autistic girl-becoming-woman in *How To Dance in Ohio*, I suggest that their value is based upon their transformation into a shared object of hope or optimism, which is contingent upon compulsory heteronormative and compulsory able-bodied containment.

Taken together, my effort in this chapter is to discern the ways in which these representations of disabled girlhood move us in specific ways vis-à-vis their reliance on fantasies of futurity, which is figured through the promise of happiness, hope, and optimism. Most significantly, this fantasy wanes as the disabled girl's childhood discursively and affectively wanes—as their bleak future approaches—a crisis emerges. Ultimately, both documentaries illustrate the ways in which disabled girls' luminosity is contingent on the securitization and management of unruly disabled girl bodies: from the third world disabled adoptee to the time-bankrupt autistic young woman.

The fourth chapter, "At the End of Rehabilitation: The Haunting of Disabled Girl Death," investigates affective attachments to representations of disabled girl death. To do this, I place an episode of the teen edutainment drama series, *Degrassi: Next Class* in conversation with representations of Jerika Bolen, a disabled girl who chose to end her life in September of 2016. The episode I critically examine, *#NoFilter*, focuses on Grace, who comes out as having cystic fibrosis and is predicted to die before she enters middle age, and her friend who has romantic feelings for her, Zoe, who is depicted as struggling to come out as gay.

Through Grace's fatal prognosis, Zoe is able to critically reflect on the meaning of mortality and the value of a good death, which in this case, is a death that is grievable. Grievability in #NoFilter is only possible through the call to come out. Grace must "come out" as disabled to be grievable. Rehabilitative logic in #NoFilter works to sustain a fantasy of neoliberal sovereignty through the affectivity of white homonormative suffering. This works to displace actual existential or ontological questions about disabled death and instead resolves a potential crisis of queer/crip-ness through a reinscribing of familiar but perhaps more flexible neoliberal taxonomies. As Zoe must urgently "figure out" if she is gay or not, Grace's disability is unwittingly placed firmly within a curative (or not!) framework.

Similarly, the event of Jerika Bolen's death is mobilized pedagogically as an example of "good dying." Investigating the affective states that reverberate in the comments on her GoFundMe as well how her "Last Dance" is staged in the local news, I suggest that the figuration of Bolen, as a disabled, black girl, is complicit in securing the ascendancy of the "choice to die" as a practice of good citizenship. Further, her blackness is commodified within this framework, and it serves to resignify "bad feelings" around disabled black death at the hands of police violence.

Ultimately, I argue that affects that circulate around the imagined death of Grace and the actual death of Bolen work to shore up illusory neoliberal evocations of "choice" and "autonomy" within our times of existential vulnerability. The figure of the exceptional disabled girl is recapacitated in her death by way of her ideological, affective labor. Both girls, in their lives and imagined and real death work to rehabilitate able-bodied folks, and this rehabilitation works to and is premised upon the shoring up of the familiar trope of the suffering disabled body.

Taken together, these case studies spotlight the figure of the exceptional disabled girl as she circulates in the contemporary mediascape, and illustrate how she operates as a reparative figure, that when deployed, shapes an emergent affective condition characterized by its attempts to secure national fantasies of a future-oriented tolerance. Reparative suggests to restore something or to renew something after it, in this case the nation, has been decayed or damaged, and although it gestures toward the past, it orients us to the future: there is something that must be compensated for and we, as a nation, are going to work toward it. I uncover how rehabilitative logic orients these national fantasies, and I contend that they are anchored through a shared affective orientation *to* disabled girlhood as well as *through* disabled girlhood. Exceptional disabled girls have become at once a symbol of and a rescue from the fraying good life. Through their role as disability educators, shared objects of happiness and optimism, and pedagogues of death, disabled girls have been deployed as guides on a new roadmap to ideal, affective post-ADA citizenhood. Habitual encounters with the figure of the exceptional disabled girl and the affectivity that surges through her work to cover over the waning fantasies of the good life that characterize our contemporary moment, as well as condemn certain bodies that work (sometimes unknowingly) to expose the contradictions inherent in our contemporary post-ADA, neoliberal imaginary.

Chapter 2

"I Am Crying…This Really Touched My Heart": Disabled Intimacy and the Thick Materiality of the Virtual (Girlhood)

"Perhaps we truly encounter the political only when we *feel."*

– Janet Staiger (2010)

"Sitting by the lonely tree, looking at others wishing that was me
As others come, think I would never know
Telling things about me, 'that she never knows'
Oh what they say, makes me cry"

– Charisse Living with Cerebral Palsy

"Charisse's Story—My Life Journey with Cerebral Palsy" is Charisse Living with Cerebral Palsy's most watched YouTube video. This video, with over 228,945 views and 800 comments, alternates between stills of old family photos and video footage of current day Charisse sitting on the floor, an Americana quit draped behind her. As the title suggests, within the space of the seventeen-minute video Charisse narrates her disability story, or "life journey." As baby pictures linger in the frame, Charisse takes us through her birth, where we learn that her umbilical cord was wrapped around her neck, cutting off oxygen for seven minutes. She explains that she was not diagnosed with low tone

Cerebral Palsy and Ataxia[7] until she was two years old. We first see stills of toddler Charisse, wearing a pink tutu, in her walker, and we follow along through school pictures, as current day Charisse narrates her journey from walker, to forearm crutches, to walking on her own with a limp. The video alternates between discussions of the materiality of her disabled embodiment, for example, her experiences with seizures, and how her embodiment structures her being-in-the-world, for example, how she did not realize she was disabled until someone at school started bullying her in the second grade, which is captured in the poem that this chapter opened with.

Similar to Charisse's other videos on her channel, which range from informative, "Talking About Driving with Cerebral Palsy," to mundane, "A Day in the Life of Charisse Living with Cerebral Palsy," "Charisse's Story" invites viewers into some of her most intimate moments. As Shaka McGlotten (2013) notes, intimacy can describe a sense of belonging or a feeling of connection; it refers to things that we feel and do: intimacy is a force. He writes, "In contemporary U.S. culture, intimacy names the affective encounters with others that often matter most, while also functioning as a juridical form, an aspirational narrative, and therapeutic culture's raison d'etre" (McGlotten 2013, 11). The YouTube video blog, or vlog, is a phenomenon that has often been theorized in media studies within the framework of a turn toward confession or therapeutic culture, and has been connected to new post-feminist, neoliberal, and, as this chapter forwards, post-ADA economies of visibility (Raun 2012; Banet-Weiser 2014). As McGlotten reminds us, intimacy is the force that constitutes these contemporary cultures and

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[7] Charisse explains that low tone cerebral palsy affects her movement—her muscle tone is low, which makes it difficult to control her movements. Her body also is subject to uncontrollable jerks because of her ataxia.

economies. Historically, disabled folks have had a paradoxical relationship to intimacy and visibility, and this chapter interrogates what happens when *certain* disabled folks are welcomed into, and work to create, a specific "intimate public." Lauren Berlant (2008) notes, "The intimate public legitimates qualities, ways of being, and entire lives that have otherwise been deemed puny or discarded. It creates *situations* where those qualities can appear as luminous" (2).

This chapter explores how disabled girls' vlogs function as intimate publics, or spaces of technologically mediated intimacy, where I understand intimacy in terms of "affects own immanence" or a "necessary precondition for certain affective states to bloom, especially those that have to do with other people" (McGlotten 2013, 9). Through a critical analysis of the virtual intimate publics that are produced by Charisse Living with Cerebral Palsy, and a fellow disabled vlogger, Rikki Poynter, I explore the mechanisms that "cause us to be moved," or generate the specific individual and collective affective states that circulate in and through Charisse and Poynter's vlogs. I explore the comment sections and argue that these YouTube videos function, in phenomenological terms, as devices of able-bodied reorientation. I argue that this able-bodied reorientation structures contemporary post-ADA rehabilitative logic. The affectivity that the disabled girl YouTuber incites reorients, or rehabilitates the able-bodied viewer into a tolerant post-ADA neoliberal citizen. Ultimately, I argue that these intimate publics are co-opted as a sign of neoliberal inclusionism. This capture is contingent on the very production and circulation of an atmosphere of post-ADA tolerant futurity, which, as this dissertation forwards, is, in part, generated through the disabled girl subject.

Disabled Girlhood 2.0

> "Hello, my name is Rikki Poynter and welcome to my channel. On my channel, you will see videos about these topics: closed-captioning awareness, Deaf awareness, me learning ASL. But being deaf isn't all that I am. I also like to talk about my favorite things: pokemon, sailor moon, coffee, YouTube. I upload videos every Monday and Thursday. So make sure you subscribe and look out for those. And I will see you later. Bye" ("RIKKI POYNTER – Channel Trailer" 2016)!

I came across and became interested in disabled girl YouTubers somewhat accidentally. I subscribe to and watch a variety of makeup YouTubers and daily vloggers, and I stumbled upon Rikki Poynter's channel organically as I was searching to expand my repertoire of channels to subscribe to. As her channel trailer up above articulates, the current videos on her channel range from informative, "3 Ways to Caption Your Videos!," to more personal, "Storytime: My Teacher Made Fun of Me in Class." However, a few years ago when I first came across her channel she was exclusively producing makeup videos. Her channel was like many of the others that I watched at the time, a profusion of "Chit Chat Get Ready With Me," "Monthly Favorites," and "Empties" videos. Her Deaf identity was not the focus of her channel when I clicked the subscribe button—it was never completely unacknowledged—but, rather, it was just not the focus of the content of her videos. I was already writing about representations of disabled girlhood in other spaces, so it was a bit serendipitous when I looked in my subscription box in early October 2014 to find her video "Q&A: Deaf Awareness Week." Poynter's departure from her typical makeup upload was so well received that she decided to change the direction of her channel shortly after, and she is now what I would term for the purposes of this project, a "disability vlogger." Poynter's transition piqued my interest in this genre of YouTube videos, and from there I stumbled across many more emergent channels that addressed the embodied reality of disability. This chapter takes Poynter and one of those channels I stumbled across, Charisse Living with Cerebral Palsy, first introduced in the opening, together as its point of departure.

Although these two YouTubers are both disability vloggers, their channels are aesthetically quite different. Poynter has been making videos since 2010, but as I previously mentioned, she rebranded as a disability vlogger in 2014, evidenced by the hashtag she promotes: #deaftalent. She has over 30,000 subscribers and 1.5 million views. Charisse has been making videos since 2009, but she is a much smaller channel with only a little under 7,000 subscribers. Interestingly, she has a comparable amount of views to Poynter's channel: 1.2 million. Poynter's channel's aesthetic has become increasingly more slick and produced (e.g. professional lighting, corporate sponsorship videos, etc.) as her brand gains traction and circulates online. Her "About Me" attests to the her productive virality as an effect of building and marketing her new brand:

> Rikki Poynter is a twenty-four year old Deaf vlogger on YouTube. After four years of being a beauty blogger and vlogger, she took a hiatus in October 2014 to focus on more lifestyle vlogs and vlogs about deafness and Deaf culture. Since making her first deaf related video on October 1st, 2014, Rikki has been on the Huffington Post, Mic News, Upworthy, ABC News, BBC Newsbeat, BBC Ouch, BBC See Her, and other news outlets in various countries. Also, she has been working on her new closed captioning campaign, #LIGHTSCAMERACAPTION, to try to get more YouTubers to closed [sic] caption their videos. After hopefully one day taking over YouTube, she wants to work on the rest of the internet.

In contrast, Charisse's aesthetic is less produced and one could consider the style of her videos derivative of early vlogging culture, characterized by dim lighting, clunkier editing, and informal filming spaces (e.g. her actual bedroom, as opposed to a dedicated filming space that imitates the look of a bedroom). One could read her "About Me" as a metonym of her channel's aesthetic:

> Hi everyone! My name is Charisse! I was born with low tone Cerebral Palsy and Ataxia. In my videos I share my disability with the world to spread awareness and understanding of disabilities. My main goal is to show others that people with disabilities can do things other people can do, we just sometimes do things differently in our own unique way. I also want to inspire others to always keep hope and never give up during struggles. I film, edit, and upload all my videos by myself. Thank you for checking out my channel!

Although the current aesthetic of their channels differ, Poynter and Charisse both produce videos that explicitly reflect on their embodied reality as a disabled girl, and their stated goal for their respective channels is similar in that they want to, as Charisse eloquently articulates, "spread awareness and understanding of disabilities." For both of the girls, YouTube is their full time job. Although they both have spoken about difficulties attaining employment, the success of their YouTube channels aids in the production of Poynter and Charisse as "future girls:" flexible, resilient, adaptive, and ultimately successful in managing their own "choice biography" (Harris 2004, 8). This apparent success in managing their lives, and their futures, is one of the ways in which Poynter and Charisse have become intelligible to the nation, and it is what undergirds the construction of their intimate publics. However, it is precisely at the intersection of girlhood and disability (and whiteness) that their luminosity emerges. In our post-ADA America, Charisse and Poynter are welcomed into the diversity economy through their capacity to successfully re-orient the able-bodied folks that participate in their intimate publics.

Virtual Disability Intimate Publics

Intimate Publics

As I outline in the introduction, the disabled girl emerges as an index of the problem of the present, or to manage the contradictions inherent in our post-ADA neoliberal moment. Within the space of Poynter and Charisse's intimate public, they offer up a roadmap to ideal neoliberal citizenship, which has been reshaped and modified over the past 30 years. In *The Queen of America Goes to Washington City*, Berlant (1997) maps the reshaping of citizenship during the ascendancy of the Reaganite right. Central to this reshaping was a privatization of citizenship, which occurred through many different forces: rhetorical shifts to a "culture-based concept of the nation as a site of integrated social memberships"; antifederal, patriotic nationalism of Reagan Republicanism; the marketing of a nostalgic American aspirationalism; and, "the expansion of a mass-mediated space of opinion formation" (Berlant 1997, 3). This reformulation of citizenship was, in part, configured through the "rerouting of energies" into the "sentimental spaces of an amorphous opinion culture," which became possible through a narrative of a traumatized national identity, premised on an entanglement of suffering and citizenship (Berlant 1997, 3). Overcoming this trauma, the personal became the (a)political; the nation's survival depended on rehabilitation through "personal acts and identities performed in the intimate domains of the quotidian" (Berlant 1997, 4). As such, Berlant argues that national politics is not exercised through a political public sphere, but rather the political public sphere has become an intimate public sphere. Thus, this new intimate public sphere figures citizenship through belonging, which is produced by "personal acts and values" (Berlant 1997, 5).

What is striking about this vexed evocation of intimacy is the ways in which it works to intertwine affective orientations and economics. Berlant notes that the Reaganite cultural revolution foregrounded "normal intimacy" as the key to a citizen's happiness whilst at the same time operated rhetorically to cover over the precarity inherent in neoliberal capitalism, espousing that

> the causes of the U.S. income inequality and job instability in all sectors of the economy can be personalized, rephrased in terms of individuals' capacity to respond flexibly to the new 'opportunities' presented to them within an increasingly volatile global economy (Berlant 1997, 8).

This configuration of the intimate public sphere works to individuate citizenship and misdirect energies from the structural into the personal.

Berlant broadens her theorizations of the intimate public in *The Female Complaint: The Unfinished Business of Sentimentality in American Culture*. She argues that an intimate public names a space of belonging wherein the participants consume common texts and things, they "*already* share a worldview and emotional knowledge that they have derived from a broadly common historical experience" (Berlant 2008, viii). An intimate public's participants structure its conventions of belonging whilst experiencing and expressing an embodied sensation of living as a certain kind of being in the world. An intimate public is a space of recognition and reflection; or, in other words, it is an achievement. Berlant (2008) argues that an intimate public,

> Whether linked to women or other nondominant people [it] flourishes as a porous, affective scene of identification among strangers that promises a certain experience of belonging and provides a complex of consolation, confirmation, discipline and discussion about how to live as an *x* (viii).

The participants in an intimate public may have freely chosen to identify as an *x* or participants may have been marked as an *x* by outside taxonomies, but regardless, an intimate public provides it's participants with an "anchor" and material for "enduring, resisting, overcoming, and enjoying being an *x*" (Berlant 2008, ix). Intimate publics provide an affective frame for being in the world.

As a mass-mediated nondominant community, an intimate public operates "juxtapolitically," thriving in proximity to the political, sometimes crossing over to the political, but largely "acting as a critical chorus that sees the expression of emotional response and conceptual recalibration as achievement enough" (Berlant 2008, x). An intimate public necessitates a turn inward, and it requires perpetual self-management and self-reflection as conditions of belonging.

Disabled Girl Intimate Publics

When people yawn

Do deaf people think they're screaming?

roll your eyes to the back of your head as far as you can and walk away from your computer.

Figure 1: Screenshot from Rikki Poynter's YouTube video "Q&A Deaf Awareness Week | closed captioned" (2014).

With over 62,000 views and 1,500 likes, "Q&A: Deaf Awareness Week" is Poynter's most watched and "liked" video on her channel. As I have previously stated, this video was the catalyst for a "rebranding" of her channel. In the video, filmed in what we would presume to be her bedroom, she sits in front of her bed on the floor. A wooden armoire sits behind her bed, and a NASCAR quilt sits on top of her bed. The video has a distinctly amateur aesthetic—characterized by dim lighting and the mundane bedroom space. During the video, Poynter toggles between educational facts and figures about deafness, personal narratives, and, what I can only describe as, pleading with her viewers—to consider captioning their videos, to consider how they are most likely complicit in the dehumanization deaf folks in their everyday lives, to consider how they would feel if they were deaf, living in an audist world. Throughout the video, and despite the different terrain that Poynter covers, she maintains a distinctly humorous and even sarcastic tone. For example, she begins the video by discussing an offensive meme that she recently came across, a picture of a green dinosaur looking inquisitive, it's claw to it's chin, with this text overlain, "When people yawn, do deaf people think they are screaming? She points to the meme that she inserted into the corner of the video frame and with an incredulous face she says, "I don't know who the hell made this shit up, but um, it's shit."

Poynter invites her viewers into the space of her bedroom—to joke with—to tell personal stories with—to plead with. This is an intimate encounter. Intimacy can describe a sense of belonging or a feeling of connection; it refers to things that we feel and do: intimacy is a force (McGlotten 2013). This video is strikingly similar in aesthetic and content to Charisse's most watched video, "Charisse's Story—My Life Journey with Cerebral Palsy," which I opened this chapter with. Both videos invite viewers into the space of the disabled girl vloggers' bedrooms, and in their direct address to their imagined audience, they narrate their inner worlds—reminiscent of engaging with a teenage girl's diary. The amateur aesthetic could be read as authenticity, and as media scholar Susanna Paasonen (2005) notes, the creators of amateur video productions are assumed to have a lack of skill, thus their videos lack an overly manufactured feel which reads as “real.” In short, something about these videos resonate with the audience, which is exemplified by their atypically high number of views relative to other lesser known vloggers’ average video views, as well as the similarly impassioned comments that are left on both videos. For example, in response to Poynter’s video, Sassy G writes: “THANK YOU SO MUCH. <333333333.” The palpable ecstatic affective state, illustrated by the less than 3 heart emoticon, is similar to It’s Your Girl Miah’s response to Charisse’s video: “You are amazing I cried watching this video love.just stay cool xxx.” The affectivity of these videos is intense.

The internet has “become an ersatz space” that facilitates “reaching out, fetishizing, and touching other individuals” (Hillis 2009, 15-16). Vlogs hinge upon touch—the viewers are touched by the vlogger and the vlogger is touched by the viewers—and this establishes virtual intimacies. These virtual intimacies manifest in various ways: through vloggers’ direct address to their viewers, the vlogs’ confessional and therapeutic aesthetic, and through the mundane and ordinary content. This is what characterizes the thick materiality of the virtual. Kuntsman’s (2012) concept of cybertouch is useful here, and although he mobilizes the term to talk about the affective entanglements of war and violence online and off, cybertouch can help us think through how Poynter, and Charisse, through their videos, “create an immediate emotional response (sadness, rage, pain, compassion, joy)—an ‘affective charge of investment, of being ‘touched’” (Cvetkovich qtd. in Kuntsman 2012, 3). This touch draws the viewers into the intimate public.

Figure 2: Screenshot from Charisse With Cerebral Palsy's Youtube video "Charisse's Story—My Life Journey with Cerebral Palsy" (2012).

It is clear that Charisse, like Poynter, touches her viewers. In "Charisse's Story—My Life Journey with Cerebral Palsy." Charisse sits stoically in the center of the frame, an Americana quilt is draped behind her forming a quite patriotic backdrop, and she stares intensely at the camera as she delivers this monologue:

> In 10th grade I started making Youtube videos and I didn't really know how many people would actually watch them. So I just continued making more and more. And later on kids from my school found my videos some told me that they understood me more now and understood more about Cerebral Palsy and that inside I'm not as different as them and I can do what they do just in my own unique way. It helped a lot, just seeing my videos they started understanding me. More and more people began talking to me at school, and it was just really great. So I continued my videos and hoping they can help others understand that people with disabilities can do what other people do, just in their unique way, and spread the awareness of the disabled and show what we can do and that on the outside we may be different, but on the inside we're like everyone else.

Her tone is unwaveringly calm, and although her ataxia affects the smooth cadence of the monologue in unpredictable ways, words crescendo into being, and her mouth slowly mimics the uptick in her narrative. She starts to smile as she articulates:

> My 12th grade year was so much better than the two past years. A lot more people started talking to me and I started helping with the mentally challenge [sic] students and I love helping them they would make me smile and amazed me with everything they do. And when I get older I would love to have a job helping with special needs children because I love being around them.

Charisse goes on to talk about how she joined the varsity basketball cheerleading squad her senior year, was able to "overcome" her fear stage fright through her drama class, started dating the boy she went to prom with, and walked across the stage at graduation. She notes that it "felt so amazing to walk across the stage because [she] struggled so much in high school." Charisse ends the video by firmly yet optimistically stating that she "knows life is going to give her more challenges along the way, but [she] thinks she is ready to face them, and [she can't wait to see what [she has] in her future."

Ahmed (2006) points out in *Queer Phenomenology*, "it involves painstaking labor for bodies to inhabit spaces that do not extend their shape" (62). When bodies "take up spaces that do not extend their shape," they effectively and affectively labor to "reorientate bodies and space" (Ahmed 2006, 61). Charisse continued and still continues to upload videos because, as Ahmed (2006) would posit, "something other than the reproduction of the facts of the matter happens" when Charisse's disabled body extends into virtual (62). Or in other words, the affective labor that she performs to create and sustain a virtual intimate public is both constitutive of and contingent upon a shifting cartography of post-ADA feeling. Charisse becomes intelligible to her able-bodied peers by way of the extension of her disabled body into the space of YouTube, and this is premised upon a thick affectivity, or through the "touch" made possible by intimacy. We can see more clearly how intimacy functions—as a force, or vital energy—an interpersonal orientation that allows certain affective states to bloom, when we turn to her viewer's comments.

"I am crying this really touched my heart" reads a comment Rafael Beck left in response to Charisse's "Charisse's Story—My Life Journey with Cerebral Palsy." Ach1088 concurs, "This video made me cry it's so beautiful and inspiring. Thanks for sharing." It's Your Girl Miah adds, "You are amazing I cried watching this video love.just [*sic*] stay cool xxx." These utterances of being driven to tears are found sprinkled throughout the comment section of Charisse's videos. Not only are commenters being driven to tears after watching Charisse recount her experience with bullying, isolation, and loneliness, but they are similarly affected as they watch Charisse perform the mundane. In response to a video where Charisse explains how she ties her shoes, AgentJayZ comments that Charisse "tugs at my heart strings…whatever they are." In response to "Baking Cupcakes with a Disability," a video where Charisse shows us her mini cupcake maker, JayGirl711 writes, "You made me cry, :"(. those cupcakes were great <3☺ Now I'm craving for cupcakes! I haven't seen a person with Cerebral Palsy. When you cracked the egg, I felt something in my heart and cried."

The feeling of Charisse's touch, "or the sensation of the skin surface" is not "in the object of the body but instead takes shape as an effect of the encounter" (Ahmed 2006, 119). The touch of a disabled body, or an encounter with a disabled body is a moment of disorientation. Moments of disorientation, according to Parrey (2016) "occur when one realizes that an encounter has led to a different sense of being in the world or, more accurately, the realization that they are already in the world differently" (n.p). Theoretically, disorientation is about "being turned" by an encounter, and in the process of "turning," one is reoriented. Through the viewer's "turning" they are affectively rehabilitated. We can see the process of this reorientation, and how this undergirds a post-ADA rehabilitative logic, more clearly in the following discussion of Charisse's "What I Want the World to Know."

Viral Intimacies: Disabled Girlhood and Affective Reorientations

In "What I Want the World to Know" Charisse departs from her typical upload. She is sitting square in the frame, the lighting is dim, and with a somber face she lifts up a white notecard. In her shaky handwriting it reads, "My Name is Charisse." The video continues with Charisse holding up a series of notecards: "This is what I want the world to know/ people with disabilities are like/ everyone else." She urges her viewers to "Please be careful with what you say" and reminds able-bodied folks that they should not "say what [disabled folks] can't do" because they "can do what others can do." She asks us to consider that disabled folks "just do things/ in their own unique way." The video ends with Charisse explicitly directing able-bodied folks away from judgment and toward a shared humanity: "Before you judge us/ Just like everyone, we want to be/ accepted the way we are/ Look past the disability/ and accept the person." She ends the video with pulling the last notecard to the side of her face and smiling directly at the camera. Like most of Charisse's videos, "What I Want the World to Know" addresses a presumably able-bodied audience; however, unlike Charisse's other "doing being ordinary" videos, such as tying her shoes, this video attempts to explicitly reorient able-bodied viewers.

As I discuss in the introduction, new modes of capitalist production require different energizing narratives; a successfully flexible subject must cultivate emotions the *right* way, or what Elman (2012) characterizes as a properly "managed heart." The intimate publics that Charisse engenders offer up a roadmap to a successful cultivation of a post-ADA managed heart. For example, in response to "What I Want the World to Know," Sam Curnow writes, "One of my classmates said that people that have disabilities are stupid when I heard it I went over and hit him and said u wach dis video and then he relised what he did." Autoteck 1951 adds, "I see a very beautiful courageous and strong young woman with a very unselfish heart making a big difference in the world." Batmanbeyond1939 writes, "Your super brave, and stronger than most people in the world. Your awesome and no one should ever change that." Similarly, William Collier writes, "Awh, I accept you and everyone like you, or with any disability, people are amazing! And it's amazing what we can do if we put are minds to it, regardless of conditions!" These comments are striking because of the ways in which they illuminate how affect, as it traverses through this intimate public, works to uphold certain contemporary truths about disability. Fritsch (2013) argues that the contemporary production of disability is tangled up with positive affects, whether it the disabled body is overcoming and inspiring hope, or suffering and inspiring a future-oriented optimism. Charisse's intimate public is at once a producer of and produced by this tangle of "positive affects." However, these positive affects are always produced as an effect of Charisse's capacity to reorient viewers. We can see this most clearly in Sam Curnow's comment, "One of my classmates said that people that have disabilities are stupid when I heard it I went over and hit him and said u wach dis video and then he relised what he did." Sam was affectively reoriented after watching Charisse, and as a dutiful member of Charisse's intimate public, he felt the call to rectify his classmate's act of ignorance.

Under the regime of ablenationalism, as outlined in the introduction, “disabled people now perform the nation’s representational work as a symbol of expansive neoliberal inclusion efforts” (Mitchell and Snyder 2015, 49). Thus, as a disabled “future girl,” Charisse not only successfully manages her own future, but she manages the future of the nation: one that is tolerant of disability, the last frontier of American benevolence.

“Good News” in Post-ADA Times

Shortly after Poynter uploaded her Deaf Awareness week video, an article was posted on the Huffington Post: “This Beauty Vlogger is Hard of Hearing, and She’s Stepping Up Her Game on YouTube.” The article ends with a similar sentiment: “If one of her goals is to raise awareness for what she calls a "hidden disability," her online presence, mixed with the vibrant colors showcased on her Instagram page, makes it pretty hard to look away” (Matthews 2014). The Huffington Post article illustrates how this video instigated a stir of public feelings—intense flows of affect over spilled from Poynter’s intimate public to other online outlets. As Poynter articulates in the video she uploaded following the Huffington Post article, “Deaf Awareness: I’m on the Huffington Post!” :

> I can’t believe I’m actually getting to say this in real life, I’m on the Huffington Post! I’m on the Good News portion of the Huffington Post world. To be completely honest with you, I thought the entire thing was fake all weekend until the very second that the article actually went live. I mean it’s not every day that somebody from the Huffington Post emails you and says, ‘Hey! I wanna write about you.’ After the Deaf Awareness video went viral after 3,000 views—FYI: to the little YouTuber people like us, 3K is viral—Cate Matthews from the Huffington Post emailed me […] and said, ‘I’d like to do an interview.’

Poynter discusses her video in terms of virality, or, "the ability to across time and space and reach a large audience" (Ash 2015, 120). If we understand affect as "what allows our content to resonate beyond ourselves," then we can consider affect as both what enables Poynter's virality as well as what sustains it (Pybus 2015, 242). Both Poynter and Charisse are welcomed home into the national imaginary, through their intimate publics because of the ways in which they work, perhaps unwittingly, to establish a rehabilitative promise of tolerance. As Wendy Brown argues, "although tolerance has been constructed as a transcendent virtue, it is instead a 'historically protean […] vehicle for producing and organizing subjects'" (qtd. in Elman 2014, 91). Tolerance, as a dominant mode of U.S. governmentality functions affectively, working insidiously through disabled intimate publics, such as Charisse and Poynter's.

For example, Deadeye87 writes in response to Poynter's Q&A:

> You are an amazing person. Thank you for informing hearing people, like me, about what it is like to be deaf. You helped me understand some of the hurdles deaf people have to jump through in life. I am not a YouTuber, but if I ever start uploading videos I will be sure to Closed Caption them. Keep doing what you're doing - you are helping make the world, and the Internet, a better place.

This comment specifically calls attention to the ways in which Poynter has "helped" Deadeye87 to "understand some of the hurdles deaf people have to jump through in life." Not only has Poynter helped Deadeye87 perform an internal epistemological and ontological shift, but now Deadeye87 will remember to always caption their videos if they decide to become a YouTuber. As Berlant would say, Deadeye87 is learning to become *x,* or we could say that they are being rehabilitated into *x*. For many, to belong to Poynter's virtual intimate public is to be rehabilitated, or *affectively reoriented* into a tolerant neoliberal (virtual) citizen.

This act of affective reorientation relies on imagining a "future-oriented" version of tolerance wherein we all imagine "a good society yet to come," which effectively depoliticizes disability (Elman 2012, 91). An affective atmosphere of tolerant futurity undergirds many of the comments that are found on Charisse and Poynter's videos. For example, Bleed peroxide comments about how Poynter's Q&A video *will* make them "pause before getting irritated" at their hard of hearing roommate for playing the television "really loud." Similarly, Robert Croft comments on Poynter's "Is the Internet Real Life?" video:

> "Coming across your videos has informed me about something I did not know . You are a very smart person and give your heart to what you believe and do . The things you bring up has given me what I can take into the real world and live it out in real life . In closing . . . Talking about issues on the internet can move us into action"

Both of these comments are future oriented as well as exemplify that this future orientation is one that is premised on a turn inward—on becoming more tolerant, more understanding, more knowledgeable—and, through this turn inward, we can take it "into the real world and live it out in real life." Thus Poynter effectively and affectively reorients able-bodied folks through her affective capacity to cybertouch her viewer's hearts and minds, as well as through her symbolic and representational value as signs of a new American tolerance, which can be illustrated through the positioning of her Huffington Post article in the "Good News" column.

What enables Poynter and Charisse's virality (if we consider virality having over 3,000 hits as Poynter argues) are their affective capacities, and ultimately, their self-brand as YouTube "disability educator." They are recapacitated through this symbolic and literal work of tolerance, and welcomed into neoliberal capitalism by virtue of and through the intimate public that they have labored over. These intimate publics unwittingly function to shore up ablenationalism. Ablenationalism is premised on a surface-level inclusionism. Inclusionism "has come to mean an embrace of diversity-based practices by which we include those who look, act, function, and feel different" (Mitchell and Snyder 2015, 4). Or, in Ahmed's (2012) words:

> Perhaps the promise of diversity is that it can be both attached to those bodies that 'look different' and detached from those bodies as a sign of inclusion (if they are included by diversity, then we are all included). The promise of diversity could then be described as a problem: the sign of inclusion makes the sign of exclusion disappear (65).

Poynter and Charisse are both producers of and produced by inclusionism; their intimate publics offer affective roadmaps for able-bodied folks to follow and attain certain virtues that scaffold the "promise of diversity." In the specific terms of post-ADA America, Charisse and Poynter are made luminous as disabled "future girls;" however, this luminosity works in concert with insidious and slippery modes of compulsory able-bodiednesss. Rehabilitation and reorientation is premised upon disability as a sign of tolerance—an exceptional and inspiring way of being-in-the-world; a hollow promise that tomorrow is a better day—not on disability as desirable, lived, and real.

Chapter 3[8]

"I'm Wanting You to See This as a Chance": Promise, Futurity, and Not the Bad Life in *Miss You Can Do It* and *How to Dance in Ohio*

"To me, you learn more about human experience from people who are struggling than from people who are, 'Everything's just fine.' "

–Alexandra Shiva

In an interview with the New York Times, director Alexandra Shiva emphasizes the pedagogical promise in her 2015 documentary—bought and distributed on television by HBO—*How to Dance in Ohio.* The documentary chronicles three autistic girls and their families for the three months leading up to a spring formal for autistic young people. The spring formal is organized as a capstone experience for those participating in the Amigo Family Counseling's treatment program, Respons.ability Social Therapy™. She goes on in the interview to explain, "I always wanted it to be some sort of bridge of understanding, and to me there was no better way to take something that we have all in some way experienced and tell the story through that. The dance is sweet and lovely, but the biggest challenge is how do we show you as a viewer, that for Marideth to just say 'Hi,' that's an accomplishment" (Genzlinger 2015)? Shiva's suggestion, here, is that the dance is just a storytelling device, a rite of passage that "we" can all relate to, but when strategically deployed, can illustrate the promise of development and growth for autistic girls, and in turn, offer "us" some insight about the human experience.

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[8] Parts of this chapter were originally published as "Disabled Girlhood and Flexible Exceptionalism in HBO's *Miss You Can Do It*" in *Girlhood Studies: An Interdisciplinary Journal*. See Todd (2016).

Similarly, in an interview with HBO, director Ron Davis says of his 2013 HBO documentary that follows the contestants and their families in a pageant for disabled girls, *Miss You Can Do It*,

> I go for inspiring stories, stuff that makes you cry out of happiness. […] Everyone comes to the table with notions about people with disabilities. Notions meaning fear. How do you talk to them, what do you say? When I flew to [where the pageant is held], I wanted to hear about their experiences and why they do it (HBO 2013).

The insinuation, again, is not only that there is something to learn from these specific disability stories, but that that "something" moves "us" forward. Implicitly, inspiration is about rehabilitation: it can be characterized as a cluster of affectivity that promises to move us *forward* from one place (one of ignorance, pessimism, depression) to another, more valuable place (one of enlightenment, optimism, happiness).

To discuss inspiration is to also discuss the underlying logic of transformation. Rebecca Coleman (2013) argues, "transformation is an organizing feature of contemporary social and cultural life so that there has become an imperative of transformation" (1). Bodies experience the imperative of transformation differently; however, it is understood that for most bodies, this imperative to transform works toward the promise of what Berlant (2011) terms the good life, a fantasy that she argues, and that the introduction and fourth chapter explores more, is "fraying" (3). Images of transformation "function not only or so much as texts 'read' from a distance," but rather "as and through affect; they are felt in, through and as the body" (Coleman 2013, 2). Further, inspiration and transformation are future oriented. The future "works to pull in some bodies more than others," Coleman (2013, 2) points out, and the need to transform and labor toward an aspirational better future, or, the 'good life,' is felt more intensely for some bodies, more than others. Most strikingly, some bodies become intelligible by way of the potentiality and vitality of their future, as it is harnessed in the present.

This chapter builds on the last and shifts our focus to examine how "images work as communication" (Coleman 2013, 17). I argue that it is no coincidence that both HBO documentaries introduced at the outset of this chapter spotlight disabled girlhood, and as this dissertation forwards, these representations work to shape the contours of a post-ADA structure of feeling in very specific ways. In the second chapter, I examine how the thick materiality of the virtual works as a technology of rehabilitation that pedagogically re-orients able-bodied folks into tolerant neoliberal affective citizens. In this chapter, I argue that these representations do similar work; however, I am more interested here in examining the temporal and relational aspect of this labor. In tracing these dimensions, I am concerned with how rehabilitation hinges on processes of becoming, implicitly future oriented, however felt in the present. These processes are necessarily exclusionary. Only certain bodies are welcomed home into the national imaginary by virtue of their affective capacities, which I argue hinges upon their recapacitation via the resignification of their future. Ultimately, this is only made possible only the backs of other ghosted[9] disabled girl subjectivities.

Following recent turns in new-materialist disability, feminist, and queer theory that "stage an encounter" between affect and biopolitics, I utilize the productive friction that emerges from that encounter to analyze representations of disabled girlhood in two contemporary HBO documentary films: *Miss You Can Do It* and *How to Dance in Ohio.* This chapter responds to McRuer's (2010) call for scholars of disability to recognize

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[9] Ghosting implies an " ongoing form of political and affective erasure" (Kuntsman 2011, 6).

“uneven biopolitical incorporation … of disabled subjects, who in certain times and places are made representative and ‘targeted for life’” (171). I first briefly outline a biopolitics of affect, illustrating the importance of this theoretical framing in helping us think through iterations of power over life. I then move into a brief interlude that considers the history and genre of HBO documentary films and how this works to position the viewers’ encounter with the disabled girls of *Miss You Can Do It* and *How to Dance in Ohio*. The chapter then turns to the analysis of the documentaries.

I look first at the opening montage of *Miss You Can Do It* and then trace how disabled girlhood is made valuable, within the space of the documentary and pageant, through affective labor, which happens specifically by way of a *transformation* into happy objects for the nation-state’s consumption. As Ahmed (2010) reminds us, happiness operates as a “promise that gives us a specific image of the future” (29). I end with focusing on Alina’s specific story, a Ukrainian adoptee participant, arguing that while she and other exceptional disabled girls are enfolded back into the nation-state and afforded certain privileges, it is ultimately made possible on the back of her own status as a transnational adoptee.

I then move to an analysis of *How To Dance in Ohio* and first look at the ways in which the autistic girl-becoming-woman protagonists embody a different crisis, one that relies on logics of normative time and reproductive futurity. I consider the affective mechanisms that attempt to contain and resolve that crisis, first looking to how the autistic girls’ affect becomes an “object-target,” and finally to how the autistic girls’ *transformation* is contingent upon compulsory heteronormative and compulsory able-bodied containment. *How to Dance In Ohio*, similarly to *Miss You Can Do It*, operates as a technology of national belonging—pointing to an affective "roadmap" that one is prescribed so that they will end up at 'not the bad life.' Or, in other words, it orients us away from the cracks inherent in the fraying fantasy of 'the good life' and toward the potentiality of future vitality through establishing the autistic girl-becoming-woman as a shared object of hope, or perhaps more fittingly, a shared object of optimism.

Taken together, my effort here is to discern the ways in which these representations of disabled girlhood move us in specific ways through their reliance on fantasies of futurity, which are figured through the promise of happiness, hope, and optimism. Most significantly, this fantasy wanes as the disabled girl's childhood discursively and affectively wanes—as their bleak future approaches—a crisis emerges. However, as *How to Dance in Ohio* illustrates, it is ultimately the disabled girl's job to orient us in the right way, and so within this space of crisis, the imperative for transformation maneuvers to the limit. Ultimately, both documentaries illustrate the ways in which disabled girls' luminosity is contingent on the securitization and management of unruly disabled girl bodies: from the third world disabled adoptee to the time-bankrupt autistic young woman.

A Biopolitics of Affect

Anderson (2012) articulates that both 'affect' and 'biopolitics' have "become increasingly popular placeholders for a broad concern with life" (1). Whereas affect has come to name the "dynamics of lived experience," or the "push" of life, biopower, names, in contrast how "life has become the 'object-target' for specific techniques and technologies of power" (Anderson 2012, 1). As Foucault argues in a lecture delivered at the Collège de France on March 17, 1976, a modern form of power has materialized, a "biopower" that is concerned with the management of "life itself" (Foucault, 1997). In contrast to a sovereign power that "lets live," a biopolitical power "makes live" (Foucault 2007, 241). Technologies of biopower take "man-as-living-being" as their referent as a method to harness, invest in, and control "life itself" (Anderson 2012). Biopower is only interested in an individual in its relation to the vitality of the species, or population. A plethora of regulatory mechanisms emerge as the population becomes regarded as a political and economic problem. These mechanisms (birth and death ratios, health statistics, disability rates) function to "measure, monitor, evaluate, and ultimately manipulate coefficients of life in order to secure and even augment 'the good life' of the social whole" (McGuire 2016, 165). Under biopower, populations are normalized and secured from abnormal, contagion populations that require intervention, and the categories of life and death are fragmented, modulated, and increasingly "extended into a kind of vital spectrum, with many gradations" (McGuire 2016, 165).

Bringing together biopolitics and affect allows us to investigate the complexities and relationality of power and life. Specifically, it allows us to interrogate the ways in which affectivity, or the "affective life of individuals and collectives is an 'object-target of' and 'condition for' contemporary forms of biopower" (Anderson 2012, 2). Or, in other words, it allows us to investigate how bodies' affective capacities are intimately connected to what constitutes a productive life worth investing in and one that is unproductive, or, a threat to the vitality of the population.

HBO: A Brief Interlude

Home Box Office Inc. (HBO) emerged in the 1970s and was based on an entirely different economic model than its major network predecessors (CBS, NBC, and NBC) (Edgerton 2008). Edgerton (2008) notes that unlike the three major broadcast network's economic model, which "sold specific audiences to sponsors," HBO's format focused on "pleasing and retaining its viewing audience" (1). This "niche-market model" was a radical departure that marked a shift in sector of America's television industry toward serving "needs and desires of […] customers" (Edgerton 2008, 1). By the 1990s, HBO expanded its offerings and shifted its brand to focus on more original series, documentaries, made-for-pay-TV movies, etc., in order to compete in a shifting terrain characterized by digital television and the emergence of the internet. Edgerton (2008) argues, "by the late 1990s, HBO had emerged as the TV equivalent of a designer label" (9). HBO, as a brand's, preeminence in the late 1990s and early 2000s is illustrated in their tag line, "It's Not TV, It's HBO" (Edgerton 2008). The United States' shift to an "on-demand nation" has "splintered" the business model of television once more, and break-out signature programming has proven to be "the essential ingredient enabling this newly emerging multidimensional personal-usage market structure to flourish (Edgerton 2008, 14-15).

While a thorough industrial history and critique are outside of the scope of this project, I do think it is important to reflect on they ways in which HBO's economic success is intimately intertwined and a product of its rise to "cultural supremacy." From its conception, as Edgerton notes, HBO's brand has been built upon a vision that foregrounds the desires of its viewers. Thus, a concern with aesthetics and affect has always been central to HBO's production of original programs. How we are moved, then, and what moves us, is a production of the larger "structure of feeling," affective economy, or contemporary cultural milieu. Thus, at once, HBO produces and circulates certain states of affectivity that reflect, expand, and shift already existing contemporary affective imaginaries. That said, it also requires, or expects of viewers a certain sensibility.

Anderson (2008) uses Pierre Bourdieu's theorization of "aesthetic disposition" to describe the ways in which HBO "requires and rewards the temperament, knowledge, and protocols normally considered appropriate for encounters with museum-worthy works of art" (24). It is imperative to note that matters of aesthetic sensibility are necessarily racialized, classed, and ableist encounters—notwithstanding that HBO is a subscription service, and thus there is an economic component—but, HBO expects that one must have a "cultural competence" needed to develop a specific aesthetic disposition. One must be "moved in the right ways" in order to be deemed worthy of HBO's target niche-audience. As Murray (2008) argues, the audience wishes to see itself as more capable, responsible, and mature (264). Although Anderson is utilizing Bourdieu's theorization in reference to HBO's drama series, I argue that a similar envisioning of an aesthetically and affectively refined audience occurs for their documentary programming. As Sheila Nevins, HBO's documentary programming president states, "We don't ever forget who our audience is and what it wants from us" (Kirchdoeffer 1998).

Documentary programming became of interest to HBO in the late 1970s, and as Mascaro (2008) articulates, "Slowly, HBO become a destination for both documentary viewers seeking original works from different producers and a valued collaborator for documentary filmmakers" (239). Sheila Nevins, president of HBO documentary programming, is most responsible for developing documentaries at HBO, and she has imprinted herself onto the programmatic offerings. "The profound and profane" is how Nevins characterizes the documentary programming that she supervises (Mascaro 2008, 241). More specifically, it "reflects the challenges of surviving a difficult world and a tolerance for people who break the rules" (Mascaro 2008, 241). It is important to note that when Nevins was younger, her mother suffered from a serious illness, which resulted in losing several of her limbs. So it is no coincidence that Nevins specifically draws upon disability in her interview about her influence in programmatic offerings. She states, "We film people in their reality […] being born with a disability, that puts people in crises and races of their own" (Mascaro 2008, 241). Literally and figuratively drawing on disability, or what Mitchell and Snyder would probably argue, Nevins incites a moment of "narrative prosthesis," or the utilization of disability as a device of characterization. They argue that textual representations of disability are mobilized to "signify social and individual collapse," which serves to shore up the normate body, or an illusion of bodily wholeness (Mitchell and Snyder 2000, 47). As such, "the materiality of the metaphor via disabled bodies gives all bodies a tangible essence in that the 'healthy' corporeal surface fails to achieve its symbolic effect without its disabled counterpart" (Mitchell and Snyder 2000, 64).

Further, "Nevins is interested in average people struggling with mundane life" (Mascaro 2008, 241). She notes,

> I am most moved […] by people who play the part of their life with bravado. […] Television is everyday. It's like cereal and milk, and you have to make that everyday occurrence spectacular, and yet at the same time you have to keep that

> humanity going. Everybody has a story and everybody has a struggle. […] And life is very, very difficult, even for people who laugh all the time (Mascaro 2008, 242).

Nevins commitment to showcasing the human struggle as well as HBO's freedom from the licensing and public-service requirements of broadcast documentaries, has manifested in HBO's programmatic offerings being able to "explore eccentric or sensational topics, […] quirky and controversial subjects, and to serve neglected audiences" (Mascaro 2008, 244). In contrast to PBS and traditional network news documentaries that could be characterized by their commitment to forwarding an "intellectual argument," HBOs offerings are distinguished through "their visceral examinations of human culture" (Mascaro 2008, 244).

Although *Miss You Can Do It* is an HBO original documentary and *How to Dance in Ohio* is not, they did acquire the rights to the documentary after it premiered at Sundance Film Festival, and thus it necessarily reflects a documentary that reflects and is deemed "worthy" to be associated and promoted by the HBO brand. As Nevins puts it, "It has to look like it's on HBO, so if you're surfing, you'll say, 'This must be HBO" (Mascaro 2008, 251).

Drawing on feminist film critic, Linda Williams, Mitchell and Snyder (2006) conclude, "disabled bodies have been constructed cinematically and socially to function as delivery vehicles in the transfer of extreme sensation to audiences" (162). Thus, this chapter interrogates how exceptional disabled girl bodies participate as "vehicles," and how the affectivity they incite offers viewers a "road map" to manage the fray of the good life.

“We Are all Sent here for a Reason”: Disabled Girlhood and Affective Labor

HBO’s documentary, *Miss You Can Do It*, opens with a waving American flag that quickly pulls away to reveal the idyllic Midwestern town of Kewanee, Illinois. Rustic bluegrass melodies that gesture toward an unspoiled era of Americana tradition play as the camera pans across quaint local businesses that line the main street. The scene shifts to a young woman putting on makeup. She starts speaking.

> Accomplishment begins with two words: I’ll try. I mean, seriously, what is the use of living if you don’t have a dream, or you don't have hope? And I knew that there was something better in my life than just being a student, or just being a girl from Kewanee. Eventually something had to be magnificent because we are all sent here for a reason or a purpose.

We then move to a flashback sequence during which the viewer comes to understand that the young woman speaking is Abbey Curran, who, in 2008, was the first disabled woman to compete in the Miss USA Pageant. We are told throughout the documentary that Curran has cerebral palsy, which impedes her ability to walk during pageants without an escort. However, she positions her disability as something that drove her to do pageants, not quite as something that has inhibited her. She remarks that she was driven to do pageants because it is “something different, maybe, for a girl with a physical disability. We also want to be looked at as beautiful … and accomplished.” Curran articulates that “being born with cerebral palsy was definitely something that I had to overcome. While others saw me as different, I simply saw myself as having more challenges.” She then explains how she created the Miss You Can Do It pageant in order to “pass the dream onto someone else.”

The flag, a symbol of US nationalism, juxtaposed with Curran’s narrative of girlhood as a process of overcoming and giving back orients the viewer toward disabled girlhood as it intersects with the nation-state. Although certain disabled girls, like Curran, become intelligible through a process of luminosity—she is the disabled future girl as described in the introduction—as this dissertation forwards, this processes is strikingly asymmetrical. I ask, which bodies can be legible as neoliberal proto-citizens, and through what mechanisms? As Berlant (2011) reminds us, "citizenship, in its formal and informal senses of social belonging, is also an affective state" (163). So, more fittingly, I ask, what disabled girl bodies *move* and *move us* in the right ways?

We could assert that this new, ideal, neoliberal girl proto-citizen is imagined as implicitly able-bodied because eventually she is called on to insert herself into the labor market, effectively excluding disabled girls from the project of neoliberal citizenship. However, Puar (2012) contends that "all bodies in neoliberal capitalism are being evaluated in relation to their success or failure in terms of health, wealth, progressive productivity, upward mobility, and [enhanced] capacity" (155). Current iterations of neoliberalism rely on the tension between "capacity and debility" as a method to "profit from both the debilitation of certain bodies but also profit from the ways in which people recover or overcome debility through processes of capacitation (Puar qtd. in Fritsch 2013, 142). The focus on "differential capacitation" of bodies overrides the past will to normalization, and certain bodies who are capacitated in the right way are afforded the status of the able-disabled: "the upwardly-mobile, … entrepreneurs, employers of attendants, consumers of therapies, supplements, and enhancements" (Fritsch 2013, 143). Abbey Curran is recapacitated, within the US cultural imaginary, by way of her ability to overcome her disability and enter into the non-profit industrial complex, a privileged position within neoliberal multiculturalism.[10] As Melamed (2011) argues, neoliberal multiculturalism privileges those subjects who "learn to do good, to feed the poor, to uplift women, [and] learn to play their parts in the civilizing/disqualifying regimes that target populations disconnected from circuits of neoliberal wealth and value" (45). As one of the able-disabled, Curran is held up as the vanguard of an exceptional, affective disabled subject. Through the creation of the Miss You Can Do It pageant, as an endeavor of uplift, and through her positive orientation to the world, Curran is effectively recapacitated.

Fritsch (2013) argues that positive affects structure the contemporary production of disability. This production circulates positive affects, specifically happiness, as a method of recapacitation. Happiness, as Ahmed (2010) argues, is a form of world making, and within that world making, there is coherence around certain kinds of bodies. Because happiness is an orientation toward certain objects—those necessary for 'the good life'—happiness functions largely as a promise that directs bodies toward objects that are "happiness means." Thus, "things become good, or acquire value as goods, insofar as they point toward happiness" (26). Certain bodies can become happy objects, and certain bodies work to circulate happiness by virtue of their happy object status. The bodies that become happy objects perform labor that is legible (and valuable) to the market. It is important to note that McRuer's theorization of "compulsory able-bodiedness" is "driven" by happy affects because "compulsory able-bodiedness is always, already, a social good in neoliberal capitalism" (Fritsch 2013, 144). Disabled bodies become valuable capital that is vital to this particular affective economy defined

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[10] The pageant does require an entry fee so Curran is also participating in the market economy in a traditional way.

by neoliberal multiculturalism. The uncomfortableness and so-called problem of disability is contained, individualized, and depoliticized through happy affect.

Within the space of the documentary, the viewer is continually enveloped in the warm glow of various narratives of overcoming, courage, determination, and, ultimately, happiness. This narrative is present in Delaney's story. She is a seven-year-old with a spastic form of cerebral palsy, which causes her muscles to stiffen and cross, that is, attempt to cross the midpoint of her body, thus impairing movement. Although her parents note that she gets frustrated at times because she is "strong willed" and "wants to do everything herself," she "doesn't really ever show that frustration. She is the happiest little girl, and very rarely do we get to see that point where she is really angry at things. She just tries no matter what—it doesn't matter if it takes fifteen times to get her shoes tied." Throughout the section of the pageant that includes an interview with the judges, Delaney excitedly discusses the new *High School Musical Three* movie, her dress for the formal wear section of the pageant, and the fact that this is her first pageant. Her performativity of happiness effectively wins the judges over, and they bombard her with questions. The judges are oriented toward Delany because within the space of the pageant, she is a happy object. Ahmed (2010) argues that an affective experience of an object is also premised on the "conditions of the object's arrival" (25) or what is around and behind the object. It is through Delaney's disability that conditions of happiness become possible, and it is her status as a happy object that renders her subjectivity intelligible to the nation. Delaney's disability is productively transformed from excess, or surplus, into value. Within the space of the pageant, her value is produced through her status as a happiness object for the judges, and within the space of the documentary, she performs larger representational affective labor as the ultimate symbol of neoliberal citizenhood evidenced through her perseverance and gumption.

Although everyone receives a prize for participating in the pageant, there is a winner who represents the pageant to the public through appearances and other promotional work. After Delaney's interview we meet Kenna, who has a learning disability that inhibits intelligible vocalizations. Kenna's interview is far less conversational than Delaney's; after her interview the camera cuts to Abbey, who states that "kids who can't speak obviously have a harder time. It's difficult because you do fall in love with the girl who is going to talk your ear off." Near the end of the documentary, Abbey explains the process that goes into deciding who is crowned Miss You Can Do It.

> It's not about the outfits, it's not about the hair, it's about the girl on the inside. We want the girl who is just so happy, so excited, who is truly going to make a difference in her life. She's … going to be able to … make differences in other people's lives.

Another judge adds: "[We] are just looking for the biggest heart and the most sparkle, and someone to represent all the disabled girls." Unsurprisingly, Delaney is crowned Miss You Can Do It and was chosen as the best fit to represent "all the disabled girls." If we consider happiness as a technology of cultivation—it cultivates subjects in the right way—we can see how Delaney is represented as being correctly cultivated. She is chosen as the winner because, through her happy affect and status as happy object, she keeps things in line, orients bodies in the right way. Delaney's duty is to generate happiness by the very act of embracing her status as disabled in the right ways—as overcoming, as excited, and as optimistic. Embracing her disabled status in these ways secures Delaney a productive role in the moral economy of happiness, but it also, unwittingly, solidifies the world of able-bodied hegemony, one which privileges bodies that can effectively and *affectively* perform neoliberal citizenship.

These luminous, desirably disabled girls, who function both as happy objects and subjects who must take up the happiness cause for others, are positioned to perform various iterations of affective labor. As a judge notes, "I think Abbey is a good example of not letting a physical limitation limit your potential. I think Abbey can show these girls that the sky's the limit, and that you can overcome whatever obstacles life throws your way and do whatever you want to do."

"Everybody Has Potential and Everybody Has Gifts": Happiness in Crisis

Within the documentary, the disabled girl's happy object status does not just circulate good feelings through the space of the pageant. The disabled girl also performs certain work in connection with the (re)production and (re)consolidation of the family as a happy object. The storyline of Alina Hollis and her sister, Margaret, illustrates how their status as happy objects rehabilitates, as well as makes exceptional, a family in crisis through a logic of flexibility.

The audience is first introduced to Margaret in her interview with the judges. A woman wearing a white rhinestone-studded dress carries Margaret into the interview room where there are four judges waiting to meet her. They ask her a barrage of questions: "What's your name? What's your favorite color? Blue? Pink?" We quickly realize that Margaret is visibly uncomfortable with all this attention; she places her hands in front of her eyes. The judges begin to laugh affectionately and coo at her gesture, which they read as shyness. Margaret's interview ends with the judges playing peekaboo with her, placing their hands in front of their faces until she removes her hands, now feeling comfortable enough to look at them. The documentary lingers in this moment—the judges and Margaret laughing together, the judges' eyes sparking, and we see Margaret's eyes through her fingers, lit up with pleasure.

The documentary then shifts to Elmwood, Illinois, where a suburban house sits squarely in the frame. The camera moves to the backyard and we see a family playing t-ball. A little girl is up to bat; she is standing in deep, lush green grass. The grass contrasts with the clear, blue sky and the massive outdoor play structure's rich dark wood and plastic in bold primary colors. The girl then hits the ball and starts running the bases, and we see a family scramble to catch her ball in the sky, laughing and hooting. The carefree, playful mood evoked by this American family's summer ritual quickly dissipates as we hear Anne, the matriarch, begin to recount the story of the birth of her first daughter.

> Originally they thought they heard a heart condition, so they took her to evaluate her. About two hours later the doctors came in and said that they had great news that the heart condition that they suspected wasn't there …. We were very excited about that. And I will never forget what the resident said: 'You guys really dodged a bullet—most babies with Down Syndrome have a heart condition.' And that was the first time anybody had even mentioned those words to us. I remember in those moments being completely devastated … and thinking about all the things that I thought I wouldn't have. One of the things that I remember from that day [is that someone] said 'remember it's okay to grieve the child that you thought you were going to have. Because in grieving that it helps you celebrate the one you have been given.' It's been an amazing gift but we did not know she was coming with this extra chromosome.

Anne explains that she wanted to have a "constant" for Margaret. She knew that Margaret "wouldn't be invited to every sleepover" and that she would "be sad for her." To remedy this problem, she and Todd, Margaret's father, decided to search for a girl with Down Syndrome to adopt.

As Alison Kafer (2013) articulates, and as Anne suggests, “a future with disability is a future no one wants” (3); a disabled child is a signal of a future of no future. Margaret is quickly repositioned in this monologue as a gift. The affective conversion of grief to celebration is important to note, because as Ahmed (2010) argues, the power of happiness becomes augmented when it is perceived to be in crisis. The crisis of having an unexpectedly disabled child is assuaged through the work of (re)producing the family as a happy object. (Re)consolidating and (re)occupying a conventional family structure is achieved through the transnational adoption of Alina.

Ahmed argues that the family is a happy object; it is “both a myth of happiness, of where and how happiness takes place, and a powerful legislative device, a way of distributing time, energy, and resources.” A happy family also circulates through objects, as evidenced by shots of the Hollis house, their backyard with the extravagant play structure which “make visible a fantasy of a good life” (Ahmed 2010, 45). Most importantly, Ahmed (2010) points out that the family “becomes a pressure point” (46): it is necessary for ‘the good life,’ and through the work that it takes to keep the family together, it becomes a happy object in and of itself. The late twentieth and early twenty-first century is marked by the proliferation of a global transnational adoption market. Transnational adoption has “become a popular and viable option for … hetero[normative] couples seeking to (re)consolidate and (re)occupy” conventional family structures (Eng 200, 1). This impetus to (re)consolidate and (re)occupy is incited by the neoliberal signification of the parent, a position that signifies wholeness, completion, and value. This value can be measured through the accumulation of affective capital, acquired through the work of (re)producing a happy family, as well through the work of (re)producing properly affective, flexible citizens.

We learn that Anne and Todd contacted an international Down Syndrome adoption agency in their search for a sister for Margaret. Anne recounts that they did not care where in the world the little girl came from; they just wanted to provide Margaret with a sister of the same age. They could not "look at the list and pick," so Todd and Anne agreed to start with the first little girl, and "if that didn't work out, then [they] would go to number two." The first little girl worked out, and after nine months, they brought her home to the United States from Southern Ukraine. The camera then pans to Margaret and Alina, giggling together in their sundresses, sliding down a slide. Then the scene shifts jarringly to a utilitarian looking gray building sitting squarely in the frame—the audience can only assume it is in Southern Ukraine. The building blends seamlessly into a bleak gray sky, and we see what looks like a dilapidated, rusted play structure behind the building. Inside the building, dozens of children bundled up in mismatched outfits eat biscuits while a menacing voice recites something to them. This scene presents the orphanage as an unhappy object, in great contrast to the Hollis's idyllic suburban backyard. The contrasting play structures are not only a matter of aesthetic choices made by the producers to affectively produce a particular audience response, they also work mimetically as stand-ins for *The Ukraine* and *The US*, which works to shore up US exceptionalism through a fantasy of American disability benevolence.

The scene then returns to the present day, and Anne recounts that the "worker at the orphanage said to [her], 'You stupid Americans, you have all these perfect kids to pick, and you pick this one of no value, you stupid Americans.'" Todd adds, "They don't understand why you're in their country to adopt this child who has no worth in their eyes." The camera shifts back to Anne and she remarks, with tears welling in her eyes, "She's perfect in her spirit, and that's what we've always focused on." The parents go on to explain how they have faced pushback with their choice to adopt a child, who, like Margaret, has Down Syndrome; to some of their family members they are "crazy," but to others, they are "saints." Anne clarifies that they are neither crazy, nor saints, and that "anybody could do it, it's whether or not you choose to." Alina is made luminous through her "perfect spirit," a happy object for Margaret and her parents alike. Further, the work of enfolding her into the Hollis family is part of the work of (re)consolidating and (re)occupying a new, flexible heteronormative family structure. This family structure is one that is benevolent, recapacitated by its valuation of disability, and unwaveringly American.

The flexible subject, as McRuer (2006) argues, is one who can weather a crisis. "[T]hey are successful precisely because [they] can perform wholeness through each reoccurring crisis" (17). Premised on the conditions that mark the late twentieth century—changing economic practices that privilege flexible production, labor, and consumption—the flexible [heterosexual] body, "tolerates a certain amount of queerness" (McRuer 2006, 12) making it through subjective crises. However, this flexibility is premised on the logic of compulsory able-bodiedness and it is through "compliant, queer disabled bodies" (McRuer 2006, 18) that can flexibly comply that the heterosexual, able-bodied subject can manage crisis.

Through their parents' retelling of a horrific hate crime, it becomes clear that Alina (and Margaret) occupy the position of this compliant disabled body in service of their brothers' flexibility. The parents explain that their house and car were recently vandalized. The narration continues over stills of their car and house with "get outta town retards," "retodds," and "fuck" written in red spray-paint. Todd and Anne explain that although the girls were too young to read and understand the hate-speech, the boys, Noah and Caleb, could read, and they had to explain to them that "retard is not a good word. People out there might not like your sisters. Because of ignorance, because they don't like people who are different," and that the boys "might have to stick up for [their] sisters one day." The scene ends with both parents crying in the middle of the frame; they explain that after this incident, they "realize[d] how much better Noah and Caleb are because of Meg and Alina. [They] couldn't have raised them to be that great without them. So the benefits of being a parent—just realizing how strong they are going to be—it makes it worthwhile."

Alina and Margaret function to rehabilitate their brothers from passive, innocent ignorance about disability and hate, to advocates of tolerance for their sisters.[11] Not only are Noah and Caleb represented as flexible, affective subjects, but we can theorize the Hollis family as attaining a similar flexibility. The family weathers several crises including the birth of Margaret and the hate crime, and in both cases, the crisis is managed through Alina, whose transnational adoptee subjectivity is contained and safely consumed through her happy object status as a compliant, rehabilitative, disabled girl.

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[11] This is illustrated clearly in a video that has gone viral several times on the Internet. The video on the "Everyone Matters" YouTube Channel is titled, "The Hollis Boys, 6 and 7, 'Speaking up for our sisters' with Down Syndrome." It shows the boys holding up various notecards that serve to educate the larger public about Down Syndrome. A series of notecards read: "Our sisters are realizing that with some hard work and help they can do anything."

I argue that Alina's storyline functions to shore up US benevolence and acceptance vis-à-vis imagined Ukrainian abjection of disability by positioning Margaret and Alina's parents as average, yet exceptional, parents. This paradox functions more clearly through Anne's remark highlighting how "anybody" can parent disabled children, as if it is just a matter of choice. This rhetoric ultimately performs in the service of neoliberal multiculturalism as well as US exceptionalism by obfuscating structural barriers to parenting disabled children under the guise of individual choice.[12] The documentary sets Ukraine as seeing "no value" in disabled children, whereas the US can see the value in them. As her mother remarks, it is Alina's perfect spirit that makes her valuable. It is Alina's status as a happy object that imbues her with value. Through the logic of neoliberalism, the United States sets up disability as the last frontier, wherein the superficial enfoldment of disability into the nation-state has effectively proven that the United States is, indeed, the harbinger of diversity and acceptance.

Berlant (2011) points out the "history of sentimentality around children [...] sees them as the reason to have optimism—for if nothing else, their lives are not already ruined" (171). Optimism, as a cluster of promises, or the force that moves "you out of yourself and into the world in order to bring closer the satisfying *something* that you cannot generate on your own but sense in the wake of a person, a way of life, an object, project, concept or scene" (Berlant 2011, 2). Thus *Miss You Can Do It* offers an affective resignification of the disabled girl, which ultimately hinges on the *promise* of their bleak future rehabilitated. It is not so much that we come to acutely understand and envision the

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[12] There are many structural barriers inherent in attempting to adopt a child internationally, and even more so if that child is disabled. Couples that are not heterosexual or married face discrimination when attempting to adopt children, and the costs of adopting a child are often prohibitive for low-income parents.

disabled girls' future as promising (insomuch as we understand and envision normative futures), but it is the promise of happiness—the fantasy in the here and now—that allows us to assuage our anxiety and believe, as Abbey articulates at the end of the pageant, "that there is a world where hopes and dreams can last a lifetime" and if we all "run toward [our] dreams [we] will get there. All [we] need is someone to push [us], believe in [us] and say you can do it." Amidst the "fraying" it is promise that keeps us all together—as a nation, as a family, and as individuals.

How to Dance in Ohio: An Introduction

The disabled girl, or maybe more fittingly, the disabled girl-becoming-woman, in *How to Dance in Ohio* performs similar work: through a crisis of happiness, she keeps us together; however, her disabled body, as it ages, becomes increasingly less luminous. The disabled girl's capacity for rehabilitation diminishes as her bleak future draws near. As opposed to the happy objects that we encounter in *Miss You Can Do It*, whose disabilities are the condition for the promise of happiness, in *How to Dance In Ohio*, we encounter disability as a sticking point; although similar rehabilitative logic structures the film, the documentary dwells, perhaps unknowingly, in the cracks of the previous films' promise. However, rather than uncovering the post-ADA fantasy of the good life, disabled girlhood in *How to Dance in Ohio* affectively maneuvers to the limits and works to recalibrate the fantasy. The documentary film works, like *Miss You Can Do It*, as a technology of belonging—pointing to an affective "roadmap" that one is prescribed to end up at "not the bad life." Or, in other words, it orients us away from the cracks and toward the potentiality of future vitality through establishing the autistic girl as a shared object of hope, or perhaps more fittingly, optimism. The following section will first look at the ways in which the autistic girl is in a different crisis, one that relies on logics of normative time and reproductive futurity. I then move to looking at the affective mechanisms that attempt to contain and resolve that crisis, first looking to how the autistic girls' affect becomes an "object-target," and finally to how the autistic girls' *transformation* is contingent upon compulsory heteronormative and compulsory able-bodied containment.

"It's Probably Easier When You're a Kid": Temporality and the Limit of Happiness in Crisis

We first meet Jessica Sullivan, a twenty-two-year-old "mom" to her new yorkie puppy, who works at Food for Good Thought, a bakery that employs autistic young people, when she, frazzled, walks in late to a young adults group meeting at Dr. Amigo's clinic. Red-faced and flustered, she asks Ashley, the creative social arts program director, if she could take a seat while the rest of her peers are learning "the Wobble," a line dance that will be performed at the upcoming spring formal. She explains that she "doesn't' feel like herself" today. Dr. Amigo finishes off teaching the Wobble and walks over to Jessica to ask how she is doing today. She explains that she has to rely on transportation providers to get access to her job, and although she gave them two hours notice today, they were still late picking her up and dropping her off to her group. He then asks her how she's been lately, emotionally, and she goes to explain that she's been really stressed out by her job, her chores, "being a mom" to her new yorkie dog, and "being not understood." Dr. Amigo interjects, "just kind of adult responsibilities?" And Jessica adds, "I'm just going through a weird kind of time in my life." He then asks, "Are you excited for the formal?" And she responds, "A little. I just got butterflies." Dr. Amigo claps and voraciously remarks, "Butterflies? That means you are alive and you're excited about it!"

Jessica's "weird kind of time in her life" is elucidated when the film follows her into the intimacy of her home after group. Jessica and her parents have a meeting with Michelle Seymour from the County Board of Developmental Disabilities. The viewer is never clearly informed on what this meeting is for, but Michelle asks Jessica numerous questions about her transition to independence and autonomous adulthood. Michelle begins by pointing out that Jessica is her own guardian, and her parents are her "daily representatives. They help you." Jessica adds, "Sometimes they try and give me too much help, and what I'm trying to do now is be more independent. And it's kind of hard for everybody to understand that, and that the reason why I explain myself even more is because so they know that I'm trying to reach their goal of me being more independent, but sometimes I get babied and I don't like it sometimes." Michelle laughs and nods her head in understanding, "Parents tend to baby sometimes."

The scene shifts to an interview with Jessica's parents, Terry and Pat, and her father, Pat, articulates: "When she was young, I thought, okay, well, she'll be like an adult…child living with us till the day we pass." As he says the word "child," he shrugs and looks at Jessica's mother, who nods in understanding. Terry's eyes appear to be welling in tears, and Pat adds, "I kind of accepted that. But I see that she can—" Terry interjects, "that's not the case." Pat nods in agreement: Yeah, that's not the case." Throughout the documentary, whenever the girls narrate how they are feeling, there is almost always a cut to a parent interview, as exemplified in the previous scene. Jessica explains that she “does not like to be babied sometimes” and that a lot of her frustration stems from navigating from a liminal space of becoming-woman, which in and of itself is a limiting and limited position to be put in—this is understandable. However, the editorial cut to the parent interview, in this scene and others that I will discuss, is a device that serves to orient the viewers away from the potential affective rupture—frustration, anxiety, and ambivalence—and directed toward the promise of transformation.

Michelle continues on with the questions on her clipboard and murmurs, “Self Administration…” She continues, “This tells me that you can or cannot take medicine by yourself. And the reason I want to do that is because if we ever look at getting you an apartment by yourself, I want to know if you’re going to be safe with taking your own meds.” She looks over at Jessica, and Jessica responds emphatically, “Yeah I don’t ever want to live alone. I would rather have somebody assisting me or a roommate.” She looks around uncomfortably and starts rubbing her hands on her pants, heavily breathing out. Michelle responds, “Okay, okay,” and attempts to back off. However, Jessica’s parents jump in, and tell her that she needs to understand that she is doing really well, that she rarely forgets to take her medication and that everyone forgets to take their medication sometimes. Michelle chimes in and reminds Jessica that even if she had a roommate, staff would still come in and check on her sometimes. Jessica is visibly exasperated at this point, and she tries to explain, “I think living on my own with just my puppy, would be too much anxiety for me. But not that I don’t want to move out of here…[in a few] years, but I don’t…know if I can make myself save enough money up for that.” She puts her face, reddened with frustration, in her hands and her mom looks at her, smiles, and explains, “She’s working on it. Yeah.”

Jessica’s conversation with her parents and the representative from the County Board of Developmental Disabilities is just but one example in the documentary wherein the work of keeping the family together, which allows it to affectively circulate as a happy object, stretches to its limits. For example, McRuer points out that, at the beginning of the 21st century, we have inherited more “flexible” family forms, as illustrated by Margaret and Alina’s family; however, as *How to Dance in Ohio* illustrates, this flexibility is complex, and it has its limits. One way to make sense of these complexities is by thinking through Jessica’s body’s relationship to logics of rehabilitation and normative time.

Intellectual disability has a robust history of being linked with childhood; in the nineteenth century, people classified as “idiots were seen as remain[ing] at an early stage of development” (Carlson 2010, 30). However, as McGuire (2016) points out in her historical genealogy of autism, clinical psychologist Dr. Ole Ivar Lovaas and his contemporaries shaped the discourse of autism as not only a state marked by inherent abnormality and lack, but “as a set of abnormal (what Lovaas terms ‘inappropriate’) behaviors understood to be correctable and therefore improvable” (45). This discursive framing has only been strengthened by more recent cognitivist and neuroscientific theories that posit the body as improvable. The cognitive paradigm describes the “model of the human mind/brain that is not only fluid, changing, unfixed, but is even much like behaviorist conceptions of human behavior, *improvable*.” (McGuire 2016, 50). Likewise, the neurosciences have introduced the conception of the brain as “plastic,” which proposes that the brain (and the mind, as McGuire reminds us, these two concepts are intertwined) is “not simply ‘hard-wired […] but it is *plastic*—it can change over time

(Nadesen qtd. in McGuire 2016, 50). Thus, contemporary understandings of autism are always marked through an understanding of a potential transformation or *return* to an approximation of normalcy. McGuire (2016) astutely points out:

> The concept of autism as a graded spectrum of impairment severities has become crucial to dominantly held contemporary understandings of the autistic body that narrate it as some 'thing' to be worked on, modified, and improved, as well as understanding the role of the advocate as the worker, the improver, the modifier (51).

A rehabilitative project, or becoming normal, is largely understood through the underlying threat or *risk* inherent in the time-sensitive loss of vital potential. Kafer (2013) argues, "Within the logics of normative time, adults work, marry, and live independently" (54). As many queer, crip, disability, and feminist theorists have argued, the figure of the child is tied to notions of futurity (Berlant 1997; Edelman 2004; Spivak 2005; Burnam 2008; Berlant 2011; Lesko 2012; Kafer 2013; Fritsch 2016). Lee Edelmen's (2004) oft quoted theorizations remind us, "the Child has come to embody for us the telos of the social order" (11). The child is the "preeminent emblem of the motivating end," moving us forward toward better futures (Edelman 2004, 13). We see the disabled girls in *Miss You Can Do It* welcomed home in the national imaginary on the terms of the promise of their potential future vis-à-vis the affective labor they perform in the present. They are figured as "time-rich," e.g., "understood as 'having more time, more future yet-to-be-realized," and as circulated as happy objects, their capacity for rehabilitation (both self and other) is envisioned as burgeoning (McGuire 2016, 120).

However, as the discursive and affective space of childhood wanes, the potential for rehabilitation weakens, and the crisis of futurity becomes pregnant with urgency. Becoming-woman requires a smooth fit between mind and body. As Jessica's parents remind us, they were worried that she was going to be like an “adult child”; presumably, Jess was imagined as “out-of-time,” her future body imagined as “fully developed” thus locatable in the future, bur her future mind “located in the perpetual past” (e.g. developmentally ‘too slow’ and always late) (Kafer 2013; McGuire 2016, 142). The disabled girl-becoming-woman’s body is located within a temporally liminal space, and it is “within this space that physiological transformations (e.g. breasts, menstrual periods) can no longer sustain dominant constructions of the disabled adult” as non-sexual and infantilized (Erevelles and Mutua 2005, 254). Jessica’s parents evocation of the grotesque potentiality of an “adult child,” rather than opening up a reimagining of disabled interdependence and kinship, is affectively redirected through the promise of the girl’s effective and affective rehabilitation: anxiety shifts to hope (“That’s not the case”), frustration shifts to perseverance (“She’s working on it”), and the crisis is momentarily contained.

“You Have to Become a Student of People”: Affect as an “Object-Target”

In a life skills group, a hallmark of Dr. Amigo’s Respons.ability Social Therapy™ program, Dr. Amigo leads the autistic teens in a discussion about how to greet people. The teens are sitting in a circle and worriedly ask how one knows if one wants to talk to someone else, how it feels to know that one wants to talk to someone else, and then what to do when one has confirmed that feeling and decides that they do indeed want to talk to someone else. Dr. Amigo advises, “Ask them how they are doing, compliment them,” he goes on, his face fills the frame and his gaze is forward-looking, almost like he is looking past the camera: “You got to really become a student of people. Like you really gotta learn people, right?” Dr. Amigo’s advice, to become a student of people, does not only serve as a directive for those partaking in the Respons.ability Social Therapy™ program, but it also functions as a directive for the viewers who are implicated in this exchange. It becomes clear as he continues:

> You know, there’s a saying that goes something like this, ‘If you meet one person with autism, you've only met one person with autism.’ Do we not know? It expresses itself in many different ways, right? In many tremendous positive ways, and some other not-so-positive, more challenging ways, right? So, I think the spring formal is gonna be a great chance to be like, ‘Wow we all share certain challenges, but look how cool it is the way we’re all so different, too.’ […] You guys are all like multi-colored M&Ms.

This directive is an orienting device, one must learn how to encounter bodies in the “right way,” both those who are already deemed deficient (autistic/disabled young folks) as well as those who may “think” they know how (neurotypical/able-bodied folks). This neurotypical/able-bodied re-orientation, or this becoming, is premised on a specific vision of individualized, neoliberal multiculturalism: “you guys are all like multi-colored M&Ms.” Autistic folks, as a population, share some similar challenges, but it is not because, perhaps, neurotypical/able-bodied folks encounter the autistic body through an ableist orientation, it is because there is some fundamental misunderstanding about what autism “truly is”—expressing itself in “many tremendous positive ways, and some other not-so-positive, more challenging ways.” Although this re-orientation is a damaging proposition that elides the structural, embodied, and psychic structures of able-ism (and realigns certain affective “truths” about disability), which will be discussed more in the conclusion, what is most significant here is how Dr. Amigo’s directive works to shape the bodies and, I will soon argue, affect, of the autistic teens. The body is “not a closed and sealed entity, but a relational ‘thing’ that is created, bounded sustained, and ultimately dissolved in a spatiotemporal flux of multiple processes" (Harvey 2000, 98). As such, the porous body, and more specifically, the "excessive" autistic body (one that is at once not enough, characterized by the well-worn metaphor of the autistic person as living in a "shell," and too much, characterized by the narrative of the autistic person as not "having a filter"), is subject to a reshaping and rehabilitation by way of "learning people." The urgency of which one should "learn" or "become a student" is premised on the notion that the autistic person is, as Berlant (2011) would say, an "embodied liability," whose recapacitation is waning (106).

We can conceptualize Dr. Amigo's directive, as well as the premise of Respons.ability Social Therapy™ as the "work of protecting, preserving, or recovering; the normative work, in other words, of biological securitization" (McGuire 2016, 141). The autistic population has emerged as a "problem population in need of an intervention;" not only does autism threaten the potential vitality of the individual autistic person, but it can be conceptualized as endemic, threatening the vitality of the species (McGuire 2016, 165). Foucault (2003) explains, "endemics, […] unlike epidemics, are permanent factors…[that] sap the populations' strength, shorten the working week, and cost money" (243-44). These techniques of dispersed management, or biopower, of the "putatively biological threat posed by certain populations to the reproduction of the normatively framed general good life of a society" animate the following discussion (Berlant 2011, 97).

We return to Jessica, as the documentary accompanies her to work. She is employed by "Food for good thought: Natural Foods and Bakery," which is specifically a job training program for, as they articulate, "young adults on the spectrum." As she starts her daily tasks, we hear her narrate: “It’s harder for people with autism to find jobs because we don’t know the social rules like everybody else does.” As Jessica mixes flour and other cupcake ingredients, we hear her peer, Sam singing “Bear Necessities” in the other room. The camera shifts to the next room and we see Sam, his face lit up, singing and washing a gigantic mixing bowl. Jessica chuckles and makes a comment about how funny and sweet Sam is, and Dr. Audrey Todd, psychologist and owner of the company, nods in agreement, but also adds emphatically: “He is a very good worker.” Jessica responds, “I wish I could be that happy at times.” This juxtaposition of labor and affect (or as Jessica articulates it as, emotion) suggests that to be a good worker is to be a happy worker.

After an incident wherein Jessica and a non-autistic employee are baking cupcakes, and Jessica decides to “do things her way” instead of heed to the instructions of the employee, for example, she decides to use measuring cups to slowly measure out the cake mix, she asks the employee if she could possibly not stand behind her and watch because it makes her feel uncomfortable, the following meeting with Dr. Todd ensues. Jessica, still in her hair net and apron, takes a seat in Dr. Todd’s office, and she seems unsure why she has been called in. Dr. Todd begins: “Well, the first thing, you really have to watch your attitude, because you act like you’re superior to others.” Upon hearing this, Jess places her face in her hands and sighs heavily. Dr. Todd continues, “…it’s very disrespectful. And they told me that yesterday you were the same way. And the tone that you—” Jessica interjects and with a pleading tone states: “I feel like…there are times where we don’t understand each other. That’s all I was trying to say. I wasn't trying to be mean.” Dr. Todd responds: “Well, first of all, I really don’t necessarily have to understand you because you’re an employee, and your function is to work.” Jess looks down and replies, “But if you don’t understand me, how can I work?”

Dr. Todd goes on, “But, you don’t—You don’t need to be always understood in the work setting. You have to work.” Jessica begins to cry, and her voice cracks as she says, “I’m not trying to be mean. I just really want to be understood. I really don’t like being written up. It makes me cry. I don’t know what kind of tone to use at work. I really don’t. I’m sorry.” The camera shifts back to Dr. Todd, and she looks to be unmoved by this; she places her hand on her chest and says in a strained tone, “Well, then you have to look to us for guidance to help you with tone. Right?” Jessica, with tears streaming down her face and hands clutched at her chest pleads, “I’m just such a tough girl. I don’t even know how to ask for help emotionally, sometimes. It’s just so harsh, I’m so used to being at home and nobody really corrects me at home ‘cause they say I’m an adult now and I have to figure it out, but I can’t figure it out, so I need help! Please!” Dr. Todd responds, “Well, you’re on a journey and a process of trying to figure it out. But, you know you’re just in your early 20s. It’s not like you’re 72—you’re 22 or 21? Adulthood is a long journey of trying to…” Jessica interjects panicked, “I’m just—I’m very confused right now. I don’t know who I am or why I do what I do, but I know a little bit about it, and I tried to explain, and I didn’t mean to get written up, and I just want to say I’m sorry.”

Dr. Todd, still with an unmoved tone, responds, “Okay. Did you hear what I said? Keep a neutral tone, even though you may not feel neutral inside. You’re actually a very—you have a very good work ethic.” Jessica lights up as she says this, “I do? I didn't know.” “Yes, you have a very good work ethic. And what you’re learning from us is part of work etiquette. Okay?” Jess ends with noting that she does have a “sensitive and kinder side" and apologizes if Dr. Todd has not seen much of it, but she is trying. She begins crying again when she emphasizes the fact that she does not want Dr. Todd to think she is a bad person. Dr. Todd assures her that she does not think she is a bad person, but that would be "black and white thinking" and "nothing is that black and white." The meeting ends with Jess trying to explain once more, she was only trying to be independent and that is why she did not want Lauren, the non-autistic employee, staring over her shoulder. Dr. Todd responds with a terse "okay" as she nods her head.

In the interaction between Jessica and Dr. Todd we can see more intimately how affect is tied to labor: Jessica is reprimanded because of the way that bodies encounter her. She has to "watch her attitude" because she "comes off as superior." She has to watch her "tone" because she is "disrespectful." As Dr. Todd reminds her, this is about "work etiquette," and as Jessica reminds us in the beginning of the scene, it is quite difficult for autistic folks to gain employment because, as she articulates, "we don't know the social rules." Again, it is not structural ableism that prevents autistic folks from gaining employment, but it is their bodies' natural, but improvable *affective* deficiencies that are the problem. Jessica's "work ethic" is very good, but she needs to learn "work etiquette"—comportment, attitude, tone—or, she must learn to move bodies in the correct way. Anderson (2012) argues, "affective life of individuals and collectives is an 'object-target of' and 'condition for' contemporary forms of biopower" (2). Both Dr. Amigo's and Dr. Todd's programs attempt to shape, manage, and transform, or recapacitate, Jessica into a proper affective citizen; her affectivity becomes an "object-target" of the dispersed management of the autistic population. As Jessica's childhood wanes, the conditions of possibility for belonging take an increasingly rigid form. Her body, as it ages, loses its ability to be circulated as a happy object because of the ways in which it becomes encountered as an obstruction and interruption, both affectively and temporally. First, instead of holding the family together, Jessica's autistic body becomes an anxious sticking point that threatens the family. Amidst the fraying welfare state, the ghost that haunts many films about the "hardship" of disability, Jessica's parents worry that she is not going to move out and implicitly secure employment to work toward 'the good life,' or more fittingly, 'not the bad life.' Thus their intersubjective relationship to Jessica is one characterized by anxiety, worry, and crisis, which are all affective states rooted in the future; however, they are felt acutely in the present. Her body, then, circulates as an object of anxiety, or of potentiality waning. Second, this idea of potentiality waning, again, reminds us of the transition from a "time-rich" girl to a "time-bankrupt" young woman.

"Dance is Like Life": Heteronormativity and Rehabilitation

Rehabilitation in *How to Dance in Ohio* is implicitly contingent upon a transformation into a properly gendered, heteronormative body. The documentary opens with a black screen, we hear a woman's voice sing: "One-two, one-two, one-two-three." The black fades away, and a bright piano melody ushers in an image of shimmering blue evening gowns, which slowly pans to a "cluster of items" sparkly silver heels a sparkly silver clutch purse, a silver tiara and a matching jewelry set. We hear the woman again, "side-step to the right. Walk forward." The scene quickly shifts to a young girl with brown curly hair and a lace top hovering above another girl, sitting, wearing a black top, and a black headband holding back her hair. The girl hovering is gently holding the sitting girl's face, and with a concentrated look on her face asks, "Okay, can you open? And just like blink on there?" We see her take a mascara wand pointedly to the sitting girl's eyes, and the sitting girl replies "yes," and awkwardly blinks her eyelashes onto the wand of the brush. As she has her face powdered, we hear a shaky voice-over: "I feel nervous. Very nervous." A similar scene is staged for the other two protagonists of the film: the viewer watches as they partake in certain rituals of femininity that typically occur before a school dance (e.g. the careful application of makeup, a trip to the salon, etc.) and then a voiceover narration occurs where the girl articulates how nervous she is. These intimate moments of normative femininity presumably set up the premise of movie as a heteronormative device, or as director Alexandra Shiva articulates, "a bridge of understanding," that functions to contain the excessive disabled body and orient the viewers toward a future that does not look so bleak.

Quite a few group sessions revolve around teaching proper heteronormative roles in preparation for the spring formal; however, they are communicated under the guise of learning proper intersubjective communication. For example, in one session the autistic young folks are practicing slow dancing. Dr. Amigo asks all the teens to "mingle" and then partner up. Marideth and another boy awkwardly approach each other and look away. Ashley, the Creative Social Arts Director, walks up and gushes, "aw you guys match perfectly, I'm gonna help you guys out okay?" She grabs Marideth's wrist and places her hand on the boy's shoulder: "This hand goes on his shoulder." She then asks the boy, Chris, to please focus, as she places his hand on Marideth's back. She walks over to help another couple and explains that the hands that are not on the shoulder or back are supposed to be held together. Marideth and Chris begin to dance, both are laughing a bit, and then Dr. Amigo walks over and slowly stops them and says with a tone of mild disdain, “You guys are like, marching to the beat of your own drum.” Placing his arm on both Chris and Marideth’s back to move them in unison, he says, “So ready, it’s like that way. I’m going to help you. Ready? It’s like a metronome, okay? Together.” Marideth laughs and remarks that her arms are getting tired, but Dr. Amigo, advises her, “You know, part of connecting to somebody is to move in similar patterns did you know that? Dance is like life. It’s a way of communicating. Do you hear the music Chris? Do you hear the pace of the music? Slow down. Slow down. Slow down. Ready? Get the beat, like this, slow.” Learning to dance, according to Dr. Amigo, is learning how to communicate and connect to another person. Within the context of the documentary, this plays out as learning how to dance with a person of the opposite gender. Thus the intersubjective performance of dancing functions metaphorically as an anticipatory promise of heteronormative coupling. Inherently, disabled girlhood challenges “heteronormativity […] and simultaneously disrupts and flirts with patriarchal norms of ‘girlhood,’” so this fantasy of proper heteronormative development contains the excessive leakiness of disabled girl bodies (Erevelles and Mutua 2005, 254).

In a previous therapy meeting, Dr. Amigo explains,

> What we do here is social skills therapy. Where individuals living with autism can learn how to communicate, how to relate to one another. For many of them, there’s like a giant wall between them and everybody else, and the simple task of learning how to say ‘hello,’ make contact, be in a back and forth conversation, can be incredibly difficult, if not crippling. Over the years, we designed these exercises and these activities that are tremendously challenging for them. And this year, we are going to have a dance, a formal dance, at a local night club.

Dr. Amigo goes on to asks how many of the young folks present in group therapy that day like formal dances. We can hear audible grunts and sighs, and the viewer can almost feel the thickness of anxiety emanating from the scene. Marideth remarks, “I don’t like touching people.” Dr. Amigo retorts as he shakes his head: “Well, we’re gonna break you of that.” He goes on, “Don’t you guys agree that when you have Asperger’s and autism, it’s probably easier when you’re a kid, but when you become a teenager, then you realize, ‘Oh this social thing’s kind of challenging,’ right?”

The documentary explicitly positions the crisis of rehabilitation as “learning how to be a student of people;” however, as the documentary unfolds toward the climactic event of the spring formal, the crisis is assuaged time and time again through the specter of heteronormativity. Marideth points out to Dr. Amigo that she does not like touching people and the way that she is “broken” of that is through learning how to dance with Chris in the previous scene. These scenes of happy heteronormative coupling “become about the possibility of a happy ending,” because heteronormative love is a device that directs us toward “what gives life direction of purpose”; it is evoked as a promise of ‘not the bad life’ (Ahmed 2010, 90). The documentary positions the girls’ disabled bodies as what encumbers their potential happiness, so then to learn how to dance, or how to communicate through touch, they are effectively and affectively rehabilitated toward a potentiality of ‘not the bad life.’ This iteration of ‘not the bad life’ is contingent upon a heteronormative framework, thus the viewers, then, are oriented toward the girls as their transformation is achieved through their ultimate participation in the spring formal.

Do You Ever Feel Like a Plastic Bag Drifting Through the Wind? Or, Uncripped Futures: "Not the Bad Life"

An article in the Hollywood Reporter remarks that *How To Dance in Ohio* is "heartening" compared to "other documentaries about the condition" precisely because it "accentuates the positive so much, showing families where the parents have managed to keep their marriages intact, where no one gets bullied, no one is a savant, and there's no mention of the debate around vaccines" (Felperin 2015). Similarly, an article in the New York Times notes that the real strength of *Miss You Can Do It* lies in its depiction of "the day-to-day lives" of the families who participate in the pageant, something that otherwise "would be invisible to anyone but close friends" (Genzlinger 2013). The documentary elucidates the rewards and struggles that ensue as the parents "come to grips with the news that their child would be disabled" (Genzlinger 2013). The article ends with a quote from one of the pageant mothers, "I know that all the other parents, even if they don't have the same issues that Tierney and I have—they still have issues. Issues that are life-changing and never-ending." (Genzlinger 2013). The power of these documentaries, as articulated by The Hollywood Reporter and The New York Times, is their ability to leverage the mundane, or day-to-day lives of the disabled girls. This leveraging operates pedagogically, offering a roadmap for what I term, 'not the bad life.' If the good life promises job security, upward mobility, and social/political equality, then 'not the bad life' operates through the recognition that the good life is not available to all. It is a fantasy that instead offers a modification, but not total repudiation of the promise of the good life. For example, as Jessica's mom articulates at the end of *How to Dance in Ohio:*

> I'm guessing anytime there is something different about your child along the way, it's almost as though this huge world slowly…the opportunities slowly close in. And you're thinking, oh, did another door close for her? Did another door close for her? Or did it open for her? It's just so exciting to see her interact, and have hopes, goals, dreams that other kids have.

Many parents in the documentaries articulate similar sentiments, and the share the understanding that the good life never was and never will be the reality for their disabled child. Within these documentaries' stories of disability—presented as a crisis of holding the family together and as a crisis of aging—the exceptional disabled girl emerges at once as a symbol of and a rescue from the immanent catastrophe that the collapse of the promise of the good life could induce. She offers up respite, not necessarily total relief, from these crises (that she is suggested to induce) by way of the hopeful and optimistic affectivity that she generates. She becomes a shared object of hope for the viewer, who in turn can rework and modify the fantasy through the disabled girl, as she is represented triumphantly navigating an "impasse," both in her own life but also as a metaphor for the emergent affective structure of feeling that we find ourselves in.

An impasse "designates a time of dithering from which someone or some situation cannot move forward" (Berlant 2011, 4). As a temporal genre, the impasse is a "stretch of time" where a body slows down and attempts to mitigate an ongoing crisis through both a "wandering absorptive awareness" and a "hypervigilance" (Berlant 2011, 4). An impasse is a cul-de-sac, Berlant (2011) argues, "in a cul-de-sac one keeps moving, but moves paradoxically, in the *same space*" (199). An impasse can be generative, "it is the name for the space where the urgencies for livelihood are worked out all over again." (Berlant 2011, 199). To triumphantly navigate an impasse is not necessarily to work past it, but it is to "work out" and cope with changing norms of living. In *Miss You Can Do It* and *How to Dance in Ohio*, the disabled girls mitigate the crises that are presented, and they do this by way of a transformation of negative affects that circulate and stick to their bodies to positive ones. They do not necessarily overcome these crises, but they manage them, whether it be through smiling for the judges or learning how to dance. Essentially, the figure of the disabled girl in these documentaries affectively teaches the viewer that to hope is to cope. Hope can be characterized as " an investment that the 'lines' we follow will get us somewhere," as well as, a "projection forward for a wish for repair of the past" (Ahmed 2006, 18; Duggan and Muñoz 2009, 275). Thus, whether it be through the warm and tender affective states that circulate in *Miss You Can Do It*, or the courageous and gumptious affective states that circulate in *How to Dance in Ohio*, the exceptional disabled girl is the girl who can carry us forward to a future that may be uncertain, but manageable. She assuages our fears about the fraying good life, and shows us if she can do it, we can too! However, through this, the disabled girls' body is depoliticized and individualized. To manage and to cope with a crisis is an individual act, and although the disabled girl is always presented relationally (through the family), it is always the exceptional disabled girl, in her individuality, that emerges heroically as the hopeful manager of her own (and everybody else's) future. As the exceptional disabled girl advises, and in the words of Katy Perry in the end credits of *How To Dance In Ohio:*[13]

> "Do you ever feel like a plastic bag / Drifting through the wind, wanting to start again? / Do you ever feel, feel so paper thin / Like a house of cards, one blow from caving in? / Do you ever feel already buried deep six feet under? / Screams but no one seems to hear a thing / Do you know that there's still a chance for you / 'Cause there's a spark in you? / You just gotta ignite the light and let it shine /

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[13] Felperin (2016) in her article writes, "The inclusion of a slowed down, semi-acoustic version over the end credits of "Fireworks" by Katy Perry, the unofficial anthem of the disability rights movement, is a little on the nose but tear-jerking all the same."

Just own the night like the 4th of July / ‘Cause baby, you’re a firework / Come on, show ‘em what you’re worth”

Chapter 4

At the End of Rehabilitation: The Haunting of Disabled Girl Death

"Death is bad for us when it deprives us of future 'goods' or a future good life, while it is good for us when it deprives us of a future bad life. In other words, loss of future 'goods' or 'bads' does not necessarily matter for a good or bad death, but the loss of a future good/bad life does."

– Lars Sandmand (2005)

"It makes my heart explode. It's so crazy. That people want to come for little 'ol me. I'm nothing!"

–Jerika Bolen

Introduction

"One Last Dance: Girl, 14, who has chosen to die next month because the pain from her incurable genetic disease is too much to bear is crowned prom queen," reads a Daily Mail article from July of 2016. Another headline from The Washington Post reads, "'I'm going to be free': Terminally ill Wisconsin teen schedules her death and one 'last dance.'" A third headline reads, "Appleton teen makes heartbreaking decision to die." Jerika Bolen, the disabled girl generating the headlines, was diagnosed with Spinal Muscular Atrophy Type 2 when she was eight months old. After 38 surgeries, and pain ranging from a 7-10 out of 10, daily, Jerika made the decision, with support from her mother, to enter into hospice, discontinue the use of a ventilator that assists with her breathing 12 hours a day, and die. Jerika articulates in a video explaining her decision to die, “I have control over my brain, eyes, nose, mouth, but I can’t swallow too much, and [move] my arms, well, like my hands and a little bit of my arms, but not too much.” Her mom adds, “It just kind of goes. Every surgery affects it. Every big surgery she would lose a lot of strength, so…” Jerika continues:

> The last big surgery I had, I was ready for hospice. I didn’t want to have surgery. But I did it for my mom, and my family because it’s tearing them apart, like making them really sad that I’m going on hospice. They’re really going to miss me, and then I realized, ‘Jerika, what is your quality of life right now?’ You lay on the couch all the time, and you have…you do homework. You lay on the couch. You get up, do homework, lay on the couch because you’re so sore. That’s not a quality of life. So I used my voice. That’s all I have. And said, ‘this is enough pain. I don’t need this anymore. It’s not fair’ (Collar 2016).

Bolen died on September 22, 2016. An equally robust flurry of news articles weighed in on her death: “Is Jerika Bolen’s decision an ‘assisted suicide’ or a nod to what is natural;” “Disability Groups Call Jerika’s Death an Injustice;” “A 14-year-old has been allowed to ‘decide’ to die.” Ranging from exclaiming that Bolen is the “new face” of the right to die movement, to arguing that Bolen’s brain was “not developed enough” to make the decision to die, these articles make clear that the event of Bolen’s death, and Bolen, in the afterlife, incite ontologically slippery questions regarding age, autonomy, choice, and the materiality of disabled embodiment. However, there are no easy answers to these questions.

This chapter attempts to discern how Bolen, the event of her death, and in the afterlife, generates and circulates certain affective attachments to disabled girl death. To do this, I place Bolen’s story in conversation with an episode of *Degrassi: Next Class*, a teen “edutainment” drama series, premiered and distributed in 2016 by Netflix in the

United States. The episode I discuss revolves around the “coming out” of Grace who has cystic fibrosis, and Zoe, who is queer. Ultimately, the episode is resolved through crip/queer love, which affectively resignifies Grace’s fatal prognosis and potential premature death by way of her grievability. Butler (2010) argues, “Only under conditions in which the loss would matter does the value of life appear. Thus, grievability is a presupposition for the life that matters” (14). In opposition are “ungrievable lives,” those lives that cannot be destroyed or lost because “they are, ontologically, from the start already lost and destroyed” (Butler 2010, xix). Some could argue that disabled folks, and especially disabled young folks, are subject to this ontological erasure—imagined as a sign of no future (Kafer 2013; Fritsch 2016). However, as this dissertation has illustrated, it is imperative to attend to the asymmetrical incorporation of disabled girlhood—in life and, as this chapter argues, in death. If grievability is the “presupposition for the life that matters,” then, what does it mean if under the conditions of death the life retroactively becomes valuable? How does disabled girl death incite affective attachments to “good dying and death”? How attachments to good dying and death work to recapacitate certain disabled girls in the afterlife?

In this chapter I begin to parse out some of the complicated entanglements that these questions bring to the fore. To do this, I first outline a brief working definition of necropolitics, which is necessary to attend to the significance of disabled girl death. I then turn to an analysis of the *Degrassi* episode #NoFilter. Disabled girl death, in this particular episode, is instrumentalized through the promise of grievability, which emerges through of an affective resignification of death vis-à-vis queer/crip love. I argue that rehabilitative logic in #NoFilter works to sustain a fantasy of neoliberal sovereignty through the affectivity of white homonormative suffering. This works to displace actual existential or ontological questions about disabled death and instead resolves a potential crisis of queer/crip-ness through a reinscribing of familiar but perhaps more flexible neoliberal taxonomies.

I then move to an analysis of Jerika Bolen's premature death. I first discuss Puar's insightful musings on hope and prognosis and how these expand our theorizations on value and the body. Through an investigation of the affectivity resonating from Bolen's GoFundMe page I discuss how this assemblage of intimacy undergirds a resignification of disabled girl death that ultimately functions to mobilize Bolen's death as a pedagogical example of "good dying." Ultimately, I argue that affects that circulate around the imagined death of Grace and the actual death of Bolen work to shore up illusory neoliberal evocations of "choice" and "autonomy" within our times of existential vulnerability. The figure of the exceptional disabled girl is recapacitated in her death by way of her ideological, affective labor. Both girls, in their lives and imagined and real death work to rehabilitate able-bodied folks, and this rehabilitation works to and is premised upon the shoring up of the familiar trope of the suffering disabled body.

Living in Prognosis: Between 'Slow Death' and 'Making Die'

Bolen's death—and the event of her dying—could be theorized as ungrievable and unremarkable. Many queer, black, disabled deaths by way of spectacular and mundane state violence are forgotten, erased, or perversely justified. However, as the introduction illustrates, and as this chapter forwards, Jerika's death and the event of her dying, at once spectacular and mundane, was not unremarkable, nor was she ungrievable.

To make sense of the specific affective attachments that are generated by and underpin disabled girl death, and to understand the ways in which certain disabled girls are incorporated into the national imaginary by way of their death, we must move beyond biopolitical consideration of how some bodies are 'fostered for life.' To move beyond biopolitics, is to consider the "centrality of death in contemporary social life" (Snorton and Haritaworn 2013, 67). To do this, many queer and trans studies scholars have moved toward a consideration of Achille Mbembe's (2003) theorization of "necropolitics." Mbembe argues that Foucault's theorization of biopower, alone, is insufficient to attend to the ways in which "weapons are deployed in the interest of maximum destructions of persons and the creation of '*death-worlds*,' or spaces wherein populations are conferred upon them the status of the "*living dead*" (Mbembe 2003, 40). Puar (2007) offers us an elaboration, "queer necropolitics," which attempts make sense of the asymmetrical incorporation of queer subjects within the contemporary frame of the U.S. war on terror. Specifically she illuminates the ways in which the expansion of liberal gay politics works to enfold certain queer subjects while simultaneously marking certain racialized queer populations for death.

As this project has brought to light, our Post-ADA moment marks the enfolding of certain disabled girl subjects into the national imaginary, but this enfolding works alongside a reconfiguration of disabled death. In the context of the necropolitical, what complexities emerge when we shift to consider what "making die" comes to signify when one is living in prognosis? How might Berlant's (2007) "subtle counterpoint" to necropolitics, "slow death," or the "extreme yet ordinary physical wearing out of a population and the deterioration of people in that population that is very nearly a defining condition of their experience and historical existence," matter for making sense of disabled death (755)? If we discuss slow death in terms of the "physical attenuation" of a population that is not always directly attributable to the violent hands of institutions or the state, and we discuss necropolitics in terms of a population deemed to be "beyond rehabilitation" and physically removed from the social realm through exposure to premature death, then how do we imagine Bolen's death (Berlant 2007; Haritaworn et al. 2014, 6)?

"No One Wants to Talk about How I am Going to Die"

As Bolen circulates as a hypervisible example of actual disabled girl death, the most recent iteration of the *Degrassi* franchise features a storyline that centers upon a disabled girl character facing the promise of premature death. In "#NoFilter," the first episode in the fictionalized *Degrassi: Next Class* universe, disabled girl death operates in affective conviviality with the real event of Bolen's death by orienting viewers through similar rehabilitative logics discussed in previous chapters. However, premature disabled girl death incites an increasingly complex and contradictory affective topography. Grace's storyline illustrates how able-bodied rehabilitation is premised on a resignification of death through queer/crip love. #NoFilter functions pedagogically, ultimately assuaging anxieties about bodily vulnerability through the way it stages Zoe's agency in reconfiguring the terms of Grace's death.

Degrassi as Rehabilitative Edutainment, or "Whatever It Takes, I Know I Can Make it Through"

Degrassi: Next Class is the fifth series in the *Degrassi* universe, developed by Linda Schuyler, a Canadian schoolteacher, who, while producing a documentary about Canadian immigrant youth and their experiences with racism, "was drawn to the educational opportunity presented by mass media" (Neihart qtd. in Preston 2017, 77). *Degrassi's* effort, from the first iteration, *The Kids of Degrassi Street* (1980), to the current, *Degrassi: Next Class* (2016), is to illuminate what happens when teenagers bump up against difficult dilemmas. The storylines depict a diverse cast of young folks "trying to 'figure out their lives, and kid viewers around the world second-guess[ing] them" (Neihart qtd. in Preston 2017, 77). As Preston (2017) points out, the franchise's model "walks the line between education and entertainment," or it could be characterized as what Elman terms "rehabilitative edutainment" (78).

Each iteration of *Degrassi* explicitly endeavors to tell its stories as they reflect what the producers imagine to be the contemporary teenage milieu. As writer and executive producer Sarah Glinski explains, "We're telling the stories that are happening in high schools today. […] Many of the stories are very similar, we're just talking about them in the way that teenagers are talking about things today" (Jarvey 2016). As *Degrassi* exposes its characters to "what is happening in high schools today," or problems to be "figured out," e.g., teenage pregnancy, sexually transmitted diseases, homophobia, racism, etc., it does so with the understanding that the television show acts as a "lifeline, a flickering reassurance that someone out there understands" (Landau qtd. in Preston 2017, 78). Thus *Degrassi* endeavors to establish an intimacy with its teen viewers through cultivating this “lifeline,” which perhaps unwittingly works to orient teenage viewers toward learning how to manage their own crises.

Death in the Time of the New Flexible, Homonormative Subject

“#NoFilter” begins in Media Immersion class—one of the hallmarks of the *Degrassi* universe—and the camera brings into focus Zoe Rivas, a former child actor whose drug addiction ended her career, and Grace Cardinal, *Degrassi*’s token rebellious feminist character. Zoe and Grace are giggling and discussing the television show *Scandal* as their teacher introduces a new project. “What will your life be like in 15 years?” The teacher asks. “That’s what I want you to show me in your first assignment. In groups of two you are going to use the animation skills you’ve been learning to create a short video about what you think your future looks like. Pair up.” Zoe asks Grace, nervously, if she would like to be her partner. Grace responds emphatically, “Yes, dummy!” and then leaves her seat to get a handout.

As Grace is up from her seat, Zoe’s friend Tristan leans over and starts to whisper to Zoe. He asks her how the “whole just being friends thing” is working out for her, and Zoe responds defensively “fine. Why?” He continues to give her some advice, “Life’s better out of the closet, Zo.” She exasperatedly replies, “I don’t even know if I’m gay.” Tristan chuckles and rolls his eyes at that suggestion. “Right,” he responds. Zoe goes on, “I’m totally fine with just being friends. Besides, friendship is basically dating without— “ As Zoe hesitates, Tristan completes her thought: “The good parts?” He then pleads with her, “You need to make your feelings known.” In a firm but nervous tone, Zoe argues, “And if she’s not into girls, then sayonara.” Tristan laughs and clicks his tongue against the roof of his mouth; he points his pencil at Grace, who is still at the front of the classroom going over the handout with the teacher: “Look at her. That hair. Those piercings…There’s no way she’s doing that to attract boys.”

As the episode continues, tension builds between Zoe and Grace as the viewers come to realize that Grace is also hiding something from Zoe. In one scene we see Zoe and Grace giggling, sitting on bean bag chairs eating lunch, Zoe is tossing her phone between her hands and looks up ruminating, “What color do you think your hair’ll be in 15 years?” Grace scoffs and furrows her brow, “No clue,” she responds. Zoe asks jokingly, “What about those piercings? Do you think they’ll be all stretched out and weird-looking?” She then moves to jokingly touch Grace’s face, and we hear Grace snort and then she pushes Zoe’s arm away. After playfully hitting each other’s arms, they end up holding hands, and we see a half-smile form on Grace’s face, her small look of pleasure is soon replaced coughing. She holds her hand to her mouth, coughs, and then looks from her hand to Zoe. Worriedly she gets up and leaves. Zoe asks, concerned, “Are you okay? But Grace does not respond—we see her walking briskly away from their moment of intimacy.

Zoe is convinced that she came on a bit too strongly to Grace and that was the reason why Grace abruptly left. On her way to Grace’s home, she is panicked and calls Tristan, “I have to explain the hand touch wasn’t a bit deal before she blows it out of proportion,” she clarifies. However, she does not have the opportunity to explain anything to Grace because her mother answers the door and nervously tells her that Grace “isn’t home” and does not know when she will be back. As Zoe leaves, defeated, she notices that Grace is watching her from a slit in the curtains in a window by the porch.

Grace realizes that Zoe sees her, and with her eyes wide and mouth nervously pursed, she closes the curtains all the way. Zoe is clearly hurt by this gesture, and she sighs and furrows her brow as she quickly walks away.

The tension comes to a head the next time Zoe and Grace come face to face in the girls' restroom at school. We see Zoe in the girl's bathroom washing her hands, as she throws the paper towel away to leave, Grace walks in. We see a surprised look on Grace's face, and she sighs, puts her arms across her body awkwardly, and says, "Hi." Zoe responds dramatically, "Oh, so now you want to talk to me?" Grace looks sheepishly to the side and tells her, "I finished the backgrounds for our project." Zoe confronts her about last night and accusingly remarks, "I am sure you had a lot of free time at home last night. Are you seriously just gonna stand there and pretend nothing happened?" Grace coughs and as she brings her arms up to cover her mouth, we see lesions or bruising on her forearms. She stutters, "You don't know the whole story." Zoe's voice starts to escalate: "What's the whole story? That you're such an emotionally damaged psycho, you can't even handle one little touch?" Grace starts to have a coughing fit and quickly turns to cough in the sink. Zoe walks over and leans to look in the sink, she notices blood and panicking she says, "Oh my god. Is that blood? I'm calling 911." Grace looks up at Zoe, blood dribbling down her mouth and tells her, "You don't have to call an ambulance." She looks up at Zoe and with a furrowed brow and eyes half closed asks her, "Can you just take me home?" Zoe, her face a mixture of concern and embarrassment, gently places her arm around Grace and walks her out.

The next time we see Grace she is laying on her bed coughing, her mom is leaning over her, and she's holding a device that her mother tells her to inhale into, "Deep breaths, sweetheart," she advises her as she is rubbing her back. As Grace's mom tells her that the nurse will be here soon, the camera pulls away, and we see Zoe standing and witnessing this interaction between Grace and her mom. She asks with a shaky voice, "What's going on?" Grace's mom continues to rub Grace's back and tells Zoe, "It might be an infection, but it might just be because she's been a little lax with her breathing therapy." "Her therapy?" Zoe asks confused. Grace's mom looks up and awkwardly laughs, "Oh, you don't know." She shakes her head and sighs, "Grace has cystic fibrosis."

As Grace's mother brings into relief Grace's hidden disabled identity, a troubling analogy also begins to take shape. As we recall at the beginning of the episode, Tristan chides Zoe, "Life's better out of the closet," and *Degrassi* sets up Grace's cystic fibrosis "reveal" as a somewhat violent instantiation of that advice. As Ellen Samuels (2003) writes, "coming out [as disabled] is primarily portrayed as the process of revealing or explaining one's disability *to* others, rather than as an act of self-acceptance facilitated by a disability community" (239). Discourses of coming out are central to liberal LGBTQ visibility politics, wherein, "certain assumptions about the correlation between appearance and identity have resulted in an often exclusive focus on visibility as both the basis of community and the means of enacting social change" (Samuels 2003, 240). Within this visibility framework, "passing," is reaffirmed as a distancing of authentic self, which manifests in a denial of potential happiness, or 'the queer/crip good life,' as Grace and Zoe's parallel storylines illustrate. The conflation of "coming out" as gay and as disabled, or perhaps the concomitant insistence on "coming out" as gay and as disabled offers a reification of neoliberal visibility politics. The idea that one is better off out of the closet conceals liberatory queer potentiality and upholds certain neoliberal fantasies about the power and necessity of visibility. The insidious function of these appeals to the visible, "out," subject become more clear in the scenes following Grace's "outing."

After Grace's mom announces to Zoe that she has cystic fibrosis, the camera shifts to Zoe's face. Her eyes are red, and attempting to hold back tears, she mutters, "Cystic fibrosis…but…not the one that kills you right?" The camera shifts again and we see Grace, looking off into the distance, and exasperatedly tells Zoe, "There's only one kind." Grace's mom quickly rebuffs, "But there have been lots of advances with the research." Zoe nervously asks, "When she's old right? Not like…soon, or now, or anything?" Grace's mom looks up at Zoe, and with a tight-lipped smile she looks down, and nods: "We're keeping an eye on it." She assures Zoe (and Grace, and herself): "We've got a great team to make sure Grace stays healthy. Lots of people with CF live well into their 30s. And with more and more therapies and medicines being developed…there's no reason to believe that she won't make it into her 50s." As Grace's mom is recounting the fatal prognosis to Zoe, soft piano music starts to play and the camera slowly zooms in on Zoe's face, her eyes welling with tears of disbelief.

After the discovery of Grace's cystic fibrosis, Zoe invites Grace to talk on the roof of school. Grace looks down and closes her eyes, "About yesterday—" Zoe quickly interjects, "No need to explain. I was up all night researching. If you ever want to talk about anything, I'm here." Grace sighs and looks down, and Zoe smiles and hands her a giant insulated cup. "What's this?" Grace asks. Looking pleased with herself Zoe tells her, "Green smoothie with ginseng, clove and cinnamon, all of which are super antibacterial, to help fight off those lung infections." Grace sighs and shakes her head and aggressively hands back the smoothie. She tells Zoe that it will not do anything, and the conversation devolves into Zoe listing off a litany of different treatment options that she read up about on the internet. She asks if Grace has heard about "that crazy new drug" that is helping people with CF "live into their 70s." Grace, her face scrunching up and brows furrowed, responds tersely "It's for a different genetic mutation. That won't work for me." Zoe continues, and finally Grace has had enough.

She yells, "Stop it!" and throws her hands up and down in the air. "You say you wanna talk? But not about how I am going to die before 35! About how there's no point in anything because I've got one foot in the grave!" Zoe looks down and thinks before she slowly responds, "With what you're up against, it probably feels like everything is pointless." Grace rolls her eyes and turns to look over her shoulder, "You're finally getting it." Zoe walks over to the edge of the building's roof, she turns around and challenges Grace, "So jump." Grace looks over to the edge of the building with disbelief, "What?" she asks. Zoe continues, the words streaming out of her mouth, "You've already decided that your life is over. You could have 20 more years, but you've already given up. You're basically dead, so you might as well just kill yourself." Grace sighs and walks toward Zoe, who is at the edge of the building, "You know…I think you're right." Zoe looks confused and mutters, "I am?" Grace sarcastically responds and gets in Zoe's face, "You've given me a new lease on life. I think I'll go to med school and dedicate my life to curing CF." Zoe, in a pleading voice responds, "I was just trying to prove that you've got stuff to live for!" Grace yells and throws her hands down: "Shut up! My whole life has been people telling me to stay positive! Everyone wants to talk about insane miracle cures, but no one wants to talk about how I am going to die!" Zoe yells back, "Because maybe you won't!" Grace disagrees, and with her voice cracking she explains: "Because people can't handle it! In middle school I was hospitalized for a month. In the beginning people came to see me. But by the end? Nothing."

Piano music starts to play, and the camera zooms out so the viewer can see Grace and Zoe both in the frame. "That's awful," Zoe remarks with tears welling in her eyes. Grace firmly explains, "This is why I don't do relationships. Hard to commit when you're one lung infection from the end. I've just accepted that there won't be anyone at my funeral." Zoe yells, "Don't say that!" Grace looks at her and growls, "Why not? It's the truth. People just can't deal. I guess I thought you were different." Grace storms off and the camera zooms in on Zoe, whose lip is quivering, and then it slowly spreads to her whole body.

This intense exchange between Zoe and Grace on the rooftop toggles between Zoe's attempts to recast Grace's fatal prognosis, first through appeals to biomedical innovations, then through a reframing of Grace's future, her potentiality, and Grace's rebuffs. As Grace becomes a visible disabled subject—living in fatal prognosis—the affective atmosphere shifts. The playful, queer intimacy that shaped the beginning of the episode, characterized by openness and possibility, which was anchored by the existential nature of the school project, shifts and is haunted by Grace's inevitable premature death. Rather than open up liberatory possibilities for imaging queer/crip intimacy, the resolution by way of Zoe's epiphanic reimagining of the school project euphemizes the death of the Other through a flexible, homonormative grievability.

Like Meg and Alina's family in the previous chapter, Zoe attains a similar flexibility through weathering the crisis of Grace's fatal prognosis. However, unlike the heterosexual flexibility that McRuer articulates, I argue that this is an example of homonormative flexibility that serves a similar able-bodied rehabilitative purpose. Lisa Duggan (2002) argues homonormativity is based on a “politics that does not contest dominant heteronormative assumptions and institutions but upholds and sustains them” (179). One way homonormativity operates is through a double deployment of exceptionalism and exception: in the wake of the deferred death of one population (e.g. unassimilable racialized queer populations) occurs the securitization of certain sexually exceptional populations (e.g. populations that are anchored in a depoliticized, privatized consumer gay culture). Sexual exceptionalism works to enfold homonormative subjects into the national body—these subjects do not undermine or challenge the existing heteronormative contract; but rather, they work to redefine the parameters of the contract’s reach. At the same time, homonormativity works to uphold narratives of U.S. (and Canadian)[14] exceptionalism through its bolstering of fantasies of national benevolence and teleological progress. One “prime mechanism of sexual exceptionalism is mobilized by discourses of sexual repression” (Puar 2007, 9). Or, in other words, “the call to come out” is mobilized as at once a modus for intelligibility and enfoldment into the national body, as well as a sign of U.S. tolerance and even celebration of difference.

In the episode #NoFilter, the call to come out takes on a reparative function that works through the promise of Grace’s premature death. The urgency with which Tristan’s advice in the beginning of the episode—“life’s better out of the closet”—is palpable

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[14] It is important to note that *Degrassi* is Canadian in origin, but that is widely watched (streaming on Netflix) and well received in the United States. Because I am discussing the affective resonances in a US context (in relation to Bolen’s death), I do not wish to conflate Canada with the U.S.; however, I do think that the globalized nature of streaming services such as Netflix allow us to discuss how *Degrassi* shapes a post-ADA structure of feeling, despite originating in Canada. This discussion of globalization and streaming services is outside of the scope of this project, but see Keatling (2012) *Netflixed: The Battle for America’s Eyeballs* for a more thorough discussion.

when Zoe encounters Grace on the roof of the school. Grace's potentially crip proclamation: "No one wants to talk about how I am going to die," is contained through the intensity of white homonormative suffering. Grace's declaration that she "doesn't do relationships" because of her fatal prognosis takes on a new affective dimension because of Zoe's unwillingness to come out. The viewers encounter Zoe's tears as reverberations of unrequited love, which is a universal appeal to homonormative happiness. Ahmed (2010) argues that love is a happiness script, or a straightening device, thus Grace's premature death becomes an affective device for forwarding a tragic homonormative love story.

The episode ends with Zoe and Grace back in the media immersion class. "So we're taking an F on this?" Grace asks Zoe, presumably because they were not able to finish their project because of the argument, which is rooted in Grace's untenable future. Zoe responds, "not quite," and stands up to present their project: "The future is uncertain. Who knows where we'll be in 15 years? Statistically, one person in this room will be in prison, and two will be dead." The camera shifts to Grace, who looks up and starts to smile. "Given her bad-ass lifestyle," Zoe continues, "I assume Grace will be one of these people." Zoe then puts their project on the computer screen in the front of the classroom. The short animation begins with a tombstone that reads, "R.I.P. Grace. I never liked you anyway." Zoe then explains the next part of the animation, which is a girl crying in front of the grave: "Here is me wearing vintage Valentino at her funeral." Grace starts to laugh, and we hear Tristan say, "Morbid much?" The teacher awkwardly thanks Grace and Zoe for presenting their project, and then Zoe sits down, and looks to the side nervously. Grace turns to her, and whispers, "You don't suck as much as most people." Zoe smiles, and a bit unsure of the compliment responds, “Thanks…I think.” The scene ends with upbeat guitar music, and the viewer sees the two girls, both with half-smiles of relief on their faces.

Zoe’s reimagining of Grace’s death illustrates her flexibility, or her ability to weather a crisis. The tragedy of unrequited love is assuaged through Zoe’s performance of tender morbidity. Through Grace’s fatal prognosis, Zoe is able to critically reflect on the meaning of mortality and the value of a good death, which in this case, is a death that is grievable. Grievability in #NoFilter is only possible through the call to come out. Grace must “come out” as disabled to be grievable. Zoe, too, through the tears on the rooftop and the smile at the close of the episode is framed as affectively coming to understand this call as it becomes more urgent in the face of Grace’s prognosis. Thus Grace’s death serves to rehabilitate Zoe. Rehabilitative citizenship depends on an “anxiety over a perceived loss; and a belief that it could be masked or repaired” (Elman 2013, 91). #NoFilter functions pedagogically, ultimately assuaging anxieties about bodily vulnerability through the way it stages Zoe’s agency in reconfiguring the terms of Grace’s death. This agency is implicitly a fact of her whiteness. As Saldanha (2007) argues, drawing on Franz Fanon, “what can be called ‘the fact of whiteness’ is that whites *continually overcome themselves”* (197). Whiteness, as a “historically contingent capacity for reinvention, a reaching beyond the self,” is what undergirds a homonormative flexible subject (Gill-Peterson 2015, 145). Zoe “reaches beyond herself” through her attempts to understand Grace’s fatal prognosis—in Grace’s own terms—and this materializes in the final project.

Rehabilitative logic in #NoFilter works to sustain a fantasy of neoliberal sovereignty through the affectivity of white homonormative suffering. This works to displace actual existential or ontological questions about disabled death and instead resolves a potential crisis of queer/crip-ness through a reinscribing of familiar but perhaps more flexible neoliberal taxonomies. As Zoe must urgently "figure out" if she is gay or not, Grace's disability is unwittingly placed firmly within a curative (or not!) framework.

"Her Body Her Pain": Jerika Bolen at the End of Rehabilitation

Sarah Jain (2007) in a piece reflecting upon cancer and its temporal dimensions, remarks, "all of us in American risk culture live to some degree in prognosis" (79). Puar (2009) concurs that "living in prognosis" is useful for making sense of the "simultaneous sense of life and death" (163). She expands this theorization, offering that living in prognosis "lends itself to both ontological and epistemological sense of hope" (Puar 2009, 163). Hope, here, both designates the generative capacity of the body relative to its affective futurity, as well as "renders in the fantasy of empirical certainty," or what Rose and Novas term, "the political economy of hope" (qtd in. Puar 2009, 163). The capacity for producing hope as a function of prognosis "modulates punitive distinctions between good and bad neoliberal subjects" (Puar 2009, 163)." A "good" neoliberal patient is, after all, hopeful. This capacity for hope is not "discretely" located in the body, but the capacity is shaped through its relationality to both bodily limits (disability, debility, and incapacity) as well as "prevailing notions of chance, risk, accident, luck, and probability" (Puar 2009, 163). Thinking through formulations of biocapital, Puar calls for a reconsideration of the value of a body. If a body's value

> is increasingly sought not only in capacity to labor but in the information that it yields—and if there is no such thing as excess, or excess info, if all information is eventually used or is at least seen as having imminent utility—we might ask whether this is truly a revaluing of otherwise worthless bodies left for dying (Puar 2009, 164).

Are all bodies then available for rehabilitation? What does rehabilitation look like if a body is literally destined for death? These tensions between prognosis, hope, rehabilitation, and value animate the following discussion of Jerika Bolen.

GoFundMe as a Technology of Intimacy

"J's Last Dance," the GoFundMe that Bolen's mom set up to fund a prom—her "last dance"—and final trip to a Spinal Muscular Atrophy fundraising race surpassed its goal of $25,000 within the two months that it was active. 834 people donated over $36,000 dollars in total to the campaign. According to their 'About Me,' GoFundMe, a crowdfunding platform, "makes it incredibly easy to raise money online for the things that matter to you most. Most people use GoFundMe to raise money for themselves, a friend or love done during life's most important moments." GoFundMe and similar crowdfunding platforms are emergent phenomena online that "facilitate private donations" otherwise characterized as "micropatronage" (Ridgway 2013, n.p.). As Ridgway (2013) articulates:

> To an outsider, crowdfunding looks normal, fair or even logical in present day capitalism. It promotes the illusion of democracy and participation by allowing the funder to chose where s/he spends her money, instead of governmental control and authority (n.p.).

Emerging as a response to recent austerity policies, the rollback on social services, and the general precarious reality of flexible, low wage labor, crowdfunding platforms offer a way for individuals to raise money, as GoFundMe articulates “during life’s most important moments.” Campaigns range from raising money for children’s cancer treatments to raising money for elderly folks who cannot afford to retire. Crowdfunding sites such as GoFundMe are perhaps a space where we can come see the ways in which the convoluted assemblage and exchange of affect, capital, and technology is at once the spectacular and mundane embodiment of our neoliberal rehabilitative imaginary. As GoFundMe points, and as Bolen’s campaign illustrates, “What’s the secret to a successful campaign? If you’re raising money for something that you strongly believe in, chances are that people in your life will be eager to support you.” Thus those campaigns that *move* us in the right way are those that we invest in.

Bolen’s mother writes on the GoFundMe:

> Dear Friends and Family:
> Like any other parent I will never forget "D-day" (diagnosis) for us. My precious 8-month-old had just spent 5 hours in an MRI scanner at Children's of Milwaukee searching for a possible tumor on her spine causing her progressive lack of movement. Instead there was not a tumor and I was told about a fatal disease called Spinal Muscular Atrophy, which was soon after confirmed by genetic blood testing. We were given a limited prognosis by the neurologist, but I refused to listen to that doctor tell me I was going to lose the best thing that ever happened to me. I immediately got on the internet and found other families like ours. My heart broke seeing all the photos of babies who lost their lives to this disease, but I also found many families whose children were living and HAPPY and I was put in touch with an amazing doctor near us in Madison. Dr. Schroth is a specialist in her disease and I can never thank her enough for all of these "extra" years we have had. Despite the fact that Jerika never crawled, walked, rode a bike or did many other things most children can she was a very happy girl. Creativity allowed for our own way of fun and we enjoyed many wonderful moments together and I couldn't begin to put words to the gift my girl has been to my life.
>
> Unfortunately, SMA is a relentless disease that has left Jerika with very little movement and an incredible amount of pain that has become too much, and like any parent, I promised my child when it got to be too much I would be behind her no matter what. She has endured more in her 14 years of life than most adults will ever have to. I am beyond proud of her for fighting so hard for this long and

> I am honored to be her mother.
>
> She has let me know now that she needs to be free of her broken body. She has a couple last wishes that I would love your help with. She wants a to have a "prom"..one night of music and dancing and fun. She wants a disco ball and black and lime green decor and to be surrounded by lots of friends she has been unable to see for a long time. She also wants to make it down to see her other SMA friends we see every year at Avery's Race the weekend of July 14th. After that she will come home and begin her journey to Heaven.
>
> I will be forever humbled by your support through the years for us and I would be forever grateful for any help you could give me with the end of our journey together and many prayers of strength to make the coming days as pleasant and magical as possible!

Similar to other interviews, Bolen's mother, Jen, articulates that Bolen's pain has become too much to bear, and it her motherly duty to honor her daughter's wishes to be "free from her broken body." She also is sure to emphasize Bolen's strength, having "fought" SMA for 14 years of her life, enduring more than most adults.

As illustrated by the amount of money raised, but also by the sheer number of comments, Bolen's campaign *moved* folks in very specific, intense ways. As Elizabeth Matzen comments, "I am moved by the courage that both you and your daughter possess. May you create many moments this summer that you can remember forever." Michele Perry concurs, "You are a true warrior. Your mother is also a true warrior. You are moving on to part 2 of life and one day your mother will join you again. May your days now be filled with love, laughter and peace. I commend you both. Jerika—you are wise beyond your years." Julie Weber writes, "We have been so inspired by your story. You are a true hero and an inspiration to many. Your legacy will live on forever." As I discuss in the previous chapter, inspiration moves us forward. Bolen and her "legacy" as many articulate moves us forward, but forward to what? Bolen is commended as "wise," "courageous," and "a true warrior." Gesturing toward an enlightened mastery of the body through her decision to end her life, Bolen is championed as the ultimate figuration of neoliberal citizenhood. As Katelyn Marie elaborates,

> This made me burst into tears, but I'm so glad that you finally got a voice to speak for yourself and make your choice that's such a hard decision. But you live with this everyday, the hurt and pain and probably thinking that your just a big pain to your family having to take care of you always because you can't do it. I wish the best for you. […] I almost took my own life not too long ago. But my mom made sure I stayed alive.

Bolen's ability to make this difficult decision is framed as an act of selflessness, and she is positioned as self-aware of the pain that she inflicts on her family because they "have to take care of [her] always because [she] can't do it." Her mother is also positioned as selfless in this event, and their relationship is upheld as an example of "true love." As Samuel Gao writes alongside his donation,

> The inspirational courage that your family endured during this gift of a time is what people take for granted. Having the courage to let your daughter go is the ultimate selfless act that any parent wish they will never have to make. Your daughter, being the caring and lovable person she is, was faced with a decision that not only broke her heart, but proved that through love, an undeniable strength comes through from the bond you have created. Both you and your daughter have faced great adversities in this life to create a love so deep, that most of us will never find but often hope for. I hope one day, when my time comes, I will be as lucky to even experience a fraction of love and bond that you and your daughter shared. Thank you for showing the world—reminding the world that even though we're in such a destructive hateful time, we can still find beauty in what it means to love one another. I cannot offer anything but a small token of appreciation and admiration of the love that you and your daughter share.

We see here another utterance of love. If love "might be experienced as the duty to be happy for another" then Samuel offers an affective resignification of Bolen's premature death (Ahmed 2010, 92). For Jen, then, to be happy for Bolen is to allow her to "free herself from her broken body," and as such free her from a future bad life. Thus Bolen, living in prognosis, and her body—imagined as a separate, broken, painful entity—is recapacitated and circulated as valuable because of her role in the neoliberal, biocapitalist affective economy of hope. As Samuel reminds us, "even though we're in such a destructive hateful time, we can still find beauty in what it means to love one another."

Good Dying and Death at the End of Rehabilitation

Aren Aizura (2014) argues it is "necessary to critically locate necropolitics in relation to value. To theorize […] death as a reflection of the non-value of […] life, […] risks bracketing the capitalist relations of production that differentiate the value of particular bodies and render them 'grievable,' killable or otherwise" (132). For Bolen, her death does not reflect the non-value of her life; but rather, her life becomes valuable, somewhat retroactively, through her death. Martin argues that the relationship between valuable and valueless lives is always shifting to reflect the logic of the market: "what is excluded is always poised to return in the form of some further productivity" (qtd. in Aizura 2014, 132). A video spotlighting Bolen's last dance, as circulated by the Post-Crescent, highlights how the affectivity incited by the staging of the first responders who escorted her into the dance positions Bolen's return in the form of "further productivity." The benevolent encounter between the first responders and Bolen's black, disabled body as well as Bolen's decision to die retroactively position her body as valuable in death.

The video for the Post-Crescent news site, "Jerika Bolen Fills the House for Prom," begins with a shot of Bolen, decked out in a sparkly blue formal dress, silver lipstick, and tiara atop her blue hair (Collar 2016). Sitting in her powerchair with a "prom queen" sash over her shoulder, the camera zooms out so we see that she is surrounded by a crowd so thick that you cannot see where it disperses, and we hear them chanting "prom queen, prom queen, prom queen!" "It's so beautiful," Bolen says as the crowd dances around her, "I mean it was just an awesome experience." She recounts that the dance was "a little overwhelming, [but] otherwise it was amazing." As uplifting guitar music plays in the background, the viewer witnesses the liveliness of the dance. Folks of all ages are dancing on the dance floor, which is lit up with multicolored strobe lights.

The scene shifts and we see Bolen being escorted up the sidewalk by her mother and the police chief, and there are squad cars behind a line of police officers who are clapping their hands. Bolen narrates over this scene: "Thank you so much for everyone who came and stopped by." The video continues with more shots of the dance and close-ups of Bolen's and her mother's face. Although the scene with the police officers may only hold a bit of space in this larger video montage recounting Bolen's "last dance," it becomes a significant part of the narrative as reflected in other news outlets. Multiple articles that I came across mention that Bolen was escorted by 17 squad cars to the dance. The Post-Crescent article quotes the Appleton Police Chief Todd Thomas offering his "best wishes" to Bolen: "We're just blessed to be able to help out. It's an honor for us, and what an amazing young lady. She makes you appreciate what you have. She makes you think about using your time wisely. She's making an impact."

Figure 3: Screenshot Image of Jerika Bolen and police at her "Last Dance" (Collar 2016).

The many images in circulation of Bolen and the police officers are striking (See Figure 1.3). Erevelles (2014) argues, in her analysis of the school-to-prison-pipeline through Michelle Alexander's theorization of the "New Jim Crow," "the relationship between disability, criminality, class, and race is fraught" (84). Alexander traces continuities from Jim Crow laws and mass incarceration, and argues despite dubious claims that the United States is a "postracial society," many poor Black communities are subject to similar Jim Crow era legal and extra-legal systems of control and surveillance as well as social and political exclusion. Erevelles (2014) expands this theorization to articulate how disability intersects with processes of racialization and articulates the ways in which, similar to the commodification of black disabled bodies for the slave trade, black disabled bodies are being produced for the prison industrial complex by way of criminalization, which depends on similar evocations of a pathologization of blackness (as always, already violent, uncontrollable, etc.).

In stark contrast to Bolen's image above are the many haunting images of black girls brutalized at the hands of the police. In June of 2015, the images of Officer David Eric Casebolt assaulting fourteen-year-old Dajerria Becton circulated widely on the internet. In a video that was recorded at the incident, Becton was wrestled to the ground violently in a bathing suit, Casebolt grabbed the girls' braids and slammed her face into the ground as he sat on top of her, waving his gun at her friends who attempted to intervene. The video prompted national outrage. In response, in an official statement, police reported that the "large crowd refused to comply with police commands," and Casebolt's lawyer specifically stated that "[Casebolt] let his emotions get the better of him" (Cleary 2015). The reference to a "refusal of compliance" is the very language of unruly blackness, or of a pathologization of the black body. This is just one example that has incited the recent and increasing public outrage at racist police/state violence. This negative affective atmosphere that is accruing around the police is complicated, because for some it reaffirms the notion that policing is imbricated in systems of racism, ableism, sexism, classism, etc., for others it opens them up to this idea, and still, for some, it strengthens their blind faith in the police.

It is clear that the image of Bolen—her black and disabled body—next to the police officers offers an attempt at an affective conversion. As Samuel noted above in his comment on Bolen's GoFundMe, she "reminds the world that even though we're in such a destructive hateful time, we can still find beauty in what it means to love one another."

What is this "hateful" time that he is gesturing toward? I am not entirely sure, but what is clear is that Bolen functions to smooth over this affective disconnect. She offers us hope that we "can still find beauty" in the world. Unlike footage of disabled black folks being obstinate, violently protesting the terms of their death or the violence that is being enacted on their bodies, Bolen walks compliantly alongside police officers to her soon-to-be premature death. Her blackness is commodified and contained through an insidious form of respectability politics. Her black disabled body circulates pedagogically, as Officer Thomas articulates, "She makes you appreciate what you have. She makes you think about using your time wisely. She's making an impact" (Collar 2016).

Katerina Kolarova (2015) argues that our contemporary moment can be characterized by a period of "anxious recognition for the global North with respect to its own biological precarity," which is a term that designates the collapse of "illusions of biological sovereignty, both individual and collective" as well as an affective sense of vulnerability (396). Examining how fantasies of sovereignty are evoked and the affective release they provide in two films, John Madden's *The Best Exotic Marigold Hotel* and Micheal Heneke's *Amour,* Kolarova ultimately illustrates that ways in which biological and social precarity are resolved by way of the debilitated body. She argues that the "debilitated body becomes the location on which social, as well as biological, precarity can be (magically and spectacularly) resolved through performances of (illusory) sovereignty performed in control over the biological body" (Kolarova 2015, 399). Evoking Puar's theorization of "debility," Kolarova (2015) is interested in how neoliberal capitalism extracts vitality from certain bodies and populations in order to "revitalize" others, as well as how "incapacities and even death are rescued for global/transnational capitalism" (399). Kolarova's theorizations, like Aizura's, help to complicate and broaden theorizations of necropolitics. As Bolen (and Grace, as we will discuss in relation to Bolen) illustrates, certain bodies and populations are made valuable through death by way of their productive affectivity. Kolarova (2015) points out that narratives circulating around assisted dying or "death with dignity" legislation evoke "neoliberal humanist principles—humanity, dignity in death, individual freedom, autonomy, and choice" (400). Assisted dying is now conceptualized as a matter of citizenship rights and a "matter of general democratization and liberalization of society" (Kolarova 2015, 400). As such, Kolarova (2015) poses a particularly poignant question,

> How should we understand the fact that while the campaign for the 'right to die' continues to gain support and popularity, doing so under the banner of the fulfillment of democratic ideals and a more noble ethics of life, 'the notion of right to health appear…more controversial and problematic than ever, as the sustainability of welfare states is increasingly and explicitly in question (400)?

The intense affectivity that is generated through the event of Bolen's death is complicit in securing the ascendancy of the "choice to die" as a practice of good citizenship. As so many of Bolen's supporters are moved to exercise their "choice" to donate money, another performative exercise in neoliberal autonomy, they at once participate and facilitate a larger restructuring of an affective atmosphere that orients us toward "good death" as the emblem, or *hope for*, "the good life" (Kolarova 2015, 406). If to hope designates the generative capacity of the body vis-à-vis its affective futurity, then the event of Bolen's death teaches us what good dying is. If we are all living in prognosis, subject to a feeling of existential vulnerability, then Bolen teaches us, or rehabilitates us, through her selfless act. She is envisioned as transcending her "broken" body through an exercise in good decision-making, and, in turn, is relieving her family of the burden of care (and implicitly, she is relieving all of “us,” or our tax money, from having to care for her). Ultimately Bolen is recapacitated, in death, as the ideal neoliberal citizen by virtue of striving toward and accomplishing “the good death.”

“My Name and Legacy Will Carry On, I Hope”

The affects that circulate around the imagined death of Grace and the actual death of Bolen work to shore up illusory neoliberal evocations of “choice” and “autonomy” within our times of existential vulnerability. The figure of the exceptional disabled girl is recapacitated in her death by way of her ideological, affective labor. Both girls, in their lives and imagined and real death work to rehabilitate able-bodied folks, and this rehabilitation works to and is premised upon the shoring up of the familiar trope of the suffering disabled body. For Grace, her suffering white, body helps to produce a new flexible, homonormative subject. For Bolen, her suffering black, body teaches us what “good dying” means. In both cases, this incitement and transformation of affectivity (sadness into peacefulness, hopelessness into hope, ignorance into understanding) works to place these newly grievable bodies in a rigid imagining of medicalized disability—a body as “broken” or self-evidently degenerating due to a problematic embodiment. Butler (2010) argues, “Without grievability, there is no life, or, rather, there is something living that is other than life. […] The apprehension of grievability precedes and makes possible the apprehension of precarious life” (15). Ultimately, Grace and Bolen only become intelligible through their imagined deaths; their grievability “precedes and makes possible the apprehension” of valuable death.

Chapter 5

Conclusion:

Feeling Haunted

"Precariousness implies living socially, that is, the fact that one's life is always in some sense in the hands of the other. It implies exposure both to those we know and to those we do not know; a dependency on people we know, or barely know, or know not at all."

–Judith Butler (2010)

"We ask one last question: What might have happened if Jerika's request for a 'last dance' had been met with overwhelming public and media encouragement to live instead of a massive thumb on the scale in support of her death?"

–Not Dead Yet

This dissertation has traced the figure of the exceptional disabled girl as she traverses from YouTube videos, to HBO documentaries, to edutainment teen drama series, and finally to the local and national news. The figure of the exceptional disabled girl moves us: from a place of ignorance to understanding, from a place of nervous anxiety to one of hopeful promise, and from a precarious present to a not so bleak looking future. As a reparative figure, the exceptional disabled girl does the affective and ideological work of bringing into relief a fantasy of an imagined future that we are nostalgic for. This strange temporal structure of desire undergirds a post-ADA structure of feeling. Nostalgia can be "future oriented, pointing to potentialities not otherwise grasped in the here and now," and in this case, the exceptional disabled girl functions to assuage our anxiety about a future that is uncertain because of a present that feels precarious (Probyn 1996, 136). At once the figuration of the exceptional disabled girl emerges as a sign of the triumph of U.S. benevolence, as well as a stand-in for the continuing fantasy and potential of the promise of the American dream, as the U.S. Department of Justice blog articulates in the introduction to this dissertation. Our intimate encounters with the figuration of the exceptional disabled girl secure affective attachments to a promise of future oriented tolerance, which in many ways, comes to also define an emergent post-ADA structure of feeling. As a "future" girl, she affectively moves us forward: she rehabilitates us into tolerant neoliberal citizens who are capable of weathering the crises that an uncertain future may present us with. Post-ADA rehabilitation is contingent upon a new valuation of disability, which welcomes home certain exceptional disabled girls who are recapacitated through their luminous affectivity. However, this project of incorporation into the national imaginary can and does incite insidious violence on even those who come to be recapacitated, like Jerika Bolen. The remaining pages of this conclusion will return to Bolen, in attempt to make sense of the implications of the figure of the exceptional disabled girl that I have traced throughout this project.

***

I have attempted this section many times. I have lost count of how many times I have sat down on the floor in my living room, which weirdly enough is one of my favorite places to work, alongside my cat lounging lazily on the rug, and opened my laptop to just close it again moments later. I normally do not have trouble sleeping, and throughout the process of writing this dissertation, I have found a welcome solitude in the moments right after I wake up, when my mind is the most quiet. During these moments I usually can make sense of a couple of thoughts that were previously buzzing around my brain the night before, tangled and half-there. When this happens, I normally reach for my phone and email them to myself before I forget what they are. I have many emails like this in my inbox, sent to myself from my phone at 6:55 am. Most of these emails are just one line, no subject, for example, “since we are all living in prognosis it teaches us good death,” or “affect as object target, exceptional thru [sic] transformation.” These early morning fragments of thought have been vital to the writing process, and it is almost like they signal that my brain is full and ready to empty itself onto a word document. However, as I was finishing up the previous chapter on Jerika Bolen, I started to have a bit more trouble sleeping. The writing process is grueling for everyone, so I assumed that maybe I was just hitting a wall, and with the impending date of my defense looming in my mind, I thought to myself that I was probably just having a bout of extreme anxiety. I knew what I wanted the conclusion to do, or at least I thought I did, and since it was my final chapter to write, I tried to press on.

I ended up turning in a skeleton of a conclusion to my committee as a first draft. For some reason I just could not find the words to articulate the affective states that I wanted to convey, and all I could muster was “I am particularly haunted by the statement that Not Dead Yet put out regarding the mourning of Jerika Bolen, as well as the following comment on Bolen’s GoFundMe”:

> J, you may only be 14, but you have become a mentor for me. I have a degenerative spinal disorder (generic term for we don’t know why this is happening), and managed it for about 15 years. Then the pain was too much for

> me to be able to work. So I am on a disability annuity now. I have told my family many times, I am not afraid of dying. I am afraid of hurting. You have given me hope. Now sometime down the road I hope I can have the courage to say no more pain, I want to be at peace. You are a wonderful young lady who is wise beyond her years. Much love, Bev.

I went on to revise my other chapters, and decided that maybe I just needed more time for the thoughts to marinate. I was confident that the theoretical sparks would go off in my mind one night, and that I would wake up one morning ready to write about what I meant when I said that these things left me "feeling haunted." As I have labored over this, sitting in different positions on the floor, I have come to realize that this difficulty is not a typical one that I have encountered writing the other chapters. I have amassed an arsenal of techniques to combat writers block—I guess that is one productive thing that you develop when you work on something like this so diligently and for so long—and none of my "go-to" techniques have worked.

When I first watched the various news videos that documented Jerika Bolen's "last dance," I found myself crying as I transcribed her interviews. I felt conflicted—that is the purpose of these videos—I would tell myself, and so I would wipe away the tears and attempt to return to my "theoretical lens." Even now as I recount this, I am tearing up. Why does Jerika Bolen make me cry? To be haunted, "is to be in a heightened state of awareness; the hairs on our neck stand up: being affected by haunting, our bodies become alert, sensitive. The challenge may simply be to sit with this state of awareness, not to flee into action" (Ferreday and Kuntsman 2011, 9). It is clear that Jerika Bolen's story incites in me, perhaps similar, perhaps different, affective states than the viewers that I set out to write about in chapter four. I find myself deeply ambivalent about the story of

Jerika Bolen. To explain, it might be helpful to first consider Bolen, briefly, in the context of Avery Gordon's theorization of haunting in relation to the ghost.

Gordon argues that "haunting is linked to the project of peaceful reconciliation which transforms a 'shadow of a life into an undiminished life' (Gordon qtd. in Back 2011, 5). Haunting is the "sociality of living with ghosts," or people (communities, generations) that are no longer physically here, but are nonetheless "demanding attention, looking for justice, challenging the way we know, act and feel" (Ferreday and Kuntsman 2011, 1). The "socio-political-psychological," or affective, state of haunting prompts "something-to-be-done" (Ferreday and Kuntsman 2011, 2). Gordon emphasizes that the ghost needs to be treated with respect "rather than simply speaking for them, or, worse, making them 'abandoned and disappeared again' through the very process of dealing with haunting" (Ferreday and Kuntsman 2011, 2).

As a ghost, Bolen demands justice, but justice for and from what? I would tend to concur with some of the profound remarks that Not Dead Yet, a national grassroots disability rights group that opposes legalization of assisted suicide made in mourning of Bolen. The "Statement on the Mourning of the Death of Jerika Bolen" outlines a series of questions regarding her physical pain, her depression and emotional pain, and the systematic medical and legal issues that Bolen's death brings to the fore. They ultimately ask, "What might have happened if Jerika's request for a 'last dance' had been met with overwhelming public and media encouragement to live instead of a massive thumb on the scale in support of her death?" But it is also important, as Gordon emphasizes, to respect her. In an interview with USA Today, Bolen remarks, "I do have a voice, and it's going to hurt my family, but they will understand." What would it mean to respect Bolen's voice? Historically, disabled folks, and disabled girls, specifically, have not had a "voice" or autonomy over their own bodies. At the whim of parents and other institutional figures (medical professionals, researchers, teachers, etc.), disabled girls have been deemed incompetent, vulnerable, and unable to understand and comprehend their own body—and the pleasure and pain that comes with living in a body. How can we hold Not Dead Yet's question in productive tension with the respect of Bolen's voice? How can we come to understand the co-option of disabled death for a post-ADA, neoliberal capitalist America, and its symbolic and affective leveraging of the ghost of Bolen, while at the same time come to honor her ghost, as she implores us to ponder the radical potentiality of desiring and enacting death on your own body and in your own terms? I am not suggesting that Bolen's "choice" to die was any less illusory and constrained than any of the other "choices" that neoliberal capitalism presents us with; however, in the tangle of uproar about her incapacity to "choose," what can we learn from her decision?

Bolen articulates that she was tired and in pain, Not Dead Yet argues that that was unusual for someone with spinal muscular atrophy part II (SMA) and were skeptical that she was receiving adequate care:

> SMA Type II is not a condition that is typically fatal in children and teens. In fact, while some people with SMA die in younger adulthood due to respiratory complications, people with type SMA Type II often live into their 60s and beyond. Certainly, SMA would not result in the death of a fourteen-year-old who is receiving appropriate medical care. Our experience as disability rights advocates, many of whom have SMA and similar neuromuscular conditions, is that people with Type II SMA and the level of function that Jerika had as a teenager live long into adulthood (Coleman 2016).[15]

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[15] http://notdeadyet.org/2016/09/statement-on-mourning-the-death-of-jerika-bolen.html

What would it mean, though, if we consider Bolen's decision a radical refusal to the call of rehabilitation, of happy futures, of the promise that things will turn out okay? Indeed, neoliberal, post-ADA futurity is organized around the figure of the suffering disabled child, and through this production of suffering, disability becomes intelligible and valuable through the recapacitation of those exceptional disabled girls who essentially cope with, but not necessarily overcome, their suffering. The exceptional disabled girls' coping is premised on a management and affective resignification of their own bleak future, which in turn, teaches able-bodied folks how to manage our own bleak futures.

Although the figure of the disabled child has been historically leveraged as "the negation of the future," neoliberal, post-ADA futurity "speaks to the difference of the future for some disabled children: biocapitalist futures, premised on the hope of overcoming disability through cure or body/mind enhancement" (Fritsch 2016, 6). What if we read Bolen's decision as a rejection of a biocapitalist future? This is dangerous terrain, as so many disabled folks do not have access to the care that they need and are relegated to death, precisely because they do not have access to a biocapitalist future, or their death is valuable to a biocapitalist future (e.g. folks disabled through incarceration, police violence, and war). Following Fritsch (2016) I ask, "Is there a way to read [Bolen] as failure, dysfunction, loss, tragedy, or suffering so as to avoid turning her into a form of difference than can be capacitated or simply left to wither?" (23) Is there a way to read her suffering as a reminder that "not all forms of disability can be easily accommodated or adapted by neoliberal forms of capacitation" (Fritsch 2016, 23)? Now how can we cautiously approach the ghost of Bolen, as she demands, "something must be done"?

Ultimately, "'the ghost asks an ethical question: I could have been you?' […] It begs a recognition of a shared past by placing the living and the dead in the relationship to one another. The ghost wants to be recognized" (Back 2011, 5). Bolen's ghost evokes a shared horizon of experience, and in begging the question, "I could have been you?" she asks us to consider our own lives as imbricated in her death. This is at once an epistemological as well as ontological question. How do we place ourselves in relation to Bolen? As a white-passing researcher who does not identify as disabled, but has had a fair share of disability experiences that shaped my girlhood—countless hours of speech therapy for a speech impediment (only a lisp lingers) as well numerous visits to hearing specialists to address my left ear's hearing loss (something about a missing bone that could be "corrected" by surgery or, as the specialists advised, I may need a hearing aid as my hearing increasingly degenerates)—how do I place myself in relation to Bolen? I am self-aware of my imbrication in the academic industrial complex, and how it operates in collusion with the non-profit industrial complex, the medical industrial complex, and the prison industrial complex. Am I participating in the very thing that I am critiquing? Extracting knowledge from Bolen's death—or recapacitating her—for the very systems that I desire to dismantle?

Maybe these are unproductive questions, however I cannot deny that they are not a part of the scaffolding of my ambivalence about Bolen, her ghost, the telling of her story, and what the something that must be done is. I think, most importantly, Bolen's ghost urges me to always return to the material, embodied reality of disabled girlhood. Although this dissertation has traced the figuration of the disabled girl, this figuration is not removed from or separate from the material reality of disabled girls. Bolen urges me to come back to the fleshy, material reality of the body as it is lived in and experienced as a reminder that as the exceptional disabled girl is welcomed home in the national imaginary, the celebration works to cover over increasingly insidious forms of normalized violence. What of the real time-bankrupt autistic young woman or the disabled girl who remains a sad object? What happens to these girls who cannot affectively resignify their bleak futures? Or who do not want to?

As I set out to finish this conclusion, I return full circle without any clear answers, but more questions about the implications of this project. I woke up this morning and sent this email to myself: “What would it mean to keep the future bleak?” I realize that I have been pondering this question since I first encountered Jerika Bolen, and perhaps I did not realize it before today. To keep the future bleak may mean to ponder the transformative potential of ambivalent affective attachments. As Bolen exposes the contradictions inherent in the post-ADA imaginary, we must diligently reject the celebration of the hypervisible disabled girl, as she emerges as an affective weapon of neoliberal capitalism. The promise that she is tasked to repair is a violent one. We must hold close these ambivalent attachments, as they urge us to consider “something must be done,” something that we may not be able to articulate, but that we can feel.

References

Ahmed, Sarah. 2004. *The Cultural Politics of Emotion*. New York: Routledge.

———. 2006. *Queer Phenomenology.* Durham: Duke University Press.

———. 2010. *The Promise of Happiness*. Durham: Duke University Press.

———. 2012. *On Being Included: Racism and Diversity in Institutional l Life*. Durham: Duke University Press.

Aizura, Aren Z. "Trans Feminine Value, Racialized Others and the Limits of Necropolitics." In *Queer Necropolitics*, edited by Jin Haritaworn, Adi Kuntsman, and Silvia Posocco, 129-148. New York: Routledge.

Anderson, Ben. 2012. "Affect and Biopower: Towards a Politics of Life." *Transactions of the British Geographers* 37 (1): 28-43. doi: 10.1111/j.1475-5661.2011.00441.x.

Anderson, Christopher. 2008. "Overview: Producing an Aristocracy of Culture in American Television." In *The Essential HBO Reader*, edited by Gary R. Edgerton and Jeffrey P. Jones, 23-41. Lexington: The University Press of Kentucky.

Andrejevic, Mark. 2011. "The Work that Affective Economies Does." *Cultural Studies* 25 (4-5): 604-620. doi: 10.1080/09502386.2011.600551.

Asch, Adrienne and Michelle Fine. 1988. "Disability Beyond Social Stigma: Social Interaction, Discrimination, and Activism." *Journal of Social Issues* 44 (1): 3-21. doi: 10.1111/j.1540-4560.1988.tb02045.x.

Ash, James. 2015. "Sensation, Networks, and the GIF: Toward and Allotropic Account of Affect." In *Networked Affect*, edited by Ken Hillis, Susanna Paasonen, and Michael Petit, 119-134. Cambridge: The MIT Press.

Back, Les. 2011. "Haunted Futures: A Response to Avery Gordon." *borderlands e-journal* 10 (2). http://www.borderlands.net.au/vol10no2_2011/back_haunted.pdf.

Banet-Weiser, Sarah. 2012. *Authentic™: The Politics of Ambivalence in a Brand Culture.* New York: NYU Press.

———. 2014. "Am I Pretty or Ugly? Girls and the Market for Self-Esteem." *Girlhood Studies: An Interdisciplinary Journal* 7 (1): 83-101. doi:10.3167/ghs.2014.070107.

Barese, Evelyn Bousquet. "Adolescent Females Identified as Seriously Emotionally Disturbed: A Qualitative Study of Their Experiences and Perceptions." Phd diss., University of Connecticut.

Bauer, Anne. 2001. “Tell Them We’re Girls”: The Invisibility of Girls with Disabilities.” In *Educating Young Adolescent Girls*, edited by Patricia O’Reilly, Elizabeth M. Penn, and Kathleen deMarrais, 29-47. Mahwah: Lawrence Erlbaum Associates, Publishers.

Baxter, Judith. 2003. *Positioning Gender in Discourse: A Feminist Methodology.* New York: Palgrave Macmillan.

Bell, Debora J., Foster, Sharon L, and Eric J. Mash. 2005. *Handbook of Behavioral and Emotional Problems in Girls.* New York: Kluwer Academic / Plenum Publishers.

Berlant, Lauren. 1997. *The Queen of America Goes to Washington City: Essays on Sex and Citizenship*. Durham: Duke University Press.

———. 2007. “Slow Death (Sovereignty, Obesity, Lateral Agency).” *Critical Inquiry* 33 (4): 754-780. doi: 10.1086/521568.

———. 2008. *The Female Complaint: The Unfinished Business of Sentimentality in U.S. Culture.* Durham: Duke University Press.

———. 2011. *Cruel Optimism.* Durham: Duke University Press.

Berman, Helene, Harris, Dorothy, Eright, Rick, Gilpin, Michelle, Cathers, Tamzin, and Gloria Bukovy. 1999. “Sexuality and the Adolescent with a Physical Disability: Understandings and Misunderstandings.” *Issues in Comprehensive Pediatric Nursing* 22 (4): 183-196. doi: 10.1080/014608699265275.

Burman, Erica. 2008. *Developments: Child, Image, Nation.* New York: Routledge.

Butler, Judith. 2010. *Frames of War: When is Life Grieveable?* London: Verso.

Carlson, Licia. 2010. *The Faces of Intellectual Disability*. Bloomington: Indiana University Press.

“Charisse’s Story—My Life Journey with Cerebral Palsy.” YouTube Video, 17:35, posted by Charisse Living with Cerebral Palsy, June 13, 2012, https://www.youtube.com/watch?v=0nnuHj5M5FE.

Chen, Mel C. 2012. *Animacies: Biopolitics, Racial Mattering, and Queer Affect*. Durham: Duke University Press.

Cleary, Tom. 2015. “Eric Casebolt: 5 Fast Facts You Need to Know.” *Heavy,* 7 June. http://heavy.com/news/2015/06/eric-casebolt-mckinney-texas-police-officer-cop-suspended-black-teens-pool-party-arrest-video-leave-investigation-photo-gun-background-name/.

Coleman, Diane. 2016. "Statement on Mourning the Death of Jerika Bolen." *Not Dead Yet,* 23 Sept. http://notdeadyet.org/2016/09/statement-on-mourning-the-death-of-jerika-bolen.html.

Coleman, Rebecca. 2009. *The Becoming of Bodies: Girls, Images, Experience.* Manchester: Manchester University Press.

———. 2013. *Transforming Images: Screens, Affect, Futures.* New York: Routledge.

Collar, Jim. 2016. "Last Dance: Huge Outpouring for Dying Appleton Teen." *Post-Crescent Appleton Part of the USA Today Network,* 24 July. http://www.postcrescent.com/story/news/2016/07/23/last-dance-huge-outpouring-dying-appleton-teen/87471814/.

Corker, Marian and Sally French. 1999. *Disability Discourse*. Philadelphia: Open University Press.

Cowley, Danielle. 2013. "'Being Grown': How Adolescent Girls with Disabilities Narrate Self-Determination and Transitions." PhD diss., Syracuse University.

Cvetkovich, Ann. 2012. *Depression: A Public Feeling.* Durham: Duke University Press.

"Deaf Awareness: I'm on the Huffington Post! | Closed Captioned." YouTube video, 3:51, posted by Rikki Poynter. Oct. 8, 2014, https://www.youtube.com/watch?v=Dmd2xUFcKDk.

Degrassi: Next Class. 2016. "#NoFilter." Directed by Stefan Brogen. Written by Courtney Jane Walker, Linda Schuyler, Yan Moore, and Kit Hood. Family Channel/Netflix.

"Donald Trump's USA Freedom Kids." YouTube Video, 7:57, posted by VICE, Feb. 9, 2016, https://www.youtube.com/watch?v=9W5rnYb70kQ.

Driscoll, Catherine. 2008. "Girls Today: Girls, Girl Culture and Girl Studies." *Girlhood Studies* 1 (1): 13-32. doi: 10.3167/ghs.2008.010103.

Duggan, Lisa. 2002. *The Incredible Shrinking Public: Sexual Politics and the Decline of Democracy.* Boston: Beacon Press.

Duggan, Lisa and José Esteban Muñoz. 2009. "Hope and Hopelessness: A Dialogue. *Women & Performance: A Journal of Feminist Theory* 19 (2): 275-283. doi: 10.1080/07407700903064946.

Edelman, Lee. 2004 *No Future: Queer Theory and the Death Drive.* Durham: Duke University Press.

Edgerton, Gary R. 2008. "Introduction: A Brief History of HBO." In *The Essential HBO Reader*, edited by Gary R. Edgerton and Jeffrey P. Jones, 1-22. Lexington: The University Press of Kentucky.

Elman, Julie Passanante. 2010. "After School Special Education: Rehabilitative Television, Teen Citizenship, and Compulsory Able-Bodiedness." *Television New Media* 11(4): 260-292. doi: 10.1177/1527476409357762.

———. 2012. "'Nothing Feels as Real': Teen Sick-Lit, Sadness, and the Condition of Adolescence. *Journal of Literary & Cultural Disability Studies* 6 (2): 175-191. doi: 10.1353/jlc.2012.011.

———. 2014. *Chronic Youth: Disability, Sexuality, and U.S. Cultures of Rehabilitation.* New York: NYU Press.

Erevelles, Nirmala and Kagendo Mutua. 2005. "I am a Woman Now!": Rewriting Cartographies of Girlhood from the Critical Standpoint of Disability." In *Geographies of Girlhood: Identities In-Between*, edited by Pamela J. Bettis and Natalie G. Adams, 253-270. Mahwah, New Jersey: Lawrence Erlbaum Associates, Inc.

Erevelles, Nirmala. 2011. *Disability and Difference in Global Contexts*: *Enabling a Transformative Body Politic*. New York: Palgrave Macmillan.

Erevelles, Nirmala. 2014. "Crippin' Jim Crow: Disability, Dis-Location, and the School-To-Prison-Pipeline." In *Disability Incarcerated: Imprisonment and Disability in the United States and Canada,* edited by Liat Ben-Moshe, Chris Chapman, and Alison Carrey, 81-99. New York: Palgrave MacMillan.

Erevelles, Nirmala and Xuan Thuy Nguyen. 2016. "Disability, Girlhood, and Vulnerability in Transnational Contexts." *Girlhood Studies: An Interdisciplinary Journal* 9 (1): 3-20. doi: 10.3167/ghs.2016.090102.

Felperin, Leslie. 2015. "'How to Dance in Ohio:' Sundance Review." *The Hollywood Reporter,* 30. Jan http://www.hollywoodreporter.com/review/how-dance-ohio-sundance-review-768569.

Ferreday, Debra, and Adi Kuntsman. "Introduction: Haunted Futurities." *borderlands e-journal* 10 (2). http://www.borderlands.net.au/vol10no2_2011/ferrkun_intro.pdf.

Ferri, Beth A. and David J. Connor 2010. "I Was the Working Class Girl: Urban Working Class Young Women of Color." *Gender & Education* 22(1): 105-121.

doi: 10.1080/0950250802612688.

Foucault, Michel. 1997. *Society Must Be Defended: Lectures at the Collége de France 1975-76.* New York: Picador.

———. 2003. "17 March 1976." In *Society Must Be Defended: Lectures at the Collége de France 1975-76,* translated by David Macey, 189-214. New York: Picador.

———. 2007. *Security, Territory, Population: Lectures at the Collége de France 1975-76*. London: Penguin.

Fritsch, Kelly. 2013. "The Neoliberal Circulation of Affects: Happiness, Accessibility and the Capacitation of Disability as Wheelchair." *Health, Culture and Society* 5 (1): 135-149. doi: 10.5195/hcs.2013.136.

———. 2016. "Cripping Neoliberal Futurity: Marking the Elsewhere and Elsewhen of Desiring Otherwise." *Feral Feminisms* 5 (2016): 11-26. http://www.feralfeminisms.com/cripping-neoliberal-futurity/.

Garland-Thomson, Rosemarie. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature.* New York: Columbia University Press.

———.2011. "Integrating Disability, Transforming Feminist Theory." In *Feminist Disability Studies*, edited by Kim Q. Hall, 13-47. Bloomington: Indiana University Press.

Genzlinger, Neil. 2013. "Challenged, but Determined to Compete for the Tiara: 'Miss You Can Do It' Showcases Challenged Girls." *The New York Times,* 23 June. http://www.nytimes.com/2013/06/24/arts/television/miss-you-can-do-it-showcases-challenged-girls.html

———. 2015. "Review: 'How to Dance in Ohio,' a Documentary on HBO, Follows Three Women on the Autism Spectrum." *The New York Times*, 25 Oct. http://www.nytimes.com/2015/10/26/arts/television/review-how-to-dance-in-ohio-a-documentary-on-hbo-follows-three-women-on-the-autism spectrum.html?_r=0.

Gill-Peterson, Julian. 2015. "Sexting Girls: Technological Sovereignty and the Digital." *Women & Performance: A Journal of Feminist Theory* 25 (2): 143-156. doi: 10.1080/0740770X.2015.1057010.

Gordon, Avery. 1997. *Ghostly Matters: Haunting and the Sociological Image.* Minneapolis: University of Minnesota Press.

Gould, Deborah. 2009. *Moving Politics: Emotion and ACT UP's Fight Against Aids*.

Chicago: The University of Chicago Press.

Gupta, Vanita. 2015. "Twenty-Five Years of Progress for Americans with Disabilities." *The United States Department of Justice*, 21 Dec. https://www.justice.gov/opa/blog/twenty-five-years-progress-americans-disabilities.

Hall, Kim Q. 2011. *Feminist Disability Studies*. Bloomington: Indiana University Press.

Hall, Stuart. 1997. *Representations: Cultural Representations and Signifying Practices.* London: Sage Publications.

Haritaworn, Jin, Kuntsman, Adi, and Silvia Posocco. 2014. "Introduction." In *Queer Necropolitics*, edited by Jin Haritaworn, Adi Kuntsman, and Silivia Posocco, 1-28. New York: Routledge.

Harris, Anita. 2004. *Future Girl: Young Women in the Twenty-First Century*. New York: Routledge.

Harvey David. 2008. *Spaces of Hope*. Berkeley: University of California Press.

HBO. 2013. "Interview with Ron Davis." *HBO*. http://www.hbo.com/documentaries/miss-you-can-do-it/interview/ron-davis.html.

Hemmings, Clare. 2005. "Invoking Affect: Cultural Theory and the Ontological Turn." *Cultural Studies* 19 (5): 548-567. doi: 10.1080/09502380500365473.

———. 2015. "Affect and Feminist Methodology, or What Does it Mean to Be Moved?" In *Structures of Feeling: Affectivity and the Study of Culture*, edited by Devika Sharma and Frederik Tygstrup, 147-158. Berlin: Walter de Gruyter GmbH.

Hillis, Ken. 2009. *Online a Lot of The Time: Ritual, Fetish, Sign*. Durham: Duke University Press.

Holmes, Martha Stoddard. 2004. *Fictions of Affliction: Physical Disability in Victorian Culture*. Ann Arbor: University of Michigan Press.

How to Dance in Ohio. 2015. Directed by Alexandra Shiva. USA: HBO Documentary Films, 2015, Television.

Jain, Sarah Lochlann. 2007. "Living in Prognosis: Toward an Elegiac Politics." *Representations* 98 (Spring): 77-92. doi: 10.1525/rep.2007.98.1.77.

Jarvey, Natalie. 2016. "'Degrassi: Next Class' Team Talk Female Masturbation Storyline, Adding a Muslim Character." *The Hollywood Reporter*, 17 Jan.

http://www.hollywoodreporter.com/live-feed/degrassi-next-class-team-talk-856501

Jenkins, Henry. 2014. "Rethinking 'Rethinking Convergence/Culture.'" *Cultural Studies* 28 (2): 267-297. doi: 10.1080/09502386.2013.801579.

Jewell, Paul. 2007. "Policy as Ethics: Sterilization of Girls with Intellectual Disability." *Policy & Society* 26 (3): 49-64. doi: 10.1016/S1449-4035(07)70115-7.

Kafer, Alison. 2013. *Feminist, Queer, Crip.* Bloomington: Indiana University Press.

Kavka, Misha. 2008. *Reality Television, Affect and Intimacy: Reality Matters*. 2008. New York: Palgrave Macmillan.

Keating, Gina. 2013. *Netflixed: The Epic Battle for America's Eyeballs.* New York: Portofolio/Penguin.

Kirchdoerffer, Ed. 1998. "Flash, Cash & the Ratings Dash: HBO's Sheila Nevins." *Real Screen,* 1 Sept. http://realscreen.com/1998/09/01/23169-19980901/.

Kolářová, Kateřina. 2015. "Death by Choice: Life by Privilege: Biopolitical Circuits of Vitality and Debility in the Times of Empire." In *Foucault and the Government of Disability, Second Edition,* edited by Shelley Tremain, 396-424. Ann Arbor: University of Michigan Press.

Kuntsman, Adi. 2011. "Digital Archives of Feelings and the Haunted Futures." *borderlands e-journal* 10 (2). http://www.borderlands.net.au/vol10no2_2011/kuntsman_archives.pdf.

———. 2012. "Introduction: Affective Fabrics of Digital Cultures." In *Digital Cultures and the Politics of Emotion: Feelings, Affect, and Technological* Change, edited by Athina Karatzogianni and Adi Kuntsman, 1-18. New York: Palgrave Macmillan.

Lesko, Nancy. 2001. *Act Your Age: A Cultural Construction of Adolescence.* New York: RoutledgeFalmer.

Maroto, Michelle and David Pettinicchio. 2015. "Twenty-Five Years After the ADA: Situating Disability in America's System of Stratification." *Disability Studies Quarterly* 35 (3). http://dsq-sds.org/article/view/4927/4024.

Martin, Randy. 2007. *An Empire of Indifference: American War and the Financial Logic of Risk Management.* Durham: Duke University Press.

Mascaro, Thomas A. 2008. "Overview: Form and Function." In *The Essential HBO*

Reader, edited by Gary R. Edgerton and Jeffrey P. Jones, 239-261. Lexington: The University Press of Kentucky.

Matthews, Cate. 2014. “This Beauty Vlogger is Hard of Hearing, and She’s Stepping Up Her Game.” *Huffington Post*, 6 Oct. http://www.huffingtonpost.com/2014/10/06/rikki-poynter-deaf-hoh-beauty-vlogger_n_5941160.html.

Mbembe, Achille. 2003. “Necropolitics.” *Public Culture* 15 (1): 11-40. doi: 10.1215/08992363-15-1-11.

McGee, Micki. 2005. *Self-Help Inc.: Makeover Culture in American Life.* New York: Oxford University Press.

McGlotten, Shaka. 2013. *Virtual Intimacies: Media, Affect, and Queer Sociality.* New York: SUNY Press.

McGuire, Anne. 2016. *War on Autism: On the Cultural Logic of Normative Violence*. Ann Arbor: University of Michigan Press.

McRobbie, Angela. 2009. *The Aftermath of Feminism: Gender Culture and Social Change.* London: Sage Publications Ltd.

McRuer, Robert. 2006. *Crip Theory: Cultural Signs of Disability and Queerness*. New York: New York University Press.

———. 2010. “Disability Nationalism in Crip Times.” *Journal of Literary & Cultural Disability Studies.* 4 (2): 163-178. doi: 10.3828/jlcds.2010.13.

Melamed, Jodi. 2011. *Represent and Destroy: Rationalizing Violence in the New Racial Capitalism*. Minneapolis: University of Minnesota Press.

Minich, Julie Avril. 2016. “Enabling Whom? Critical Disability Studies Now.” *Lateral: Journal of the Cultural Studies Association* 5 (1). http://csalateral.org/wp/issue/5-1/forum-alt-humanities-critical-disability-studies-now-minich/.

Mirzoeff, Nicholas. 1998. *The Visual Culture Reader*. New York: Routledge.

Miss You Can Do It. 2013. Directed by Ron Davis. USA: HBO Documentary Films, 2013, Television.

Mitchell, David. T and Sharon L. Snyder. 2006. *Cultural Locations of Disability.* Chicago: University of Chicago Press.

———.2011. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann

Arbor: University of Michigan Press.

———. 2015. *The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment.* Ann Arbor: University of Michigan Press.

Murray, Susan. 2008. "*America Undercover*." In *The Essential HBO Reader*, edited by Gary R. Edgerton and Jeffrey P. Jones, 262-273. Lexington: The University Press of Kentucky.

Overboe, James. 1999. "Difference in Itself: Validating Disabled People's Lived Experience." *Body & Society* 5 (4): 17-29. doi: 10.1177/1357034X99005004002.

Paasonen, Susanna. 2005. *Figures of Fantasy: Internet, Women, and Cyberdiscourse.* New York: Peter Lang.

Parrey, Ryan C. 2016. "Being Disoriented: Uncertain Encounters with Disability." *Disability Studies Quarterly* 36 (2). http://dsq-sds.org/article/view/4555.

Phillips, Nelson and Cynthia Hardy. 2002. *Discourse Analysis: Investigating Processes of Social Construction*. Thousand Oaks: Sage.

Preston, Jeffrey. 2017. *The Fantasy of Disability: Images of Loss in Popular Culture*. New York: Routledge.

Price, Margaret. 2012. "Disability Studies Methodology: Explaining Ourselves to Ourselves." In *Practicing Research in Writing Studies: Reflexive and Ethically Responsible Research*, edited by Katrina M. Powell and Pamela Takayoshi, 159-186. New York: Hampton.

Puar, Jasbir. 2007. *Terrorist Assemblages: Homonationalism in Queer Times*. Chapel Hill: Duke University Press.

———. 2009. "Prognosis Time: Towards a Geopolitics of Affect, Debility, and Capacity." *Women & Performance: A Journal of Feminist Theory* 19 (2): 161-171. doi: 10.1080/07407700903034147.

———. 2012. "Coda: The Cost of Betting Better: Suicide, Sensation, Switchpoints. *GLQ: A Journal of Lesbian and Gay Studies* 18 (1): 149-158. doi: 10.1215/10642684-1422179.

Probyn, Elspeth. 1996. *Outside Belongings.* New York: Routledge.

Pybus, Jennifer. 2015. "Accumulating Affect: Social Networks and Their Archives of Feelings." In *Networked Affect*, edited by Ken Hillis, Susanna Paasonen, and Michael Petit, 235-250. Cambridge: The MIT Press.

"Q&A: Deaf Awareness Week | Close Captioned." YouTube video, 22:22, posted by Rikki Poynter, Oct. 1, 2014, https://www.youtube.com/watch?v=5PApS9aKH58.

Raun, Tobias. 2012. "DIY Therapy: Exploring Affective Self-Representations in Trans Video Blogs on YouTube." In *Digital Cultures and the Politics of Emotion: Feelings, Affect, and Technological* Change, edited by Athina Karatzogianni and Adi Kuntsman, 165-180. New York: Palgrave Macmillan.

Read, Jason. 2003. *The Micro-Politics of Capital: Marx and the Prehistory of the Present.* Albany: SUNY Press.

Reiff, Philip. 1966. *Triumph of the Therapeutic: Uses of Faith after Freud.* Chicago: University of Chicago Press.

"Ria Cheyne: Affect and the Disability Encounter." YouTube video, 40:13, posted by Center for Culture and Disability Studies, Oct. 14, 2016, https://www.youtube.com/watch?v=bIatu7kZyLg&feature=youtu.be.

Rice, Elisabeth Hess, Merves, Esther, and Amy Srsic. 2008. "Perceptions of Gender Differences in the Expression of Emotional and Behavioral Disabilities." *Education and the Treatment of Children* 31 (4): 549-565. doi: 10.1353/etc.0.0035.

Ridgeway, Renée. 2013. "Crowdfunding or Funding the Crowds? A New Model Distribution of Wealth?" *APRJA* 2 (1). http://www.aprja.net/?p=495.

"RIKKI POYNTER—Chanel Trailer." YouTube video, 1:05, posted by Rikki Poynter, May 10, 2016, https://www.youtube.com/watch?v=KMIxKwCXpBM.

Ringrose, Jessica. 2007. "Successful Girls? Complicating Post-feminist, Neoliberal Discourses of Educational Achievement and Gender." *Gender and Education* 19 (4): 471-489. doi: 10.1080/09540250701442666.

Rose, Gillian. 2007. *Visual Methodologies: An Introduction to the Interpretation of Visual Media.* London: Sage Publications.

Rose, Nikolas and Carlos Novas. 2005. "Biological Citizenship." In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Prbolems,* edited by Aihwa Ong and Stephen Collier, 439-63. Malden, MA: Blackwell.

Russell, Emily. 2012. *Reading Embodied Citizenship: Disability, Narrative, and the Body Politic.* New Brunswick: Rutgers University Press.

Saldanha, Arun. 2007. *Pyschadelic Whiteness: Goa Trance and Viscosity of Race.* Minneapolis: University of Minnesota Press.

Samuels, Ellen Jean. 2003. “My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse.” *GLQ: A Journal of Lesbian and Gay Studies* 9 (1-2): 233-255. doi: 10.1215/10642684-9-1-2-233.

Sandmand, Lars. 2005. *A Good Death: On the Value of Death and Dying.* Maidenhead: Open University Press.

Serlin, David. 2006. “Disability, Masculinity, and the Prosthetics of War, 1945-2005.” In *The Prosthetic Impulse: From a Post-Human Present to a Biocultural Future*, edited by Marquard Smith and Joanne Morra, 155-183. Cambridge: MIT Press.

Shandra, Carrie and Afra Chowdhury. 2012. “The First Sexual Experience Among Adolescent Girls With and Without Disabilities.” *Journal of Youth and Adolescence* 41 (4): 515-532. doi: 10.1007/s10964-011-9668-0.

Sharma, Devika and Frederik Tygstrup, ed. 2015. *Structures of Feeling: Affectivity and the Study of Culture.* Berlin: Walter de Gruyter GmbH.

Shildrick, Margrit and Janet Price. 1998. *Vital Signs: Feminist Reconfigurations of the Bio/logical Body.* Edinburgh: Edinburgh University Press.

Smith, Bonnie G., and Beth Hutchinson. 2004. *Gendering Disability*. New Brunswick: Rutgers University Press.

Snorton, Riley C. and Jin Haritaworn. 2013. “Trans Necropolitics: A Transational Reflection on Violence, Death, and the Trans of Color Afterlife.” In *The Transgender Studies Reader Vol. II*, edited by Aren Aizura and Susan Stryker, 66-76. New York: Routledge.

Spivak, Gayatri Chakravorty. 2012. *An Aesthetic Education in the Era of Globalization*. Cambridge: Harvard University Press.

Staiger, Janet. 2010. “Political Emotions and Everyday Genres.” In *Political Emotions*, edited by Janet Staiger, Ann Cvetkovich and Ann Reynolds. New York: Routledge.

Titchkosky, Tanya. 2003. “Governing Embodiment: Technologies of Constituting Citizens with Disabilities.” *Canadian Journal of Sociology/Caheirs Canadiens de Sociologie* 28 (4): 517-572. doi: 10.2307/3341840.

———. 2007. *Reading & Writing Disability Differently: The Textured Life of Embodiment.* Toronto: University of Toronto Press.

Todd, Anastasia. 2016. “Disabled Girlhood and Flexible Exceptionalism in HBO’s *Miss You Can Do It*.” *Girlhood Studies: An Interdisciplinary Journal* 9 (1): 21-35. doi:

10.3167/ghs.2016.090103.

Tremain, Shelley. 2008. "The Biopolitics and Bioethics of Disability." *Bioethical Inquiry* 5 (2/3): 101-106. doi: 10.1007/s11673-008-9105-6.

———. 2015. *Foucault and the Government of Disability, Second Edition.* Ann Arbor: University of Michigan Press.

Van Eck, Caroline and Edward Winters. 2005. *Dealing with the Visual: Art History, Aesthetics, and Visual Culture.* Aldershot: Ashgate.

Williams, Raymond. 1978. *Marxism and Literature*. Oxford: Oxford University Press.

"What I Want the World to Know." YouTube video, 4:09, posted by Charisse Living with Cerebral Palsy, Sept. 11, 2012 https://www.youtube.com/watch?v=n_VADDvHxCY.

APPENDIX A

“CRIP IRRESOLUTIONS”: FEELING THROUGH METHODOLOGY

Even today, “disability is still an emotional shorthand, a word where sorrow, suspicion, and a host of other emotions love to cling.”

–Martha Stoddard Holmes (2004)

“Disability encounters are necessarily affective encounters.”

–Ria Cheyne (2016)

The Encounter: Personal

This dissertation emerges from various and varied disability encounters: some serendipitous and some less so. I initially set out to examine a multitude of representations of disabled girlhood out of both academic and personal curiosity.[16] As I discuss briefly in the conclusion, I have had a multitude of personal disability encounters, or as Ria Cheyne (2016) would characterize them, individual disability encounters. As a young girl, I was subject to countless hours of speech therapy to correct different speech impediments. I have many fuzzy, ephemeral, and honestly traumatic memories of being taken out of class in elementary school to go meet with my speech therapist. Even more traumatic are my memories of mandatory hearing tests every year from kindergarten to senior year of high school. Each time I would inevitably fail the test, which most importantly to me meant that I was the last one to walk back to class, alone. None of my classmates really understood because I was not “actually deaf.” This was an anxious encounter. I have similar fleeting memories meeting with different audiologists to diagnose this degenerative hearing. I was born with fewer bones in one ear. Or at least that is what I remember understanding in fifth grade, the last time I met with a specialist,

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[16] It is important to note that I began this project in the hopes of including a qualitative interview component. Three interviews and countless hours fruitlessly recruiting later, I had to make the decision to change the parameters of the project and omit the interview component.

who told me that I could either have surgery then or just wait it out and eventually go deaf in one ear. I remember crying hysterically, and as a treat my mom took me to a diner where I ordered barbecue ribs, and I vaguely contemplated deafness over ribs and mashed potatoes.

I think it is important to mention that I do not currently identify as disabled, but these encounters with disability have oriented me to the world in a specific way that has become clearer to me as I have undertaken this project. With that said, this project, or the knowledge that I have produced, is necessarily mediated in part through these formative disability encounters. Many feminist scholars argue that it is imperative to remember that knowledge is always mediated by a host of factors related to an individual's particular position. As I set out to delimit the parameters of this project, I realized that what had become the most generative were my own traces of affective memory: the wince and recoil following a speech therapist's hand in my mouth demonstrating where my tongue should go when I articulated certain letters and sounds; the feelings of shame as I walked back to class from the hearing test; the heat of anger as my classmate laughed at my pronunciation of the word "minus" in a math unit in first grade.

This specific iteration of the project began to take shape after my encounter with HBO's *Miss You Can Do It.* Something about the documentary *stuck* with me. After watching the documentary countless times, I found myself dwelling in a state of ambivalence. This affective state was immensely productive, as I found myself unable to make quick or stock critiques of the film. The ambivalence forced me to reckon with the contradictions inherent in the film, and it also provoked me to sit with my own ambivalent feelings about the way that the figuration of the disabled girl was deployed.

As I worked to refine my artifacts for this project, I always came back to the ones that, similar to *Miss You Can Do It*, stuck with me. These ambivalent artifacts, films, news stories, YouTube videos, and television episodes left me feeling unsure, one way or another, of how I felt about them. In viewing these ambivalent artifacts, I felt moments of elation and disruption—when the disabled girls and their witty and nuanced way of being-in-the-world took center stage—but I also felt moments of distress and capture—when the disabled girls were insidiously, sometimes violently, deployed for the obvious purpose of shoring up ableism. Encountering this productive tension, which toggled between elation and distress, disruption and capture, guided me in both the delimiting and analyzing of the artifacts. Plainly, I felt that there was *something more* about the figuration of the disabled girl than I could immediately get at in each of the artifacts that I gathered for this project. This something more, or what I have articulated as ambivalence, is both the guide for analysis as well as the "stuff" of my analysis.

This appendix is an attempt at an emergent theorization of ambivalence as methodology. What follows is a brief discussion of visual culture as a method to contextualize my use of affect. I will then discuss my methodological deployment of affect, as both a guide as well as an object of analysis. I will finish with a consideration of the notion of crip irresolutions, or, what I consider to be a methodological orientation toward and commitment to open-endedness that encapsulates the productive friction of ambivalence.

Beyond a Critical Visual Methodology

My emergent methodological framework necessarily draws from critical visual methodologies as they have been articulated in cultural studies. In critically interrogating visual artifacts of disabled girlhood, and the affects that they incite, I seek to understand more fully how figurations of disabled girlhood function to create meaning and structure the post-ADA culture that we are all imbricated in. Culture has become a crucial means by which scholars of social sciences and the humanities understand "social processes, social identities, and social change and conflict" (Rose 2007, 1). Stuart Hall (1997) posits:

> Culture, it is argued, is not so much a set of things […] as a process, a set of practices. Primarily, culture is concerned with the production and exchange of meanings—the 'giving and taking of meaning'—between the members of a society or a group. […] Thus culture depends on its participants interpreting meaningfully what is around them, and 'making sense' of the world, in broadly similar ways (2).

Those meanings may be may be "felt as truth or as fantasy," but regardless, these meanings or representations "structure" the way we live (Rose 2007, 2). The cultural construction of social life in contemporary Western societies is centered upon the visual (Rose 2007)[17]. Nicholas Mirzoeff (1998) suggests that, "the postmodern is a visual culture" (4). This suggestion is not to imply that visual images are more and more ubiquitous, but that "we interact more and more with totally constructed visual

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[17] It is important to note that ableism is always evoked but not always discussed when claiming that the West is structured by ocularcentrism. I recognize and acknowledge that visual culture is not the only space where cultural meanings are produced and contested, and I also would like to acknowledge that visual culture is an exclusionary space. As such, this project is interested in how visual culture operates as just one space where representations circulate and where meaning is made, and I acknowledge that it is not the only or most important space wherein these processes occur.

experiences," and thus the "modern connection between seeing and knowing is stretched to breaking point in postmodernity" (Rose 2007, 4).

The primacy of the visual has only further solidified with the rise of convergence culture, or the "collision" between "old and new" media that produces an expansion of participatory possibilities and communicative capabilities. Mark Andrejevic (2011) insists that, "convergence marks the mainstreaming of participatory fan culture, [and] it has the potential to cut both ways: the increasing influence of participatory consumers on the production process and the facilitation of monitoring-based regimes of control" (612). Thus convergence culture marks a growing influence of consumers, audiences, citizens, fans, within the realm of visual culture, as well as an attendant expansion of flexible regimes of control. It can be characterized as a mixed media ecology where "diverse kinds of media producers—including governmental, activist, religious, educational, nonprofit, and semi-commercial content creators—have tapped into the affordances of digital networks" and "influence each other in often unpredictable ways" (Jenkins 2014, 280). As such, the visual continues to operate as an "embodied, material, and often politically charged realm" and the contemporary study of visual culture necessitates innovative and new ways of making sense of how our encounters with the visual, and the representations that populate it, structure the way we live (Rose 2007, 3).

I align myself with feminist and postcolonial scholars of visual culture, and seek to examine how certain social constructions of difference, such as disability, are produced, upheld, and circulate through visual artifacts and how relations of power are imbricated in these processes. As such, this project explores how certain visual artifacts of disability and girlhood "work by producing effects" and, I would add, affects, "every time they are looked at" (Rose 2007, 10). Thus, "taking an image seriously" involves considering how the image works, or what it does, as always in relation to the viewer and the world (Rose 2007, 10). Caroline Van Eck and Edward Winters (2005) suggest that "there is a subjective 'feel' that is ineliminable in our seeing something," and that although it may be impossible to fully articulate this "feel" in words, it should be integral to our attempt at understanding the meaning of images or figurations (4). I recognize that "the senses, memory, body and history are all part of the analytical process," and thus, "one needs all of one's senses to justice to material reality" (Rose 2007, 3).

With all this said, although my approach to analysis draws from discursive methods as they have been deployed in previous studies of visual culture, I seek to go beyond a simple textual, discursive analysis by foregrounding this "feeling" that Van Eck and Winters are gesturing toward.[18] I turn then to affect, as a way to get at this "feeling," as it both informs the technique that I utilize to gather my artifacts, as well as analyze them.

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[18] Discourse analysis is rooted in a post-structuralist paradigm, and its specific interest is in explicating the way in which language and practice both perform as sites for the production of social meanings; however, discourse and discourse analysis have variegated meanings and approaches (Hall 1997). For the purposes of my project, I define discourse as both "an interrelated set of texts, and the practices of their production, dissemination, and reception that brings an object into being," and a "form of social/ideological practice" (Phillips and Hardy 2002, 3; Baxter 2003, 7). Discourses are enacted and embodied through a variety of texts and also extend past the individual texts that constitute them (Phillips and Hardy 2002). Thus these texts can take a variety of forms—written texts, pictures, narratives, symbols, spoken words, etc. Individual texts themselves are not imbued with "meaning" per se, but it is through a representational system, and their linkages with other texts—their intertextual relationship—through which they are made meaningful (Phillips and Hardy 2002; Rose 2007). Discourse analysis is thus concerned with uncovering the ways in which texts are made meaningful through various processes locatable within a contextually and historically specific space and how subjectivities are constituted (and disciplined) by and through these various processes.

The Encounter: Affective

Disability encounters are necessarily affective encounters (Cheyne 2016). Or, in other words, when one encounters disability, both real and representational, there is always a blurring of emotion, sensation, and cognition. While the feelings generated by such encounters may be discrete and recognizable emotions such as fear, pity, disgust, inspiration, and awe, most often, the feelings generated are complex, ephemeral, and in flux. Affect productively encompasses these complexities. Although there are competing definitions, and thus methodological uses, of affect—some scholars arguing for the total separation of affect and emotion—for the purpose of this project, I define affect as feelings that combine the emotional, the physiological, and the somatic. Margaret Price's notion of "bodymind" is useful here, which refers to the imbrication of body and mind. Affects always work through and on the bodymind: feelings are bound up with cognitive processes, and what we know is bound up with what we feel. Quite simply, affects are feelings you feel in your body and your mind. For example, just as I cannot truly separate out the hot flush of my cheeks and the feelings of shame that I felt walking back from taking hearing tests, I cannot separate the knot in my stomach from my feelings of distress while watching Jessica in *How To Dance In Ohio* being scolded by her boss.

My deployment of affect in this project is specifically informed by feminist cultural theorists who have utilized affect to explore how feelings are negotiated in the public sphere and experienced through the body. This approach prioritizes texture, signals a politically engaged approach, and is necessarily messy and resolutely open-ended. My definition of affect, as feelings that combine the somatic, physiological, and the emotions, is intentionally imprecise, which I hope, reflects the slippages and ambiguity between feelings as embodied sensations and feelings as psychic or cognitive experiences (Cvetkovich 2012). Further, this reflects, or attempts to get at, the "texture" or qualitative, embodied experience that has the capacity to exceed social subjectification as through discourse. Theorists of affect "argue that constructivist models leave out the residue or excess that is not socially produced, and this constitutes the very fabric of our being" (Hemmings 2005, 549). Affect offers a new way to conceptualize subject formation, emphasizing "connected and relational modes" over the oppositional binarism of power/resistance. An affective critique emphasizes the "unexpected, the singular, or indeed quirky" over the "generally applicable, which "offers a different world-view than the rather narrow one governed by a repressive/subversive dichotomy" (Hemmings 2005, 550). Sedgwick suggests that affect can challenge what Probyn names "the twinned problematics of discipline or transgression," which "anchor poststructuralist critical inquiry" (e.g. discourse analysis) (Hemmings 2005, 553). Affect affords feminist theorists the opportunity to consider the nuances and complexities of being an intersectional body in the world. As many feminist disability studies scholars have argued, scholars of disability must attend to the embodied, the real, and the fleshy "texture" of disabled people's lives, and a deployment of affect affords me the opportunity to remain committed to this.

Affect signals a political engaged approach to the subject of feeling. My use of the framework of "encounters" in this appendix also gestures toward this. It is imperative to recognize that certain feelings and emotions that are generated or that are at play in a disability encounter could perpetuate oppression or perhaps challenge it and be transformative. Deploying affect takes into the consideration histories, contexts, and politics that produce, are produced, and are intimately tethered to feelings. My use of affect takes into consideration how these feelings and emotions circulate within an affective economy, or how affect circulates and configures certain bodies, how it moves bodies together, and how it pulls them apart. Ahmed (2004) suggests, “Emotions are not something that ‘I’ or ‘we’ have. Rather, it is through emotions, or how we respond to objects and others, that surfaces or boundaries are made: the ‘I’ and the ‘we’ are shaped by, and even take the shape of contact with others” (10). Or in other words, my study is not so much concerned with what affect is, but what affect *does.*

Ultimately, affect speaks directly to why and how we do disability studies. What is at stake here is more than a question of methodology and its attendant considerations (although I have attempted to address these in this appendix). What is at stake here are the very bodies that inhabit this intersection. Attitudes and prejudices are not often formed on any basis of fact or any measure of reality, but rather formed on a feeling. Encounters with disabled folks are not separate from, but are co-constituted by these very representational encounters that form the basis of this project. Studying and working with affect, then, is an urgent political intervention that considers how affective encounters with disability inform, uphold, or potentially transform ableist systems, feelings, hierarchies, and ways-of-being in the world. Affect presupposes transformation (Gould 2009).

Crip Irresolutions

Affect as methodology works alongside and expands feminist disability studies methodologies, which “ask difficult questions but accepts provisional answers,” privileging the "partial, the provisional, the particular" (Garland-Thomson 2011, 40-42). Affect as methodology is necessarily a methodology of questioning that is "resolutely a work in progress, open ended, aiming for but never reaching the horizon" (Kafer 2013, 18). Scholars of disability studies have posited that a critical disability studies is itself a methodology, one that involves the scrutinizing "the social norms that define particular attributes as impairments, as well as the social conditions that concentrate stigmatized attributes in particular populations" (Minich 2016, para. 6). Thus the meaning of a disability studies methodology, "cannot be arrived at, but must continue to be challenged and changed as both the world and the meaning of disability itself change" (Price 2012, 26). Thus, affect as methodology works with the promise of a critical, feminist disability studies methodology: it takes into consideration the malleable nature of disability and the ways in which feelings stick and transform what disability comes to mean.

However, there are limitations to the study and deployment of something that is so ephemeral. As I discussed in the beginning of this appendix, I utilized my feelings of ambivalence as a guide to both collect my objects of analysis as well as a method to analyze said objects. A feeling of ambivalence, or a feeling of going one way or another, is inherently a slippery feeling. Ambivalence is my own interpretation of the affective state that was incited through my encounter with these figurations of the disabled girls, and this "feeling through" methodology is, as I have stated, is imprecise. For different folks, maybe some who have not had personal disability encounters, ambivalence may not be the affective state incited through their encounters with my objects of analysis. This could mean that other scholars could reach different conclusions about the deployment of the figuration of the disabled girl. Although this could be a limitation, it is also a sign of the radical possibilities when deploying affect or ambivalence as methodology. A methodology that is admittedly imprecise may seem untenable, or risky, but affect is imprecise, and it undeniably structures our being-in-the-world. Scholars of social justice must be willing to take these risks, however, because if we are not open to the radical limitations that may befall us when deploying affect as methodology, than we will also forgo the radical opportunities for transformation that affect can afford us.

Specifically, ambivalence, encapsulates this volatile, rich realm of possibility.[19] Ambivalence, I contend, is resolutely crip in that it allows us to acknowledge, desire, and get at the contradictory feelings that figurations of disability incite, and in doing so, it affords us the opportunity to complicate certain representations that may otherwise be written off as unproductive. Dwelling in the cracks and fissures of ambivalence allows us to forge alternative possibilities for disability presents—not just futures.

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[19] Media studies scholar Sarah Benet-Weiser (2012) specifically explores the structuring logic of ambivalence in regard to a discussion of convergence culture—specifically brand culture—and her theorization is helpful in articulating my own use of ambivalence: “To theorize ambivalence as a structuring element of brand cultures means not that all cultural practices are spaces of possibility but rather that some carry more potential than others” (218).