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Compulsory Futures:
Childhood Disability and Growing Up Straight

A dissertation submitted in partial satisfaction of the
requirements for the degree of Doctor of Philosophy
in Gender Studies

by

Amanda Elizabeth Apgar

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ABSTRACT OF THE DISSERTATION

Compulsory Futures:
Childhood Disability and Growing Up Straight

by

Amanda Elizabeth Apgar
Doctor of Philosophy in Gender Studies
University of California, Los Angeles, 2018
Professor Purnima Mankekar, Co-Chair
Professor Helen E Deutsch, Co-Chair

This dissertation analyzes memoirs written by parents of children with disabilities, a subgenre of “special needs” memoirs. Using tools of narrative analysis and feminist interpretive methods, I contextualize my analyses to the social, political, and economic conditions that enable, or limit, recognition of non-normative identities and embodiments. I demonstrate that the figure of the disabled child uniquely articulates how gender, heterosexuality, and typical ability are mutually constituted, and significantly, how the life stages of childhood and adulthood are not only relational, but made intelligible by developmental paradigms that assume heteronormative-ability. In the absence of typical ability, heteronormativity is a narrative device that causes disabled children to “overcome” their disabilities and achieve a “normal” childhood (and future normal adulthood). I organize “special needs” memoirs according to three narrative registers: the ordinary, the extraordinary, and the disruptive. My analyses show how these narrative templates, which intend to be recuperative and to promote inclusion, inscribe disabled children into a normative life course overdetermined by limited narratives of progress, individualism, and autonomy. I demonstrate that the subgenre of parenting memoirs as a whole, as well as the narrative templates that dominate it, align with neoliberalism’s mandates for self-improvement and to make a project of one’s life.

The dissertation of Amanda Elizabeth Apgar is approved.

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For Jane

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Languages

American Sign Language
Hebrew

Introduction: Neoliberal Narratives

That spring I dressed Katherine in her prettiest dresses, smoothed her hair, held it back with butterfly barrettes, and took pictures. I posed her carefully and waited until the grimaces had passed to push the button. … Kat looked stunning. Not one picture showed her with her hand in her mouth or her eyes crossed. Pictures don't lie, I thought, overcome with a surge of hope.

I rushed to a friend who knew about, but had never met, Kat to show them to her.

"She's beautiful," she said, "and she looks completely normal and healthy."

"She does, doesn't she? She's going to be okay. She's really going to be okay," I said, totally believing it for a few hours.

…

I might have been able to kill Katherine gently, quietly in the womb. If there had been a genetic marker indicating the tragic life ahead of her, I could have ended it before it began. She would never have breathed the air, felt the wind, heard the birds. I might have been able to say, "This is a life not worth living"… If I'd never known Katherine, I might have been able to say, "It will be too hard for me, for Paul, for the other children we'll have. She'll slow us down. She'll be in the way. She'll never be able – no matter how hard she tries – to do anything for herself."… I could have looked at pictures of other girls with Rett syndrome with their beanpole legs, wringing hands, and distant looks and said, "No, I'd never want a child like that. She has nothing to give. There is no reason for her life."

But I met Kat. I carried her inside me. I carry her outside me. I wrapped her soft body next to mine and I watched her leave me. I could tell she didn't want to, but she couldn't help it. I saw my life shatter. I tried to penetrate her distant world. I tried to grab her back to me. I *stopped. I watched. I learned her subtle messages. Without knowing, over a period of many years, I realized who the real teacher of my life is: the quiet child who asks nothing of me but love. The one who, by her presence, forced me to look inward, who created the reason for the journey, who by doing nothing gave me the push. …Quietly, she presented me with the ultimate test. Her deafening question rang in my ears year after year. Sometimes I tried to ignore it, to act as if it and she weren't there. But it always was, and she waited patiently for me to respond to it: Did I have it in me to love without dreams – to love simply for the sake of love with no look to the future, no promises given, nothing expected in return?*

The foregoing excerpt is from *Keeping Katherine, A Mother's Journey to Acceptance*, by Susan Zimmerman. Katherine has Rett syndrome, a neurodevelopmental disorder marked by intellectual disability, loss of purposeful hand use, seizures, and mobility limitations. The onset of Rett syndrome occurs after a year or two of typical infant development and affects females almost exclusively ("Rett Syndrome Fact Sheet"). Zimmerman's memoir was first published when Katherine was seventeen years old under the title *Grief Dancers* (SusanZimmermann.com). Her narrative is indeed marked by sorrow, thick descriptions of loss and mourning for the child Katherine was not and the adult she would not become. Katherine is described throughout the memoir as a perpetual child, marked by her innocence, gentleness, and simplicity, and how she does nothing, but, in the words of her mother, "simply is." For Zimmerman, Rett syndrome took Katherine away from the promises on which our ideas of childhood depend; namely, development and an independent future adulthood. At the same time, the devastation of Katherine's disability became for Zimmerman the impetus for self-change. With Katherine silently directing her, Susan Zimmerman became a better person and more capable of loving others.

Keeping Katherine begins and ends with the following phrase: “We are our stories.” Stories, Zimmerman writes, give meaning to our lives, and in sharing them, we realize we are part of something larger and grander than we previously understood (11, 235). My dissertation research begins here. Drawing on memoirs written by parents of disabled children, my project examines narrative constructions of disabled childhoods in relation to dominant cultural, medical, and scientific discourses about disability and childhood. I explore the ways in which notions of normative childhood are mutually constitutive of normative gender and ability; how disability disrupts our notions of childhood; and how parents and caregivers resist, comply with, or otherwise engage with the cultural scripts for normalcy.

There is considerable variance within disability studies literature, disability advocacy, and among disabled individuals themselves over the preferred terms of address for those organized under the rubric of “disability.” “Individuals with impairments” reflects the social model of disability, locating impairment in the body and framing disability as the social conditions that privilege non-impaired bodies (Shakespeare 215). I use the phrase “disabled children” to align myself with a social-relational model of disability. I find this terminology particularly useful in indicating that in addition to issues of physical accessibility, individuals are disabled by their social worlds because of social meanings attached to certain bodies (Shakespeare 215).

In what follows, I argue that special needs memoirs can be categorized according to three primary narrative registers: the ordinary, the extraordinary, and the disruptive. In narratives of ordinariness, parents claim their lives and their children’s lives are relatively normal, despite disability. These narratives challenge the notion that childhood is fundamentally changed by disability and foreground the ways disabled children are similar to able-bodied children. These claims are often substantiated by describing the child’s normative gender and sexuality (or nascent sexuality). In many ways, children in these memoirs “overcome” their disabilities through normal life experiences. Extraordinary narratives frame disability as the catalyst for profoundly positive change in the life of the parents. In these narratives, disability is a part of what makes the child special and endows her or him with certain gifts or super-abilities. These two themes describe the majority of special needs memoirs, and each draw on broadly familiar cultural scripts of gender, ability, and childhood. The third group of memoirs disrupts cultural norms for childhood in divergent ways. In some memoirs, a child’s death, or impending death, causes parents to abandon the normative expectations of childhood that are linked to time and development. In others, non-normative gender or sexuality, or the truly positive embrace of neurodiversity or disabled embodiment challenge the cultural limits placed on childhood, beauty, goodness, and health. Each of these themes is elaborated upon below and the subject of one chapter of this dissertation.

My theoretical objective for this research is to explore the production of normalcy and its relationship to gendered neoliberal subject formation. By normalcy, I refer specifically to prevailing medical and social understandings of childhood, gender, and ability that are culturally and historically contingent, and which regulate bodies and behavior. My dissertation will interrogate the ways in which gender and ability are co-implicated in the construction of “normal” childhood and the attendant locations of abnormality and queerness. I engage with neoliberalism as a political rationality, and as the governing normative reason in the contemporary United States. Neoliberalism refers not only to economic and political policy, but also to the extension of market rationality into extra-economic spheres of life, and the ascendance of entrepreneurialism, self-improvement, and productivity as the dominant modes of conduct for both persons and states. Childhood, disability, and neoliberalism converge around a specific futurity, one that has “improved” upon the present. This conception of a better future is itself contingent on assumptions of progress, which, in turn, build upon specific temporalizing discourses. My argument is that appeals to neoliberal subjectivities and to a “better” future evince the cultural thrust of normalization and the absence of meaningful life outside of market rationality.

Background: gender, childhood, and ability

My research engages with a concept of childhood as temporally distinct from adulthood (Duane 5) and I argue that childhood is made intelligible by gendered ability. The temporal distinction between child and adult life stages operates through discourses of developmentalism and nostalgia. Both developmentalist and nostalgic discourses construct childhood via the axis of ability: children become adults by growing and developing skills and abilities, and by replacing play, dependency, and vulnerability with responsibility, independence, and mastery. What happens, then, when a child does not grow, or does not meet the developmental milestones plotted out for her? Disability upsets these narratives by complicating ideas about how bodies behave and by bringing into relief the false stability of the meanings of growth, development, dependency, and mastery.

In medical and developmental models, childhood references a gender-neutral life stage positioned relationally to adulthood. As “children,” these bodies are not gender-marked: they are babies, children aged birth-to-five, toddlers, schoolchildren, kids, middle-schoolers, teenagers. They are distinguished from each other by age or grade in school, which corresponds fairly neatly with developmental expectations (e.g., kindergarten children are learning their letters but are not expected to demonstrate the fine motor mastery expected of a middle-school aged child). This implied gender neutrality can be seen, for example, in The Center for Disease Control’s (CDC) Developmental Milestone Chart for Children, Birth to Age 4. The chart features six children of various ages placed along a colorful, winding path. At the start of the path, an infant looks ready to crawl. Towards the end of the path a small child stacks a number of brightly painted blocks. In between there are developmental markers indexed to age: during the first 6 months the child “sits without support for a short time”; by twelve months, “says ‘mama’ and ‘dada’”; by four years old “draws squares and circles.” The CDC chart, along with the American Academy of Pediatrics developmental milestones checklist (“Ages and Stages”) are not gender differentiated: expectations are the same for boys and for girls until puberty. Medically speaking, childhood development is disentangled from toy cars and dollhouses and sex is irrelevant to learning to walk, talk, run, or engage in social life (Spock and Needleman, 731; Hathaway et al. 494).

But in practice and in discourse, gender informs the interpretation of ability as well as what counts as normal childhood development and behavior. The following examples from two popular parenting websites illustrate this: “Boys’ gross motor skills (running, jumping, balancing) develop slightly faster, while girls’ fine motor skills (holding a pencil, writing) improve first” (*Child Development 101*). At Parenting.com we learn “As early as three hours of age, girls excel at imitation…. As toddlers, girls zoom ahead of boys on imitative behaviors” (Sethi). For disabled children the influence of sex or gender on development seems to be negligible. Developmental delay is suspected when a child fails to meet developmental milestones beyond the spectrum of what is typical for their sex; this demonstrates the ways in which the categories “boys” and “girls” are based on able-bodiedness and able-mindedness (Kafer 57). While boys are expected to run and jump and girls to talk and imitate, at some point both groups “catch up” with the other and comprise the gender-neutral category, “most children.” Disabled children are displaced. This discursive exclusion demonstrates that the shift from sex-differentiated development to gender-neutral mastery occurs under an already gender-normative rubric of able-bodied development, and as Kafer argues, works to render disabled children genderless in medical and public perceptions (57).

I define gender as relationally positioned and culturally specific notions of masculinity and femininity that preserve the assumption of dimorphic sex. Behaviors, interests, and activities (and just about everything else) are coded “masculine” when they align with expectations for men and boys, and “feminine” when they align with expectations for women and girls.[1] Gender is largely understood as binary and proceeding from biological sex, also understood as binary (male and female) (Lorber 56). This notion of biological determinism posits that one’s genitals (or chromosomes, or hormonal makeup) predicts one’s future disposition, social role, intellectual abilities, and concerns of the heart (Lorber 56). Feminist efforts to differentiate sex from gender have resulted in disrupting the biology-as-destiny paradigm by arguing that gender is something that is culturally constructed, shaped by external influences that act on an otherwise “blank slate.” Simone de Beauvoir was one of the pioneering feminist philosophers to argue that gender is not inborn (301). Judith Lorber’s influential “Night to His Day” argues that gender is an ideology and a process for creating social stratification (60). In their paper, “Doing Gender,” West and Zimmerman write that gender is a social production, an enactment, a way of managing social expectations and asserting one’s identity and one’s identification with a sex category (127). And Barrie Thorne describes the way children learn to “do” gender difference in games, sports, academic competition, and the use of space. Critically, feminists of color have advanced the understanding of gender to account for the ways in which normative masculinity and femininity are also racialized, classed, and heterosexual (e.g. Spillers; Musser; The Combahee River Collective). Kimberlé Crenshaw articulated the need for intersectional

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[1] Many cultures have more than two genders. Berdaches, hijras, and Two-Spirit are all third genders. The discussion in this chapter does not seek to enact another form of erasure of these understandings of gender difference by foregrounding Western-European binary gender divisions. Rather, I engage with dominant Western-European notions of gender difference and gender norms because these are the categories and frameworks by which normalcy is constructed in the United States and thus relevant for analyzing memoirs about life in the U.S.

analysis and activism for gender-linked issues, noting that women of color face obstacles to equality that exceed sex and racial categorization and rather are unique to their statuses at the intersection of multiple identity categories.

In these works, gender is understood as a cultural construction, a means by which to distinguish between bodies and behaviors, and a way to at once conceptualize and deconstruct relationships of power. But, as Judith Butler has pointed out, because gender is often viewed as binary, or even as the two ends of a single spectrum, much feminist work presumes (and perhaps upholds) the stability of binary sex. She explains, “the presumption of a binary gender system implicitly retains the belief in a mimetic relationship of gender to sex whereby gender mirrors sex or is otherwise restricted by it” (*Gender Trouble* 9). Butler writes that sex is itself a discursive construct, culturally conceived as comprised by two discrete and oppositional parts: male and female. But she goes on to argue that sex is made known (that one comes into being as a sexed subject) not through biological sex, but rather through the consolidation of one’s gender. She explains in *Gender Trouble* that gender is “performative,” meaning that gender has “no ontological status apart from the various acts which constitute its reality” (173). Gender, she argues, is an effect of reiterative practices, rather than individual acts, that give the overall impression of being a woman or being a man (*Gender Trouble* 10). Gender relations are “prior” to the person; indeed, we are brought into the social world through the language of gender, or through the naming “he,” “she” (Butler *Bodies* xvii). In other words, one “does” gender less than one is done by gender. Through the enactment of crucially meaningful gendered behaviors, we make ourselves recognizable as (gendered) individuals. Key to Butler’s framing of gender is the way hegemonic discourses, or, in this case specifically, the dominant ways of understanding gender, are constrained by binary rationality. Masculinity is not femininity and the consolidation of these “intelligible” genders sets a boundary around “the imaginable domain of gender” (Butler *Gender Trouble*

13). Likewise, “sex,” the sexed body, is in and of itself an effect of regulatory discourses, materialized on the basis of exclusion of everything it is not (Butler *Bodies* xx). Recognizing gender as an effect of regulatory practices unveils the false stability of “coherent” gender categories, which creates potential for imagining “incoherent” genders (Butler *Gender Trouble* 23).

Butler’s influential work and the works of the feminist scholars noted above (among many others) have generated liberating ways to understand gender in a relational, social context. Yet, arguments for biological gender endure in medical, psychological, and scientific literature, not to mention as cultural common sense. Gender — the enactment of behaviors coded as masculine or feminine — is persistently linked to genetic (chromosomal) sex status; but also, gender is increasingly understood to become biology through learning and doing, behaviors that shape the structure of the brain itself (Eliot 6). Like the critical theories described above, medico-scientific explanations for sex difference rely on an assumption of binary sex. For example, Simon Baron-Cohen, a clinical psychologist and one of the world’s leading autism researchers, argues that the cultural explanations for gender differences described by social scientists and humanists are “too simplistic” (*Essential* 15). Drawing on “decades” of data (*Essential* 15), Baron-Cohen explains that men and women are fundamentally different at the biological level to a statistically significant degree (*Essential* 10). Boys and men have what he calls a “systemizing brain,” which causes them to be interested in how things work (*Essential* 4). Girls and women have an “empathizing brain,” which causes them to be interested in people and relationships (*Essential* 2). According to Baron-Cohen, the differences between male and female brains are due primarily to the influence of prenatal testosterone. Baron-Cohen’s research is supported by studies that show male rats finding their way through mazes faster than female rats (evidence of systemizing ability; *Essential* 96); studies of young male monkeys engaging in rough and tumble play (evidence of reduced empathy; *Essential* 95); and a study that measured the number of times infants in a hospital nursery looked at a smiling face or a more “mechanical” image (*Essential* 55) and which found that infant boys looked less frequently at the face (evidence of interest in solving a puzzle and less interested in a face; *Essential* 56). Baron-Cohen also notes that brain structure and size may have something to do with sex difference. Prenatal testosterone is argued to increase the right hemisphere’s rate of growth, though Baron-Cohen cites no studies on fetal brain hemispheric differences (*Essential* 104). He also suggests that since men’s brains are statically heavier than women’s brains, “having more brain cells may lead to a greater attention to detail, which itself would lead to better systemizing” (*Essential* 112).

Baron-Cohen’s theory reinforces the idea that there are two brain “types” that are opposites, essentially and fundamentally different. But, as Lise Eliot demonstrates in *Pink Brain, Blue Brain*, the small biological differences that emerge during fetal development have little to no bearing on infant cognition, interest, or behavior (3, 5, 6-7). Rather, the types of differences we see between girl and boy children and adult men and women described above by Baron-Cohen are due largely to social influence, which shape young people’s developing brains. Eliot often supports her argument by drawing on studies with two groups: girls with male twin brothers, and girls with congenital adrenal hyperplasia (CAH), genetic females who produce very high levels of androgens (Eliot 36). Both groups of girls are exposed to higher than typical levels of prenatal testosterone and both groups exhibit some “masculinized” anatomical and behavioral traits, including larger teeth in girls with male twins, and an enlarged clitoris and more pronounced interest in rough and tumble play among girls with CAH (Eliot 36). What Eliot points out, however, is that as they grow older, girls with CAH demonstrate no difference in cognitive skills (especially the gender-associated verbal and spatial skills) when compared with girls without CAH; neither do girls with male twins (Eliot 40). Moreover, girls with male twins are slightly more interested in “boys’ games” than girls with female twins, though not nearly as interested in these activities as girls with older brothers (41). These data suggest that while prenatal testosterone has some influence on early childhood behavior and human physiology, significant differences are borne out through the brain-shaping activities of everyday life like communication and play.

Lise Eliot’s work forges a sort of middle ground between the biology-as-destiny paradigm and the competing notion that gender is entirely a product of social influence. She explains that our brains become conditioned according to how we use them because of neural plasticity, stating, “your brain is what you do with it. Every task you spend time on … reinforces active brain circuits at the expense of other inactive ones. Learning and practice rewire the human brain. … So it’s all biology, whether the cause is nature or nurture” (6). Considering Judith Butler’s arguments outlined above, it may seem irrelevant to revisit the nature versus nurture debate. If the body is itself discursive, made meaningful, indeed materialized, only through regulatory discourses (*Bodies* xix), then we can restate Eliot’s arguments in similar terms: what we call a “brain” that has been hardwired according to gendered activities comes into being in that naming; there is no gendered brain apart from the gender that makes those circuit connections meaningful. So, what, then, is the point of rehashing this debate?

My objective is twofold. First, I want to suggest that each position in this debate relies on the assumption of normative ability. To argue that gender is performative, the effect of reiterative and citational practices, or acts, implies a body that does things in predictable and typical ways: a blank slate, so to speak, upon which familiar enactments can be expressed. To argue that gender is linked to biology relies on the same assumptions of embodied behaviors. These include walking a certain way; talking in a particular tone and with a distinct inflection; sitting; moving: using space; thinking; rough and tumble play or playing house;

excelling in language arts or being drawn to science; and as we shall see in a later chapter, being straight and having sex; being reproductive: becoming a mother; becoming a father. If one is to do gender, and if gender is the effect of citational practices and thus engendered by hegemonic modes of representation, one must be *able* to do gender. Moreover, if gender is the effect of biologically-determined dispositions and interests, one must still be able to do gender. This is why Tobin Siebers, and elsewhere Alison Kafer, have argued that there is no gender without ability; "in the absence of ability," Siebers writes, "gender identity has no future and risks to disappear entirely" (Siebers 175; see also Kafer 57). Bodies that do not conform to expectations of normative ability cannot provide the structure for the enactment of normative gender. At best, these bodies emerge as, in Judith Butler's words, "developmental failures" (*Gender Trouble* 24). Butler's choice of words here is significant. As the work of both Eliot and Baron-Cohen shows, gender informs the interpretation of "pathological" childhood development.[2]

Second, I wish to address the importance of recognizing the corporeality of bodies that fall outside the privileged ability assumptions upon which this debate is predicated: bodies not only "materialized through discourse," but bodies that push the limits of hegemonic discourse, that resist the constraints of intelligibility through the enfleshment of incoherence. Butler's discursive body is the one that is materialized predictably and stabilized

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[2] Studies have shown, for example, that girls are under-diagnosed or diagnosed at a much later age than boys for autism spectrum disorder (ASD) because girls with autism are often better able to successfully imitate others and engage in reciprocal exchanges (Hiller, Young, and Weber; Rivet and Matson). Though ASD is characterized by a diversity of symptoms — or as autistic individuals and advocacy groups often like to remind us, "if you've met one person with autism, you've met one person with autism" ("Countdown to the Conference") — atypical social behaviors and communication practices are among the primary diagnostics for ASD, especially high-functioning ASD (DSM5.org; Sipes et al). This does not mean to imply that girls have some sort of autism-for-girls (Rett syndrome notwithstanding, "Rett Syndrome Fact Sheet"), but rather that a condition that is defined by the DSM-5 as a social communication disorder is a condition that is diagnosed in relation to existing ideas about what characterizes typical social behavior and typical communication, both heavily gendered assessments. Thus, autistic girls behaving femininely complicate the existing diagnostic criteria for autism. When Simon Baron Cohen describes autism as the "extreme male brain" he refers to a set of characteristics, interests, and behaviors that he genders as masculine, including an interest in systems (4) and underdeveloped empathizing skills (*Essential* 2) that are exaggerated among people with autism (*Essential* 139, 137). These examples point to the way gender is implicated in assessing able-mindedness.

through the reiterative enactment of gender norms. Because, according to the terms of hegemonic discourse, disabled bodies cannot achieve normative gender status, it follows that disabled bodies are not materialized as "sexed" in the same way. I want to go beyond this body of discourse and the discursive body itself to make the argument that Butler's materialization-as-citationality relies on the assumption of a typical, non-disabled body. The sexed body, discursively constructed, is normative by all counts because it is made intelligible by normative gender. This body is not the spastic body, the seizing body, the stimming[3] body, the body missing limbs or digits, or the body that operates with diminished sensory perception. Butler's discursive body is a body that does not need to give an account for itself, but rather is accounted for through able-bodied gender recognition.

Research questions

By examining narratives like *Keeping Katherine,* I ask how the disabled child figures as a critical site for the production of normalcy. In this dissertation, I ask:

- How are childhood norms gendered? How is the gendering of childhood accomplished through ability? How and when do narrators normalize their children's identities in terms of gender? When is gender queered, neutralized, or resisted?
- In what ways do narratives of childhood disability engage with dominant cultural ideas about the meaning of childhood? Why does disability disrupt the normative narrative of childhood? How is gender implicated in this disruption?
- Do memoirists discursively construct adult identities for their children? Do these identities rely on redemptive and/or rehabilitative future statuses? In what ways is gender encoded in notions of health, rehabilitation, adulthood, and wholeness?

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[3] "Stimming" refers to self-stimulation, a common practice of autistic individuals. Self-stimulation includes flapping hands, rocking, spinning, or other repetitive movements.

- What does an analysis of childhood disability narratives tell us about the pervasiveness of neoliberalism as a governing rationality in the United States? Do narrators describe their children as special, exceptional, or “gifts,” or in some other way ascribe market value to their children? When and how do narratives modify “value” to include the “valuable experience” of raising a child with a disability? In what other ways are children positioned as market actors (e.g., consumers, workers, producers, sellers, or clients)? How are these market actors gendered?
- Finally, do narrators celebrate their children’s gender? How do they frame sex and sexuality? How might claiming gendered and sexual identities for children – around boyhood, girlhood, and normativity – be potentially liberating?

Normalcy, The Neoliberal State

“The thing is,” I said, “... people don’t know how lucky they are to have a teenage son who messes up his room, and puts stupid posters on the wall, and stays out too late, and has a girlfriend, and applies to college.” The tears brimmed and slid out onto my eyelashes. I sniffed.... “I just want him to be normal. That’s all I want. Just normal.” (*Expecting Adam* by Martha Beck, 264-265)

What does it mean to be a normal child? What does it mean to live a normal life?

In the section below, I outline the development of the concept of normalcy, from the emergence of the statistical norm to the disciplinary “normative.” I focus specifically on what constitutes “normal” childhood and adulthood. I then draw a connection between normal development and neoliberal subjectivity by arguing that the “normal” adult subject is the autonomous consumer citizen of the neoliberal social and political order.

Normalcy and its partner abnormality are socially constructed categories that have a clear lineage in Western popular-scientific thought. The isolation and identification of "norms" followed eighteenth and nineteenth century developments in the field of statistics, and especially the work of Adolphe Quetelet (1796-1847) (Davis "Introduction" 2). Quetelet formulated his concept of *le homme moyen,* or, "the average man," an abstract creature who represented the averages of all physical and mental attributes in a given country. Lennard J. Davis points out that the norm implies that "the majority of the population must or should" fall under the statistical umbrella of the *middle,* and by nature of this implication, the norm quickly morphed into the ideal, as the epitome of humankind ("Introduction" 2-3). As Quetelet's concept took hold in statistics and mathematics, developments in biological sciences caused a shift towards using normalcy as a framework to describe the natural world. For example, in the early nineteenth century the identification of the cell as the fundamental unit of life came to shape popular and scientific theories that all living things had a vital and irreducible life force that propelled normal development (Steedman 51, 60).

This influence of normalcy on biological and evolutionary theory had significant social consequences, primarily because developmentalist sciences gained popularity concomitant with the rise of the eugenics movement (see Steedman 53). An important implication of the idea of the norm is that it divides the total population into standard and nonstandard subpopulations. As Claudia Castañeda argues, theories of normal development had a generative effect, in that "normal" development produced pathological development at its margins (26). And because normalcy was (and remains) idealized, stigma became attached to its deviations. Davis explains that once a population has been separated into normal and abnormal, the next step is "for the state to attempt to norm the nonstandard" ("Introduction" 6-7). The goals of eugenics were to improve the overall health and appearance of the population by eliminating so-called "undesirable traits" from the collective gene pool (Davis "Introduction" 3). These so-called undesirable traits included criminality, pauperism, alcoholism, mental illness, tuberculosis, birth defects, and those that fell under the umbrella category “feeblemindedness,” a classification that included cognitively disabled individuals, as well the deaf and blind (Davis “Introduction” 6-7).

By the early twentieth century, the eugenics movement generated a number of institutional practices aimed at eliminating “defectives.” These included the development of “hereditary theories of defect transmission,” the invention of intelligence testing, the codification of prohibitions against marriage and reproduction and the forced sterilization of the “feebleminded,” as well as wide-scale institutionalization of so-called unfit children and adults (Davis “Introduction” 6-7). Eugenicists targeted women and people of color in particular, because they were seen as less intelligent, less capable, and more immoral than white men (Snyder and Mitchell 86, 88). The linking of femininity with defect can be traced to dualist theories of a mind/body distinction that emerged during the Enlightenment. Descartes’ dualism, for example, separated the soul and mind from nature and the body, and accordingly, rationality (as masculinity) was positioned as essentially distinct from animality (as femininity) (O’Brien 38). Seventeenth century empiricism, and later, Darwinian evolutionary theory worked to solidify these distinctions by asserting that humans were absolutely superior to nature (O’Brien 40). In the nineteenth century, humanist metaphysics influenced the development of a bourgeois liberalist ethos that maintained the Enlightenment distinction between the mind and the body and, influenced by theories of the norm, began to associate the body with abnormality, vileness, and shamefulness (O’Brien 36-42). By nature of their embodied “difference” (being not-men), women were located on the same plane as other “too corporeal” subjects; disabled bodies, bodies of color, and female bodies were all too unpredictable, too sexual, and too close to nature (Samuels 11). Women were assumed to be naturally inferior in intellectual and temperamental ability, lacking in mental endurance and of delicate nervous disposition (Baynton 42). Their inherent weaknesses and feeblemindedness were caused in part by the loss of “vital energy” that accompanied menstruation and reproduction, and could easily be exacerbated by formal education, suffrage, or general "overuse of the brain" (Baynton, 43; Trecker 356-357). Douglas Baynton examines the ways in which the concept of normality was used to justify unequal treatment of African Americans, women, and immigrants (39). Black "deviance," the term used to describe running away or seeking to avoid hard labor, was medicalized and argued by eugenicist doctors to be biological (Baynton 38). Xenophobia worked in tandem with the notion that physical and mental fitness could be measured by external appearance; thus, immigration restrictions were levied against Jews and Southern Europeans (in particular), whose "ugliness" evinced their intellectual inferiority (Baynton 47-48). These groups were stigmatized as disabled and categorized alongside criminals, "pathological monstrosities," the "feebleminded," and "idiots" (Baynton 41).

Eugenic rhetoric was thus used to deny enfranchisement and ultimately full citizenship to people of color, immigrants, and women, on the basis of abnormal or arrested development. Theories of normal development also had a significant impact on popular, scientific, and medical understandings of children and childhood. Because shifts in the vitalist life sciences emphasized material progression and the notion that all living things contained their future form, the developmental promise of children became the living evidence of theories of interiority, life force, and maturation, as well as the most important symbol in the rhetoric of advancing humankind. A child's development embodied the evolutionary stages of the genus (from savagery towards civilization) (Steedman 84). With so much at stake, childhood became increasingly medicalized, and as a result, naturalized to the body (James and James 142). The medicalization of childhood — operated through eugenic technologies of surveillance and regulation — led to the institutionalization of child development and child-raising expertise (Ehrenreich and English 201-230). Maturation and progress had been posited as inevitable and natural, but because "normal development" existed on one end of spectrum of developmental outcomes (Castañeda 26), childhood development became a subject of great concern, policy, and practice. Beginning in the early nineteenth century and continuing on until today, policies and programs directed at providing opportunities for children's development indicate the cultural anxiety around ensuring and enforcing normalcy (Castañeda 43). While the specificities of methods and techniques varies among experts in educational and child psychology, both fields share the common understanding of children as "the future" or as the potential link to a higher plateau of evolutionary development (Ehrenreich and English 171). Experts thus sought and continue to seek to define the methods by which to raise a child to become a moral, civilized, and well-adjusted adult worthy of citizenship.

James and James argue that compulsory schooling and the medicalization of childhood work together to regulate normal childhood and shape the social realities of children within the nation state. School, they write, is a system for cultural reproduction (117) that evinces the tension between the child's status as non-citizen and future citizen (119). The medicalization of childhood development naturalizes the state of childhood in the body and works to identify deviance through medical technologies like height and growth charts (142). The medicalization of childhood therefore operates as a technology of surveillance that regulates the health of the nation and attempts to reduce or eliminate health-related threats. Articulated in this way, James and James draw attention to the shift that has occurred between early twentieth century eugenicist attempts to eliminate the genetically unfit from the population to contemporary regulation of the population according to norms.

These processes of surveillance and regulation to the norm evince biopolitical governing. Biopolitics names the governing processes that addresses economic and political effects of the bio-phenomena (the stuff of living) of the subject population, and that seeks to optimize life for the subject population through enforcing norms (Foucault 247). As discussed above, norms are produced through the acquisition of data about the population — in essence, statistical information about biological processes, including birth and death rates, sexuality, old age, hygiene, and accidents, to name a few. These processes and events become the first "objects of knowledge" that biopower targets to control in order to maintain an overall "state of equilibrium" for the population, not the individual (Foucault 246). The regulatory mechanisms of biopower insist on compliance with norms based on the statistics produced about bioprocesses. Statistics are collected and norms are enforced with the aid of complex technologies of surveillance and ubiquitous contact zones between citizens and those in charge. For example, professionals such as doctors, psychiatrists, teachers, and prison wardens, as well as non-state institutions, observe, examine, and judge individuals according to statistically produced norms, and then categorize the individual as compliant or deviant, healthy or sick, normal or abnormal, and instruct them on how to maintain or increase in health.

An example of biopolitical management related to children and development is the Center for Disease Control's (CDC) developmental milestone chart for children, birth to age 4, mentioned above. The chart features six children of various ages placed along a colorful, winding path. At the start of the path, an infant looks ready to crawl. Towards the end of the path a small child stacks a number of brightly painted blocks. In between there are developmental markers indexed to age: during the first 6 months the child "sits without support for a short time"; by twelve months, "says 'mama' and 'dada'"; by four years old "draws squares and circles." These charts are found in pediatricians' offices throughout the United States, often accompanied by height and weight charts and vaccine schedules. These charts allow pediatricians and parents to make determinations about an individual child's development relative to the population. The ubiquity of the CDC guidelines makes standards for development and behavior seem a lot like common sense, at the same time they make deviations easy to identify. This is how they function to regulate the population and explains how something that is a “norm” — i.e., a characteristic of the population — becomes “normative,” in that these norms denote what ought to be. In the absence of eugenic techniques like institutionalization or “mercy killings” of genetic “defectives,” normative developmental models determine which bodies and behaviors are considered normal, and by extension, good, preferred, and valuable.

Embedded in these evolving theories of development and practices to ensure normalcy is the abiding logic that children are distinguishable from the adults they will become. The notion that children are essentially different from adults seems unquestionable; how that difference has been understood, however, is socially and historically specific, and subject to change over time. In one of the earliest works on childhood, for example, Phillipe Ariès argues that the concept of childhood as we know it in the West did not exist prior to the seventeenth century, but came into social consciousness at specific historical junctures that evince changes in religious thought, governance, and political economy. According to Ariès and scholars of childhood studies, childhood is socially constructed — a particular way of imagining a life stage that reflects and relates to a broader context. In the contemporary moment, one of our primary modes for imagining childhood in the United States is through a narrative of becoming, or the “teleological model” (Castañeda 4) This model of childhood positions the figure of the child as an adult-in-the-making and childhood as a point of origin for the future adult. The teleological model of childhood is sustained by cultural and medico-scientific discourses of development, discourses that depend on a shift from a state of dependency to one of autonomy and independence. For example, the differences between children and adults are articulated in terms of physical difference, like size and motor control, and a developing ability to think rationally. Children are also distinguished from adults by interests, activities, and social roles that are considered immature (in both the sense of being underdeveloped and having a youthful or childish appeal). The most defining feature of childhood is that it is marked by a level of dependency on others that is assumed to be absent, or overcome, in adulthood. At birth, infants are completely dependent on a caregiver. With growth and the mastery of physical, intellectual, and social skills, independence increases, until the fully autonomous adult emerges from childhood. Indeed, adulthood is predicated on this state of independence (Duane 2); this implies, in turn, that childhood is made intelligible by a feature that is temporary, one that will be lost. As such, both childhood and adulthood are separated into distinct life-stages primarily differentiated along axes of ability and mastery of skills. The teleological model of childhood thus presumes and regulates able-bodied and typical childhood development and non-disabled adulthood. As such, it reflects culturally pervasive ableism, produced by cultural and scientific narrative constructions of normalcy and typicality.

This figure of the dependent child, constructed as “passive, victimized, silent, and sheltered,” has become the “placeholder for what full citizen subjects need to define themselves against" in the contemporary U.S. (Duane 5). Martha Fineman writes in *The Autonomy Myth* that self-government, or autonomy, is the ideal that “defines the individual subject” in American society (18). Autonomy is demonstrated by independence — self-determination or self-reliance — and results in financial and material self-sufficiency (9). It is enshrined in the Constitution and the Bill of Rights, which “develop the concept that individual rights define the relationship between the government and citizen” (18). It is a central founding and sustaining myth of American-ness, a quality considered inherent to securing our inalienable rights to life, liberty, and the pursuit of happiness. Fineman goes on to explain that in the contemporary moment, individual autonomy is closely linked with economic status. Self-sufficiency, or being able to satisfy one’s basic needs without the help of others, requires the financial means to do so. Economic self-sufficiency and independence “buys” an individual “the right to self-governance and ‘control’ over will and action” (Fineman 22). In this sense, economic status allows the individual to further secure their freedom to self-determination. Our idealization of autonomy and self-sufficiency stigmatizes dependency and accepting help from others or the state. This denigration of dependency is prevalent throughout American society, despite the reality that dependency is a part of all human life; all infants are dependent, and all of us become temporarily or permanently dependent due to accidents, illness, or old age. As Fineman points out, however, these states of dependency are broadly considered private matters, “hidden within the family” (54), which sustains the myth of autonomy in the public sphere. Dependency and the reliance on help or subsidies are seen as un-American and as a threat to other national ideals, including freedom and equality. Our cultural beliefs about the inherent equality of all members of American society includes the notion that each individual has the same opportunities and capacity to achieve self-sufficiency (Fineman 34).

In this way, dependency, like autonomy, is an issue of choice; it is the result of poor choices and the failure to actively realize one’s potential. While Fineman rightly points out that the idealization of autonomy and individuality is enshrined in our Constitution and central to American founding mythology, this rhetoric of choice has particular salience (and, as I shall argue, disciplinary power) in the contemporary moment. I want to articulate here a shift from the notion of “inalienable rights to freedom” to the individual’s responsibility for self-management and securing autonomy. This latter framework positions all citizens as individually responsible for their own well-being and the reduction of risk. It maintains that those in a “cycle of dependency” are there because of their poor choices while those who have secured economic wealth and self-sufficiency have merited that status through hard work and being a smart consumer. Moreover, a state of dependency constrains one’s choices, while autonomy infers greater personal and economic freedoms. Indeed, “freedom,” in the contemporary moment, refers to the freedom to make individual choices.

The prevalence of the choice framework for conceptualizing autonomy and freedom evinces the effects of biopolitical governance manifested alongside neoliberal social and economic policies in the U.S. since the late 1970s. As a theory, neoliberalism “holds that the social good will be maximized by maximizing the reach and frequency of market transactions” (Harvey 3). As economic policy, neoliberalism is characterized by a deregulated global economy, free trade, monetary policies that favor businesses, strong private property rights, and a free market (Harvey 2). Technically, neoliberalism refers to a rejection of state interventionist policies and the embedded liberalism of the post-war period (Harvey 20-21). The state’s role in neoliberal economics is to ensure the free market and entrepreneurial freedoms (Harvey 21). As Wendy Brown, David Harvey, and others have argued, however, neoliberalism has “disseminated market values to all institutions and social actions” (Brown “Neo-Liberalism” n.pag), and has emerged as “an ethic in itself, capable of acting as a guide to all human action” (Harvey 3). In other words, neoliberal rationality has exceeded political and economic spheres to code all behavior in terms of the market: investment, profitability, utility. At the same time, citizens figure primarily as consumers, and understand freedom as the “liberty of consumer choice” (Harvey 41). Above all, neoliberal subjects are constructed as rational beings that strategize to further their own self-interests and are responsible for — or free from government “intrusion” into — their self-management. As Brown explains, under neoliberalism the individual citizen “bears full responsibility for the consequences of his or her action no matter how severe the constraints on this action, e.g., lack of skills, education, and childcare in a period of high unemployment and limited welfare benefits” (“Neo-liberalism” n.pag).

In this dissertation, I engage with neoliberalism as a political rationality, and as the governing normative reason in the contemporary United States. Brown argues that neoliberalism involves a normative claim about the pervasiveness of economic rationality and "advocates the institution building, policies, and discourse development to appropriate such a claim" ("Neo-Liberalism" n.pag). Neoliberal ways of thinking have permeated all areas of life to become the primary framework by which we make our experiences meaningful and comprehensible. It has become "common sense." Common sense "is a form of 'everyday thinking,' which offers us frameworks of meaning with which to make sense of the world" (Hall and O'Shea 8). Drawing on Gramsci's definition, Hall and O'Shea explain that common sense is "popular philosophy" shared by everyone, and which feels natural, but is shaped by history and sustained by the broad circulation of limited discourses. Neoliberalism, as common sense, is based on the idea that we are all equal as market actors, and by reducing all relationships to that of commodity exchange, we are promised greater freedoms through personal choice (Hall and O'Shea 11). In the contemporary moment, neoliberal ways of thinking sustain the notion that independence and autonomy — the capacity to make personal choices — are considered essential qualities of a citizen. As the hegemonic mode of reason in the U.S., and as the lens by which we determine who is and is not behaving as a citizen should, neoliberal rationality has shaped the contemporary "normal," and has defined the terms of citizenship along the developmental axis. The normal life path in the neoliberal moment is the one that shifts not from dependent to independent, but from dependent to autonomous market actor: consumer, worker, producer, seller, or client.

Importantly, neoliberalism and normativity converge around a specific futurity, one that has "improved" upon the present. In its early Twentieth-Century iteration, normalcy was regulated by eugenic medical and scientific ideology, which hinged on the goal of human "betterment" and a utopian future in which disease and disability were absent. This conception of a better future is itself contingent on assumptions of progress, which, in turn, build upon specific temporalizing discourses, including the idea that children contain their future selves and thus embody the link to a higher plateau of evolutionary development (Ehrenreich and English 171). In its contemporary iteration, the imperative to improve upon the present is refracted through neoliberal injunctions for individualism, self-management, self-care, and self-improvement, which are “rationalized as an investment in the self towards a more normal, if not better, future” (Sharon Lee 26). In these terms, there is “no future” (Kafer 28) for bodies that are irreconcilable to narratives of progress. Bodies that are sick, disabled, or deformed, bodies that we assume cannot fit into the economy, individuals that fail to achieve independence and autonomy are marginalized by existing cultural representations and scripts. To reimagine disability outside these limiting representations requires reimagining the future itself.

Methods: Creating and sustaining “common sense” through narratives

We live in a world where a baby like Henry demands a story (Rachel Adams, *Raising Henry*, 108).

Cultural narratives, like those of disability, gender, sexuality, and life stages, circulate in texts, films, media, and discourse. Lauren Berlant’s work in *The Female Complaint* shows us how individual narratives appeal to a broad audience because the reading or consuming public “already share [with the narrator] a worldview and emotional knowledge that they have derived from a broadly common historical experience” (viii). In other words, widely circulated narratives enjoy broad reception because they appeal to a sort of common sense and continuity between individual experiences that ties readers and narrators together in the social world.

This dissertation is a narrative analysis of memoirs written by parents of children with disabilities in which I argue that the "common sense" to which narrators appeal is neoliberal rationality and the conventional expectation that disability is a tragic and unwanted condition of being. As "narrative analysis," this project at once does literary criticism and cultural theory. It is not a narratological study per se, though I do depend on the distinctions between story and discourse articulated by narratologists Prince, Bal, and Suleiman; but where Prince and Bal lift narratives out of context in order to "distill" their structures (Warhol *Gendered Interventions* 4), this project draws on Suleiman's and Warhol's work that interprets narrative in context. Suleiman identifies context as an element of story (what happens in the narrative) and Warhol analyses context in narrative discourse (how the narrative is told) (*Gendered Interventions* 4-5, see also Abbott 16-19). I analyze both story and discourse and use a feminist-critical disabilities studies interpretative method to do so. Warhol writes that feminist interpretative methods use a gender-centered method to view the elements of narrative (story and discourse) and to demonstrate the ways in which the relationship between masculinity and femininity provide an analytical framework for examining other relationships of power (in Herman, et al. 9-13). Ally Day demonstrates that feminist interpretive methods can be applied to disability literature when we refuse to essentialize the disabled experience (as we might refuse to essentialize the experience of "women") or reduce the disabled person's life and experience to a single quality of disability (n.pag). My feminist-critical disabilities studies interpretation foregrounds the ways in which normative gender and ability are mutually constructed and uses a gender/ability-centered method to examine narrative elements.

Typically called "special needs memoirs," the texts I examine are a subgenre of memoir (which may itself be a subgenre of autobiography or biography (Couser *Memoir* 18) that take the lived experience of disability as their primary point of focus and narrative anchor. Many disabled people and activists take issue with the phrase "special needs" because it reinforces the idea that disabled people should be, or are somehow inherently, set apart from typically developing or neurotypical peers (Linton 15). Despite these sentiments, "special needs" remains a popular euphemism for describing disability, and childhood disability in particular. I have identified thirty-six "special needs" memoirs penned by parents of disabled children. This is not an exhaustive list (though it quite nearly exhausts the subgenre), and these thirty-six texts were chosen with specific criteria in mind. Because my project seeks to explore the way parents engage with dominant cultural stories, I chose publications that have enjoyed some popularity, which I largely determined according to Amazon sales rankings.[4] The data on any particular title's popularity is difficult to find. Nielsen BookScan ratings provides the most comprehensive data to the publishing industry, but still captures between only 60-75% of sales (personal email). Moreover, the data is not publicly available. A book's popularity can also be measured by examining bestsellers lists published by *Publisher's Weekly* and *The New York Times*. Since very few parent memoirs made bestsellers lists, this was not a viable option for this research. On Amazon.com, books are ranked by sales within specific browse categories automatically assigned through the publisher and/or manually selected by the author. "Special Needs" names one of four "Specific Groups" categorized under "Biography and Memoir" in Amazon's book department. (The others are "Crime and Criminals," "LGBT," and "Women.") Under the browse category "Special Needs," titles are organized by sales rankings and other data (including "New Releases" and "Top Rated). I limited my archive to memoirs written by parents about raising their children (thus excluding parent and child co-authored books and books written by siblings or other family members). I followed Amazon's recommendations ("Frequently bought together" and "Customers who bought this item also bought") to find

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[4] My method for selecting data was inspired by Karin A. Martin's research on parenting advice books.

other memoirs. I also visited webpages that offered resources to parents of newly-diagnosed disabled children and browsed their recommended reads. I compared these titles with lists on Goodreads.com and their popularity on Amazon. In the end, the thirty-six memoirs I read comprised almost the entirety of special needs parenting memoirs available for sale—and being purchased—in 2016-2017.

With the exception of one memoir about raising a child in Canada, these stories are based in the United States. The collection features a variety of atypical bodily and neurological statuses. Ten memoirs are about children with Down's syndrome; seven are about children with autism; three memoirs are children with multiple disabilities; and three are about children with cerebral palsy. The other disabilities represented include Rubenstein-Taybi syndrome, schizophrenia, Radical Attachment Disorder (RAD), Tay-sachs, Rett's syndrome, Pervasive Developmental Disorder (PDD), optic nerve hypoplasia, Albinism, bilateral perisylvian polymicrogyria (a rare neurological condition), and cardiofaciocutaneous syndrome (a rare genetic condition). Among the parent-authors five are academics. Several parent-authors have written novels or other non-fiction works prior to penning their memoir; and one author is a memoirist, who published a personal memoir several years before writing about raising a child with Tay-sachs.

I chose texts that were published between 1950 and 2016 with the vast majority (twenty-nine) published since 2000, and more than half (twenty-two) published since 2010. I did not intentionally limit my sources to memoirs published recently; rather, the number of memoirs that were published prior to 2000 is very small (Couser *Memoir* 3-4). The range of publication years, limited as it may be, is nonetheless highly useful for contextualizing my analysis in terms of the rise of neoliberal political rationality since the early 1980s. Not including those in the anthologies, all but three of the child-subjects of these sources were born after 1980. I have included on memoir of raising a child born in the 70s, and one about a child born in 1953, both because these are early examples in the genre and because they might provide perspective on how narratives of childhood and disability have been inflected by neoliberal rationality since the 1980s. It is important to note that of the memoirs that meet the criteria for this analysis, very few (three) are about a raising a child of color. Indeed, of special needs memoirs more broadly, the published narratives are almost entirely about the experiences of white families and white people; moreover, parents who write special needs memoirs are almost entirely middle- or upper-class and highly educated. The reasons for the homogeneity of the genre may be due to structural oppressions like publishing bias. These speculations aside, that white children dominate special needs memoirs has important implications for broad cultural understandings of childhood disability. Because these narratives are in large parts attempts to recuperate a disabled child's access to a meaningful and valued place in the social world, it is imperative to interrogate the ways the published narratives re-enforce limits around just exactly which disabled childhoods can be reimagined as good and valuable. This is explored in greater depth in the conclusion of this dissertation.

I have chosen to study memoirs for several reasons. First, memoirs have broad cultural appeal in the contemporary moment. As Thomas Couser has noted, in the last twenty years memoir has exceeded fiction in popularity; between 2004 and 2008, for example, publications of memoirs increased over four hundred percent (*Memoir* 3-4). On illness and disability narratives more specifically, Couser notes that illness or "anomalous somatic conditions" feature alongside childhood trauma as the top three themes that characterize the recent boom in life-writing (*Signifying* 2). Ann Jurecic cites Virginia Woolf who explained that before the 20th century the commonness of illness prevented it from being a theme in literature, unlike love, battle, and jealousy, which were considered special experiences (5). However, the emergence of HIV/AIDS narratives in the 1980s reflected the need people had to tell their stories "in an era when religious and folk explanations no longer [gave] a satisfying and complete meaning to their experiences, and when biomedicine largely exclude[d] the personal story" (Jurecic 9).

Second, like autobiography and other forms of life writing, memoirs make certain truth claims about the world (Couser *Memoir* 13-14). When we speak of autobiographical truths, we do not necessarily mean verifiable facts; rather, the truths claimed by autobiography and memoir reside in the intersubjective exchange between narrator and reader that produces a shared understanding of life (Smith and Watson 16). This relates to my third point, which is that typical forms of memoir enlist readers into a reciprocal relationship with the text. Because of memoir's obligation to the truth, or "real world," these kinds of narratives draw readers into a specific stance in relation to the processes and events that unfold in the narrative (Couser *Memoir* 14). Life writings are thus discursive formations of truth telling that are sustained by multiple cultural registers of intersubjective recognition and differentiation.

Fourth, Couser argues that the primary work of memoir is to make identity claims and to discursively "create the self," typically in relation to a significant event in the narrator's life (*Memoir* 13-14). Indeed, the narrative arc of memoirs (and perhaps particularly of illness and disability narratives) seems to thematize the distinction between the narrator's earlier and present selves (Frank "Rhetoric" 43-44; Couser *Memoir* 38). Narrators identify themselves to readers through personal stories that are located within broadly recognizable cultural identities (the "self-made man" or the "bad girl," for example) and narrative templates (Frank *Letting Stories Breathe* 14). This discursive construction of the self—or the autobiographical subject—is thus deeply implicated in regimes of knowledge that regulate which identities are recognizable. Moreover, identities constructed by memoirs are validated by the experiential evidence the memoir presents; in other words, our identities do not exist before experience. As Smith and Watson explain, "experience is the process through which a person becomes a certain kind of subject owning certain identities in the social realm, identities constituted through material, cultural, economic, and psychic relations" (27). Experience is itself therefore discursive, embedded in the languages of everyday life and the knowledge produced at everyday sites (32). Drawing on Foucault's concept of discursive regimes, Smith and Watson explain how domains of discourse (like medical discourse) are cultural registers for what counts as experience and who counts as an experiencing subject (32). These discourses are historically specific. Smith and Watson go on to write that while experience is discursive, there are human experiences outside discursive frames: bodily feelings, spirituality, sensory memories, events, and images, the material experiences of hunger, hurt, and desire, and the material universe that affects us; but, we make meaning of these events "discursively, in language and as narrative" (32). Autobiography can thus be imagined as one technology by which subjectivity is constituted according to discursive regimes of knowledge.

This dissertation explores the ways in which parents of children with disabilities make truth claims about their lives and construct recognizable identities according to culturally available narratives. Why these memoirs get written is another question. One way of approaching narratives is to think of stories as ways people make sense of their worlds (Mitchell and Snyder 1). Echoing Rachel Adams, who writes, "a baby like Henry demands a story" (108), Couser explains that marked bodies demand a response to the question, "What happened to you?" (*Signifying* 16). Stories emerge from the unexpected, when something out of the ordinary has happened and which compels evaluation and resolution (Frank, *Letting* 26). Frank writes that illness narratives are a kind of experiential narrative that invokes change, referring both to the cultural understanding of illness as a moment of change and to self-change as a culturally valued project ("Rhetoric" 39). He also suggests, citing Michel

Foucault, that we might read illness narratives as a "technology of the self," another iteration of the socio-political mandate for self-regulation and the policing of change ("Rhetoric" 49).

Because narrative resources are culturally and historically limited, and because the production of truth and autobiographical selfhood is intersubjective, the stories parents tell about their children must reference familiar narratives in order to make any recognizable sense out of their experiences. An analysis of parent memoirs of raising disabled children pushes the analytical frameworks described above in a number of new directions. First, the narrative templates to which these memoirs appeal are significantly intertwined. Narratives of both disability and childhood rely on interrelated social and medical discourses about normative development, mastery, and autonomy. Relatedly, disability is often infantilized in discursive and visual manifestations (Thomson "Seeing" 340-341), while the category of childhood is often differentiated from adulthood along the axis of ability. Second, parent-authors of memoirs often engage in not only the construction of their own identities as parents of disabled children, but they also construct identities for their children. My project engages questions of agency and self-representation in tension with the power differentials of parent/child and able/disabled dyads. Third, given that disability is culturally positioned antithetically to the neoliberal citizen subjecthood, narratives of childhood disability engage in complex discursive maneuvers that both resist normalization and can be regulated to existing paradigms, particularly of gendered and neoliberal subjectivity.

Bearing in mind the efforts of disability scholars and activists to de-medicalize disability by disassociating it with illness, Ann Jurecic's *Illness as Narrative* is exceptionally useful in outlining the unique challenges to literary criticism presented by stories of "life's fragility," including narratives of disability. Jurecic argues that, on the one hand, the hermeneutics of suspicion (the preferred critical framework of poststructuralism) insists that illness narratives have been constructed by medical, social, and other discourses (3). For example, some critics have argued, “life writing [including autobiography and memoir] is a product of ideology, and to trust a narrative to “to provide access to the experience of another person is a naïve understanding of how texts function” (3). On the other hand, anthropologists and psychologists have found that the act of writing helps people organize and make sense of their lives and selves. In the case of illness and disability narratives, life writing can also be useful for medical humanities by providing students and practitioners with opportunities to expand their empathic imaginations (11). But Jurecic states that between these two models - didactic humanism that sees narrative as redemptive, or radically suspicious disembodied criticism – literary criticism cannot productively engage (14). Neither reading practice is useful on its own: the “paranoid reading” invalidates everyday attitudes and experiences of narrators by arguing that they are just a bunch of dupes; while the “humanist reading” takes the everyday experiences described in the narrative as self-explanatory and refuses to interrogate claims of value and selfhood (113). Jurecic argues that literary criticism cannot always be about “dismantling illusions” and needs to have interpretive approaches that “enable [critics] to assemble meaning in the face of life’s fragility” (4).

Drawing on Eve Kosofsky Sedgwick’s notion of reparative reading, Jurecic forwards a reading practice that privileges a place of not knowing and a refusal to master the material. Reparative reading allows oneself to be surprised by the text, rather than suspicious and ready to attack, as one would proceed by paranoid reading. Reparative reading leads us to the place where we cannot figure everything out (Jurecic 130), and where one recognizes that both the narrator and the reader are constrained by the discursive regimes of knowledge and power at play. This recognition is as much about knowing as it is about the “limits of knowing and knowability and about how self-perception is mediated by the other” (Felski 49 cited in Jurecic 124). It is reading empathically, as a practice.

Chapter outlines

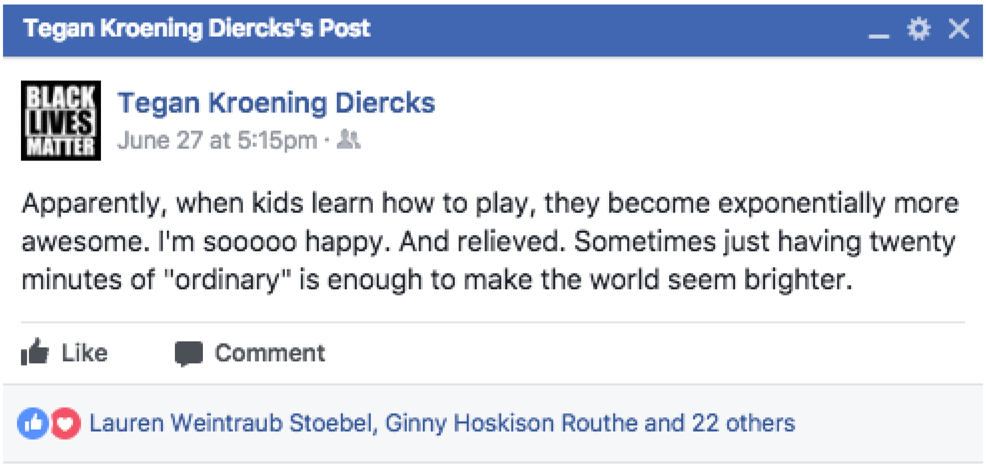
In my first chapter, "'As Ordinary As Possible': Gender, Disability, and the Normal Life," I demonstrate how parent memoirists attempt to mitigate the exclusions to dominant childhood narratives engendered by disability by claiming their children's lives and experiences are fairly ordinary. In this chapter I argue that gender, often understood by critical theorists to be inherently limiting, can and does give parents a means by which to challenge exclusion and claim access to childhood narratives for their disabled children. This argument seeks to challenge anti-normativity sentiment sometimes found in queer, gender, and crip theory and the compartmentalizing of liberating positionalities and potentialities. At the same time, I engage the tension between the liberating potential of gender normativity that comes at the cost of perpetuating ableist expectations for normalcy. My central argument in this chapter is that gender norms figure prominently in constructing narratives of a normal childhood. This happens when gender is engaged explicitly through, for example, a focus on a child's interests and behaviors; it also occurs when parents express expectations for their child's future in terms of sexuality and employment. But gender also informs the construction of ordinary childhood experience when it is only implicitly assumed, for example, when narratives prohibit the possibility of sexual or gender queerness. By relying on gender normativity and an ordinary life, parents construct open futures for their children, retaining the possibility that they will grow to become increasingly more independent, if not necessarily autonomous.

Dominant ways of knowing disability include the assumption that disabled people never achieve independence or become productive (or reproductive) citizens. Chapter two, "Teacher, Gift, Guru: (Re)Valuing Disabled Childhoods," demonstrates the ways parents negotiate positions for their children in alternate economies, including moral, gift, and spiritual economies. These narratives challenge the commonsense notion that disability is unwanted and tragic, and speak back to the continued discursive and material investment in the elimination of disability. In these memoirs, disabled children "give back" to their parents and communities. Parents explain how disabled children show them how to become better people by teaching them about their capacity to love, or to find beauty and value in what they once thought was ugly or lacking, or by bringing them closer to spiritual and moral truths. I argue in this chapter that narrating the disabled child in this way allows parents and children to figure within a neoliberal schematic for self-improvement.

"Hetero/Able Futures and Crip/Queer Discontinuities," my third chapter, engages with parent memoirs that demonstrate the potential for destabilizing childhood narratives and temporalities through appeals to gender fluidity, queerness, and a critical perspective of disability that refuses to see disability as a tragedy or only tolerable to the degree that it can be rehabilitated. This chapter draws from crip and queer theory engagements with temporality and complicates the relationships between gender, sexuality, ability, and time. I argue that in the contemporary U.S., the temporal logics that govern dominant ideas about childhood are distinctly able-bodied and heteronormative. This chapter features the memoirs that upset these discursive regimes. I highlight stories of resistance to medicalization, narratives that question gender and market roles and the value system in which parents find themselves negotiating a place for themselves and their child, and narratives that reject the future, or due to illness and death, cannot imagine themselves or their children within it. By disentangling the narratives of gender, sexuality, and ability, new possibilities emerge for imagining children and adults atypically positioned within these categories.

My conclusion addresses the cultural climate that grants privileged recognition and inclusion to limited identities, embodiments, and ways of being. I focus on four specific structural obstacles: publishing bias, the whiteness of "childhood," rapid developments in genetic testing and prenatal diagnosis, and the criminalization of Black disabled bodies. I argue that these obstacles intersect to exclude children of color from becoming the subjects of popular special needs memoirs. I argue further that the recuperative aim of special needs memoirs reflects a racist logic that it is white disabled children alone who deserve to be reconsidered as fully human. The whiteness of the special needs genre, I suggest, evinces not merely a racist readership, but rather a cultural climate that sees Black bodies and bodies of color as not fully human to begin with, and hence unable to be reimagined in the narratives for disability and the life course.

Chapter 1: “As ordinary as possible”: Gender, Disability, and an Ordinary Life



Tegan Kroening Diercks
June 27 at 5:15pm ·

Apparently, when kids learn how to play, they become exponentially more awesome. I'm sooooo happy. And relieved. Sometimes just having twenty minutes of "ordinary" is enough to make the world seem brighter.

Lauren Weintraub Stoebel, Ginny Hoskison Routhe and 22 others

Image: Facebook post. Used with permission.

Growing up autistic

Ezra Fields-Meyer was born in the mid-1990s in Los Angeles. When he was three years old, he was diagnosed with autism. Ezra is the middle child of three brothers (1). His family is Jewish and his mother is a rabbi. His father, Tom, is a writer and the author of *Following Ezra; What One Father Learned About Gumby, Otters, Autism, and Love from His Extraordinary Son*. Through the memoir, readers learn that Ezra loves dogs and Disney movies, that he has an excellent memory for facts and figures, and that he has trouble controlling his impulses. Like children with autism in other memoirs, Fields-Meyer sees Ezra’s abilities and autistic traits as intertwined (ex. 142; cf. Collins 161); but unlike other parents, Fields-Meyer does not attempt to make his son more like his neurotypical peers, to try and unlock that “inner,” ostensibly “more normal” Ezra (125). Fields-Meyer’s memoir is titled *Following Ezra*, because he accepts his son Ezra as he is, and because he abandons his expectations for what Ezra “should” be and instead follows Ezra’s lead (3; 22; 111).

The memoir spans Ezra’s life from age three to thirteen. The narrative, however, is not exactly linear. It is instead organized thematically according to Ezra’s interests and his development, which are loosely chronicled to his age. Moving forwards and backwards over the years, Ezra's childhood blurs together, punctuated by small movements in time correlated to interests: now animals, now Homer Simpson, now Thomas the Train, now *Star Wars*. Written in this way, Fields-Meyer bookends Ezra's entire childhood by two significant events: Ezra's autism diagnosis (43) and his bar mitzvah (226). In Jewish tradition, a bar mitzvah marks a boy's passage from childhood into adulthood.[5] Typically, the child reads a passage from the Torah (the first five books of the Jewish scriptures), and then delivers a speech on the passage. In Ezra's speech, he deviates from traditional expectations and discusses the relationship between Judaism and his own experience with autism: "Sometimes I think all Jewish people are autistic," he states. "Jews repeat things all the time. And Jews have a very good memory. We repeat Shabbat every week. …And we also have holidays that help us remember things that happened thousands of years ago. …That's part of being Jewish" (232).

Following Ezra's bar mitzvah, his father Tom reflects on how much Ezra has changed, how much he has overcome in the ten years since his diagnosis. At three, Ezra fled his own birthday party, hid alone in his room, indifferent to the celebration, overwhelmed by the noise and number of children and adults there to engage him (20-21). At thirteen, Ezra is "present in full force," in a way his father "never imagined" (229). Over the months preceding the bar mitzvah, Ezra's father Tom questioned the relevance of the ritual for a child who was still in many ways like a toddler (212). Ezra surprises his father, successfully performing the rite of passage and, in a grand gesture, claiming his place in the community. Ezra's autism becomes neutralized through Ezra's performance of his Jewish identity, an identity that, importantly, is made intelligible through gender and developmental achievement.

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[5] Girls participate in a different ritual called a bat mitzvah.

Growing up straight

In stark contrast to Fields-Meyer's commitment to "follow" Ezra's lead, Paul Daugherty's guiding principle for raising his daughter, Jillian, is "expect, don't accept" (52; 265; 354). Daugherty writes in his memoir of raising Jillian, *An Uncomplicated Life; A Father's Memoir of His Exceptional Daughter*, that he and his wife, Kerry, expected Jillian to "overcome" (239) Down syndrome and achieve an ordinary life, to belong, to have "a seat at the table" (245). And while Daugherty's orientations toward Jillian's disability vacillate—she is special (6) and miraculous (22), enabled by her disability (311), yet also "simply a child" (83) and imprisoned by Down syndrome (169)—his understanding of an "ordinary" life is remarkably consistent and conforms predictably to heteronormative gender expectations. Ordinary, for Daugherty, means, quite unambiguously, heterosexual. On the day Jillian was born, for example, Daugherty mused about future kisses under a porch light with a young man who made her happy (182), and of walking her down a church aisle one day (11). He thought of future dances, dresses, lipstick, and womanhood (11; 188). Then, Jillian was diagnosed with Down syndrome, and Daugherty no longer believed these things would happen for his daughter. He grieved and writes, "I had hurt for my baby girl and what I believed would be a half-full existence. A life without Homecomings and proms—and the promise of both—is no life at all" (188). He grieved for "the loss of the perfect" (315): the dress, the senior prom, the wedding, and moonlit orchids on the porch (315-316) with a man and his cologne (182). Daugherty writes that experiencing the mysteries of love and attraction was "his greatest hope" for Jillian (182).

To Daugherty's enormous relief, Jillian met a young man named Ryan, and they fell in love (234). Ryan, who also has Down syndrome, took Jillian to her first dance (188). He became her boyfriend (225-6), and later the two moved out of their parents' homes and into an apartment together (326). Nothing, he writes, compared with Jillian's first kiss underneath the porch light (245). It was "life-ecstasy" (245), though it's unclear exactly to whose life he refers. It is clear, however, that Ryan, and the access to gender-normative heterosexuality he makes available for Jillian, allows Daugherty's greatest hopes for his daughter to be realized and immediately recuperates her into a "full existence" (188). *An Uncomplicated Life* concludes with a discussion of Jillian and Ryan's first sexual encounter (for which they were carefully prepared by the couple's parents) (326-332), and finally, their engagement (367) and wedding (371). In this way, Daugherty's narrative of raising his daughter begins and ends with the church aisle: a wish, and a wish fulfilled. Daugherty explains that before Ryan, he "worried Jillian's disability would come to define her" (190). But after Ryan arrived, "everything was possible again" (190). By "everything," Daugherty means heterosexuality and/as an ordinary life.

Jillian also goes to college (269) and holds jobs during and after (272; 296). And while these might also be considered important components of achieving an "ordinary life," in Daugherty's memoir they do not signify belonging to a degree comparable with that of Jillian's heterosexuality. Her story—and by extension her recognizable and acceptable identity—depends on her gender normativity. In the memoir's first pages, Daugherty writes, "My wife of six years had given birth to a girl. My girl. Daddy's girl" (11). On the last pages, Jillian says to her father, "I'll always be your little girl" (337). She says this though she is moving into her apartment with her fiancé; he includes this though she a 22-year-old woman, literalizing in one fell swoop the infantilization of "normal femininity and of intellectual disability. Disability "threatened to define" Jillian's identity and in Daugherty's memoir this implies there is some other identity by which Jillian should be made known. Daugherty thought Down syndrome would limit his daughter's experiences and reduce the richness of her life; but in becoming a sexually active, straight woman, Jillian has overcome her disability, and claimed her place at the table and her rightful identity. As the memoir's title states, Jillian's life is uncomplicated. On the one hand, Daugherty's expectations for Jillian seem low, rather sexist, and antiquated: he just wants her to fall in love with a man. On the other hand, the persisting cultural assumption that people with intellectual disabilities are incapable of forging appropriate sexual and romantic bonds (DesJardins 69) may indeed make Daugherty's hopes for Jillian quite radical. He wants her to have an ordinary, uncomplicated life with the promise of love and happiness in a world that assumes these are things she can neither appreciate nor understand.

The following sections explore gender-based scaffoldings that enable narratives of inclusion on the basis of ordinariness, including a same-gender sibling story and an analysis of United States' expectations for mothering that emerge in mother-authored memoirs. While I am interested in the ways parents explicitly engage gender norms to claim a normal childhood experience, it is important to note that normativity regulates identity and bodies in covert ways. This happens, for example, when disabled boys and girls are born into families with siblings and they automatically become brothers and sisters; or when parent-narrators imagine their child's future and describe them wearing a gown or tuxedo to high school prom, or as becoming—or not becoming—a bride or groom, as Paul Daugherty has written. The regulatory effects of gender normativity are at work when parents do not allow for the possibility that a child might be gay, might not be cis-gender, or might be genderqueer. In other words, gender is in some ways even more powerfully normative when it operates as the assumed status quo, the background details for narratives of childhood.

Ordinary

Despite Fields-Meyer's and Daugherty's subtitular descriptions of their children as "extraordinary" and "exceptional," both narratives privilege ordinariness and achieving the expected. Their children are extraordinary and exceptional because Ezra and Jillian emerge as ordinary members of the social world despite the disabilities their parents assume will hold them back. Significantly, ordinariness does not imply normality or typicality. Normality indicates that whatever characteristic is being measured is statistically average (Davis "Introduction" 2-3). "Normal" is inherently comparative, beset by above- and below-average categorizations. "Normal" and "abnormal" evoke the medico-scientific genealogy and deployment of *normality* (Cryle and Stephens) and, as Simi Linton argues, reinforce a sense of relative value to both descriptors (24). "Normal" is both statistically produced and prescriptive; it signals: *this is how people are,* and *this is how they should be*; "abnormal," on the other hand, denotes both relative rarity (*this is not how people are*) and failure (*this is not how it should be*). Similarly, "typical" is often combined with "-developing" or "neuro-" to describe children that are neither disabled nor neurodiverse. In memoirs and educational, medical, and cultural discourse, disability and typical are mutually exclusive categories; for example, Whitney Ellenby writes of her son, "Despite his autism, there are still many ways in which Zack is typical" (227); and Schuyler Rummel-Hudson's doctor remarks, "From examining this MRI, I can tell you that I certainly didn't expect to walk in the room and find a little girl running around and playing like a typical child" (Rummel-Hudson 174). "Typical" packs a less eugenic punch than does "normal," in that it refers to a common characteristic of a group and its antonym, "atypical," suggests something uncommon but not necessarily as invidious as an abnormality (though in medical literature the atypical and abnormal are used quite interchangeably (see Healthychildren.org). Typical and atypical seem to work sort of euphemistically in the contemporary moment when the concept of "normal" is so frequently challenged and deconstructed. However, typical and atypical development refer precisely to children that reach or do not reach developmental milestones within the normal window.

Children with disabilities cannot be "perfectly normal," not only because they are atypical: deficient, deformed, dysfunctional, "special," disabled, but also because the failure to meet developmental milestones marks them as more than simply "children." Parents of children with disabilities recognize the impossibility of normalcy, even when they recognize that normalcy is a moving target (see Cohen; Schank). And so, with no chance of being "normal," parents hope their children will be "as ordinary as possible" (Adams 85), or that their lives will resemble those of their "normal" peers. Carolyn Walker, for example, whose daughter Jennifer has Rubenstein-Taybi syndrome, writes, that "normal," in its common sense, "flew in the face" of what was obviously *not* normal about Jennifer (52). Walker "walked away" from normal (52), but writes, "everyday normal would be good enough" for her (16). Over the course of her mother's memoir Jennifer gains employment, begins a heterosexual relationship with a disabled man, and moves into a group home, all of which Walker describes as part of "normalizing" Jennifer, allowing her to "fit into the world" (161).

Walker's "everyday normal" refers to a sense of ordinariness and predictability. As the notion of "fitting in" suggests, "ordinary" conveys the absence of anything remarkable, rather than imply its inverses (extraordinary, unusual) as does normality. Feminist disability scholar Rosemarie Garland Thomson argues that fitting and mis-fitting are materializations that ground a discursive construction (like gender or ability) in nature; fitting occurs when generic bodies are at ease in generic worlds. Thomson writes, "the dominant cultural story of proper human development is to fit into the world and depends on a claim that our shapes are stable, predictable, and manageable" ("Misfits" 598). In other words, ordinary. Kathleen Stewart describes "the ordinary" as the present moment (2). It is the sense of "the everyday," the run-of-the-mill moments between the events that shape life and which disintegrate into banal exercises, habits (see also Das). Stewart goes on to write that the ordinary connects to *some*thing (12); it pulls (29) and, thus, suggests that *some*thing is in circulation (40). The compulsoriness of this circulation gives the ordinary a sense of urgency: an insistence. In many ways Stewart's conception of ordinary as unremarkable and yet urgent is similar to how normativity functions as "the production of stability and conformity" (Waldschmidt 193). Anne Waldschmidt contrasts normativity with normality, or the actual formation of normal distributions of any given data set. Normality, she explains, is "less static, and less oriented towards stability; [it is] based on change and dynamics," since norms are determined statistically (194). In other words, normality refers to any given characteristic's majority subset of variation at a moment of time, while normativity functions by means of reducing variability. Normality allows for abnormality, indeed, creates it; but normativity seeks to (re)produce the unremarkable, the ordinary. The production of ordinary is in this way an ongoing and future-oriented process, much like gender; it is continuously achieved through repetitive and reiterative practices, even as it threatens to continuously fail.

The distinction between normal and ordinary can be further illustrated by the pursuit of normality that defines some memoirists' experiences of raising a disabled child. Stephen Gallup's memoir, for example, is a nearly four-hundred-page account of Gallup and his wife, Judy's, attempt to "fix" his son Joseph, to cure him of the symptoms of his brain injury, NOS.[6] Joseph was developmentally delayed in infancy and showed an abnormal brain scan (18), but the etiology of his injury was unknown. For Gallup, "normal" was Joseph's, and every child's, birthright (328). Receiving little direction from Joseph's medical team, the Gallups sought any and all alternative means of diagnosis and treatments they could find to determine the cause of Joseph's injury and to spur his development, including iridology (the study of irises 49), psychism (48), allergy testing and elimination diets, chiropractic, behavior modification therapy (67), spiritual healing by a famous evangelist (338), sensory integration therapy, herbal foods, acupuncture, adaptive alternative communication (339), a little-known

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[6] "Not otherwise specified," a qualifier given to a general diagnosis in the absence of a more specific diagnosis.

"balancing therapy" for which they traveled to Taiwan to learn (341), and finally, "scientific prayer," a practice of "affirming wellness in prayer," and aligning their thinking with their belief that Joseph was still, inherently, a potentially "well boy" (328). Stephen and Judy Gallup invested most of their energies into "patterning," an intense form of physical therapy in which teams of adults manipulate a child's body in the movements of crawling, and later walking. The repetitious movements are argued to provide sensory input to the brain, to basically instruct the brain in what it feels like to execute a movement. The goal of patterning is for brain-injured children to attain normal growth in all areas (physical, social, intellectual).

Patterning required of Gallup and Judy to stimulate Joseph's brain in typical movement for up to twenty-four hours a day. To accomplish this, the Gallups enlisted neighbors and congregants from local churches to fill a patterning schedule. Volunteers arrived at the Gallup's apartment every two hours, every day, for years, to assist Judy in patterning while Stephen Gallup was at work. Their initial goal was to get Joseph to crawl 800 meters a day (150). Joseph's regimen for recovery was determined through initial and follow up visits the Gallups made to the *Institutes for the Advancement of Human Potential* in Philadelphia, the home of patterning. These visits were funded by donations collected from local churches and neighbors.

The effectiveness of patterning has been questioned since its inception. The American Academy of Pediatrics describes patterning as "based on an outmoded and oversimplified theory of brain development" and having the potential to cause real harms to families of disabled children due to the financial burdens and time investment it requires (Committee 1149). Gallup and Judy disregarded Joseph's medical team's advice to avoid the *Institutes* and patterning, because the Gallups interpreted this as conventional medical practitioners' disinterest in helping Joseph realize his right to wellness. Gallup "could not accept this" (21). He was committed to healing Joseph: "My boy *was* going to recover from whatever it was that had afflicted him" (36). He was also committed to following the *Institutes* regimen until Joseph became "normal" (206). Judy Gallup shared her husband's perspective, stating, "nothing is going to make me change my expectations! Joseph is going to be perfectly well" (274). Gallup operates from a "basic assumption" that, with effort, the passage of time brings development, "improvement" (350). Propelled by this expectation, Gallup and Judy refused anything less or other, and held in contempt parents who "accepted" interventions like special education or mobility devices (315; 207).

Ordinary, with all its potential non-normality, figures nowhere in Gallup's plan for Joseph. This distinguishes Gallup's memoir from others under analysis in this chapter, texts or stories which recognize that children with disabilities often do not develop within typical timeframes or to typical levels of mastery, but still may be understood as children: different, but still essentially just boys and girls. At the level of common sense, boys and girls and men and women are understood to be different creatures and to be ordinary is (among other things) to be able-bodied, heterosexual, and *either* a man or a woman (or a boy or girl). The debates may rage within the academy and online forums on parenting websites over the causes of these differences (as discussed in the introduction), but that gender denotes difference is a stable and persistent logic. The expression of those differences depends on able-bodiedness and a predictability of form, shape, and function. So, while the presence of disability disrupts the discursive and/or material structures by which gender is made intelligible, gender remains a powerful organizing category and among the most meaningful means of social recognition. By claiming recognizable gender, disabled children can be reinstated into existing narratives of ordinary childhood and from there projected into an ordinary future adulthood.

Invoking gender norms to convey a sense of ordinariness is not unique to Daugherty's or Fields-Meyer's memoirs. Rather, the language of gender normativity, and importantly, the absence of gender ambiguity or queerness, is ubiquitous in special needs memoirs. Jane Bernstein, for example, explains how as a young girl, her daughter Rachel, who has optic nerve hypoplasia and is intellectually disabled, was so “sweet-looking,” “so lovely” (*Rachel In the World* 39), and as a teenager “still cute” with her ivory skin and the dark curls that hung over her eyes (*Rachel In the World* 64). Amy Julia Becker describes her daughter Penny’s delicate fingers (79), her future beauty (65), how others remark on her loveliness (160), and her pretty little blue eyes that are slightly slanted due to trisomy 21 (132). Susan Zimmermann, whose daughter Katherine has Rett syndrome, suggests that Katherine’s beauty, gentleness, and innocence are the substantive characteristics of Katherine’s existence; “she can’t talk, can’t tell us what’s wrong or how she feels,” Susan writes, “but look how beautiful and gentle she is. Isn’t that enough in this life, to just be?” (228). Melanie, who has cerebral palsy, is a beautiful little bird (Harry); Kelle Hampton’s memoir about her daughter Nella, who has Down syndrome, is filled with images of Nella in pink hats and booties, frilly dresses, and with flowers in her hair; and Jesse, who also has cerebral palsy, is his mother Marianne’s “warrior boy” (Leone). Jeremy, who has pervasive developmental disorder (PDD), obsesses over trains and cars (Kephart). His first friendship with another boy evolves after they find they both are interested in swords and playing with knights (164). Later, Jeremy is bullied in school, and Kephart comments on the commonness of this in a boy’s life (223).

These are more readily apparent examples of gender-norming from a handful of memoirs. And these sorts of narratives are not unique to parents of disabled children; indeed, most parents of typical children also use gendered language and narratives to describe the lives of their little princesses and superheroes.[7] Few parents raise their children with gender identity as an open question. Rather, it is a taken for granted assumption by most parents that

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[7] See Barrie Thorne, *Gender Play* for a detailed analysis of the organizational uses and impact of gender in childhood.

gender, sexuality, and sex status will align with a child's genitals and/or genetic material. This is precisely the point: by drawing on the familiar narratives—the gender stories that are widely recognized as typical—parents of disabled children challenge ableist exclusions. Gender normativity becomes the scaffolding for ordinariness and an anchor for the child's future.

"Sisters. So much alike." (Marchenko 116)

Gillian Marchenko's memoir *Sun Shine Down* illustrates the role siblings play in shaping narratives of difference and normalcy. Polina, Marchenko's third child and third daughter, was born while the family was living in Ukraine where Marchenko's husband, Sergei, was working as a missionary. Polina, or Polly as she would come to be called, was diagnosed with Down syndrome and her mother plunged herself into despair and worry. She had wanted another baby (30), but few parents expect their child will be disabled and after Polly was diagnosed Marchenko cried to her husband, "I don't *want* this, Sergei, I don't *want* this" (58 emphasis in original). Over the course of the memoir Marchenko's sense of disappointment deepened. Polly seemed so different from her sisters, who were "perfect little creatures" (61). Desperate for a sense of familiarity and normalcy, the family moved back to the United States. There, Marchenko "wallowed in depression" (80) and began drinking heavily, in secret (81). She found herself unable to accept Polly (71) and unable to think about Polly's future (80). And then, when Polly was twenty-one months old, something shifted. Gillian Marchenko saw her child Polly in a new light: no longer a child with Down syndrome, but as her baby, an ordinary child (119-122).

On reflection, Marchenko writes that she had been "poked and prodded along to love [Polly]" over the preceding months by Polly's sisters, Elaina and Zoya (119). Initially, Elaina and Zoya signaled to Marchenko everything Polina was not: beautiful and healthy (54), typical (96), and expected (61). But Elaina and Zoya did not seem to care much about the ways Polly was different from them (117) and they loved and doted on their baby sister (e.g. 79). Over time, Marchenko began to see Polly as more similar to her sisters than she had expected her to be. At the pediatrician's office, for example, when questioned on Polly's development she notes, "[Polly's] a lot like Elaina and Zoya so far," and comments that this has surprised her (91). One night, while drunk, Marchenko stumbled into her girls' shared room in search of Polly (82). She wanted to hold her. The girls' room, she writes, "smelled like little girl sweat, sweet and pungent" (82). There, in the dark and when they are asleep, Marchenko senses no difference between her three girl children. Later, she recounts the way Elaina and Zoya drew their baby sister into small dance parties in the living room (115). Polly would mimic her sisters, and then demand they mimic her (116). Marchenko would watch the three sisters "in awe" (116). "So much alike" (116), she writes. In another year, she found herself no longer perceiving herself as a "mother to a child with special needs," but a mother of "three girls: Elaina, Zoya, and Polly" (122).

Sun Shine Down is a narrative that arcs from grief to acceptance. The grief is predicated upon disability; the acceptance, upon a sense of ordinariness. The turning point in Marchenko's story is abrupt— "I breathed her in for the first time, without feelings of fear or regret…. On this morning, something deep inside me cracked open: unabashed love, thick like wet clay … a light switched on inside" (119)—but it was preceded by a number of small moments of recognition, a gradually thickening sense of familiarity, and family. Each of these moments is embodied: Polly rolls over, eats well, sleeps soundly, dances with her sisters. With each familiar performance of ability, Marchenko is surprised. Her preconceptions about Down syndrome, and her daughter, Polly, are challenged. As Polly becomes, in Marchenko's eyes, more able-bodied—or less like the disabled child Marchenko imagined Polly would be—Marchenko is increasingly able to see Polly as not very different from her other two children, and increasingly able to accept her third daughter as she is: her sisters' sister, one of three girls, part of their family.

In *The Shape of the Eye*, George Estreich writes that his youngest daughter, Laura, who has Down syndrome, pesters her older sister, Ellie, "the way sisters do"; "this is life," he writes, "in every sense, normal" (244). And when Rachel Adams' son Henry, who also has Down syndrome, learns from his brother "forbidden" activities like blowing raspberries and jumping on the couch, Adams cannot help but take pleasure in seeing her sons unified in their bad behavior and enjoying one another (139). Tom Fields-Meyer, discussed above, consults Ezra's brothers, Noam and Ami, when debating what Ezra's bar mitzvah should look like. "He should do what I did and every thirteen-year-old does," Ami says (220). Kelle Hampton's narrative pivots on overcoming the idea that she had failed to provide her firstborn, Lainey, with the sister and best friend she had promised her (70). In each of these examples, the disabled sibling has at least one older sibling. It is worth noting that when the disabled child is the firstborn, parents sometimes opt against having another child (ex. Gallup; Kephart; Rummel-Hudson) and sometimes have more children (ex. Cohen; Zimmermann; Becker), but in the latter case, the older, disabled child's gendered sibling status has little reported effect on the younger sibling's development or how the parents perceive them in relationship to their older sibling. One exception can be found in Fields-Meyer: Ezra's younger brother Noam "trailed after Ezra, imitating him" until age two, and Fields-Meyer prophesies that Noam will soon move on to do what "most little boys do" (200), again demonstrating the way typical development and typical gender are made intelligible in and through each other.

Sociologist and women's studies scholar Judith Lorber argues that gender is a process of social interaction that creates difference (32). It is "constructed and maintained" through expectations, meaning gender is a product both of learned concepts and conformity to or rebellion against them (Lorber 32). Gender expectations are built into social structures (like family), and are reinforced through interactions with parents, peers, siblings, teachers, and persons of authority (Lorber 32). Parents, for example, are among the most influential when it comes to instructing young children in gender norms and behaviors (Witt 253). Studies on siblings have shown that the younger child of a pair of same-sex siblings is more likely to demonstrate sex-stereotyped behavior than the younger child of a pair of opposite-sex siblings; yet other studies have shown that younger same-sex siblings are more likely to develop dissimilar interests and behaviors (including those that are sex-typed) than their older siblings in an attempt to reduce or avoid competition and rivalry (Stoneman, Brody, and MacKinnon 497). But the reproduction of binary gender is no more effective in consolidating a notion of gender than is a refusal to do so; in both reproduction and resistance to it, gender persists, statically, as that which behaviors can be measured against and understood as normal or not normal. This persistency, and the dual attraction of normality (Berlant *Female Complaint* 5) and membership in the dominant group is what makes binary gender narratives a resource for parents of disabled children. When typical (read: gender normative and able-bodied) children become older siblings to disabled children, the older children serve as both a model of how the younger child is different, and how they are the same.

Intensive Mothering

As discussed in the introduction, the constructed-ness of disability and the narratives and rationales on which our notions of disability rely reflect a cultural fetishization of normalcy and simultaneously reinforce the boundaries around which bodies are good, beautiful, and whole. When atypical development, motor function, or neurological status present in children, parents encounter the limits the disability category places on childhood "as we know it" and are made aware, often painfully, that negative attitudes about disability limit their children's opportunities and inclusion in their social worlds. At the same time, their children's disabilities often make parents *themselves* feel out of place. Ron Fournier's memoir, *Love That Boy,* for example, is a chapter-by-chapter exploration of how Fournier's son Tyler's autism caused Fournier to evaluate not only his expectations *as* a parent, but also the dominant paradigms for what good/typical parents expect from their children in general. His chapters — "Normal"; "Genius"; "Successful"— demonstrate the way parenting expectations are rooted in a very narrow concept of human flourishing, one in which people with disabilities cannot often be imagined. Daugherty, in contrast, is keenly aware that the world expects little of his daughter Jillian. Pushing back against this, he does not modify his expectations and refuses to be an atypical parent. The sense that disability might preclude an "ordinary" parenting experience features prominently in parent memoirs. This is likely because childhood disability often does indeed usher in the unexpected, like learning to insert nasal tubes in order to feed a weak infant (e.g. Bérubé *Life* 37-39); or connecting with Early Intervention Services in the weeks immediately following the child's birth (Adams 73); or joining playgroups not because of proximity or age or the parents' friendships, but on the basis of the children's shared disability (Schank n.pag). Hana Schank explains how her daughter Nora's albinism brought into relief her taken for granted assumptions and expectations about childhood: "We lived in a world where infants did not need to visit neurologists and everyone could see." After Nora, Schank describes her life and her experiences as a parent as out on the "edge of normal" (n.pag).

Often, but not always, these reflections on expectations and displacement are connected to how the parent-author sees themselves as a mother or father, rather than a neutral "parent." Fields-Meyer writes, for example, that when they visit the Los Angeles Zoo, Ezra, captivated by the animals, is calm and quiet, and the two of them "fit in with the crowds, just like any other father and son" (73). The zoo trips are "foundational" (73) to

Fields-Meyer's efforts to forge a connection with Ezra. In the moment of togetherness, Fields-Meyer does not describe them as a "parent and child." When the challenges of Ezra's autism "melt away" (73), a father and his son emerge and fade into the crowd; again, the absence of the disability creates the space to claim a gendered role. The significance of identifying with a gendered parenting role is apparent when considering the subtitles of parenting memoirs. Of the thirty-six memoirs I analyze here, eleven were written by fathers, seven of which call attention to the author's parental role in the subtitle: e.g., "A Father's Journey" (Ian Brown; Collins; Rummel-Hudson); "A Father's Memoir" (Daugherty); "What One Father Learned…" (Fields-Meyer). These fathers write about how they come to know themselves *as fathers* through parenting their disabled child. They reiterate tired tropes about "daddy's little girl" (Daugherty 11) and chasing off potential suitors (Rummel-Hudson 254); and they also reflect on their own fathers and how they feel they measure up to a "dad" ideal (e.g. Fournier 101). They write about how disability makes them feel unlike a "regular father" (Ian Brown 7).

Of the memoirs written by mothers, ten mention motherhood in the subtitle, and three are subtitled "A Mother's Story" (Davenport; Harry; Leone). Like narratives written by fathers, mother-memoirs often explore motherhood as an identity category and the meaning of motherhood itself. Gillian Marchenko, for example, worried she would no longer appear as "an ordinary mom" (54) after bearing a child with Down syndrome; and Kerry Cohen's entire memoir explores what it means to be a "good mother." Marianne Leone identifies herself as a "warrior mother" who battled for accommodations and wellness for her son, Jesse. After Jesse's death, Leone uses her "mother warrior skills" to train other mothers of children with cerebral palsy for the trials they will likely face (248). Although Beth Kephart questions her ability to mother her son Jeremy appropriately (e.g. 39; 59), her memoir concludes with her understanding that, under his instruction, she has *become* Jeremy's mother (245).

While a smaller proportion of mother-memoirs bear “mother” or “motherhood” in the subtitle than do father-memoirs bear “father,” mother-memoirs comprise the bulk of the special needs parenting memoir subgenre (twenty-five of thirty-six). Moreover, with greater frequency than do father-memoirs, mother-memoirs tell a story of how the mother’s life was dramatically changed by the child’s disability either because the mother undergoes a dramatic self-change (e.g. Helene Brown; Hampton; Marchenko; Soper; Zimmermann), or because the child’s care needs consume the mother’s time and energy (Barnett; Kephart; Zimmermann) and sometimes even become the impetus for a disability-related career change. Beth Harry, for example, became a special education specialist after her daughter Melanie was born with cerebral palsy; Donna Thompson, whose son Nicholas also has cerebral palsy, founded a nonprofit organization to support disabled adult children; Jane Bernstein became a spokesperson and advocate for people with disabilities after her daughter Rachel was diagnosed with optic nerve hypoplasia (*Loving Rachel)*; and Dana’s mother Gayle Slate became a psychologist specializing in disability in families after Dana passed away due to complications resulting from a traumatic birth. Two father memoirs are quite literally about their child’s disability becoming a life project, including Paul Collins’ “lost history of autism,” and Ian Brown’s memoir, which chronicles his worldwide search for models of disabled and able-bodied interdependence and community living. And while Steven Gallup’s memoir (discussed above) painstakingly details the depth of commitment the Gallups maintained to curing their son Joseph of his brain injury, Steven Gallup kept his day job during the years of patterning and seeking alternative medicines. His wife, Judy, was Joseph’s primary care manager, and the unending stress of doing so would eventually compromise Judy’s health and prematurely end her life (Gallup 346-354).

It’s important to consider both why mothers seem to be the primary authors of special needs parenting memoirs, and why their narratives more frequently convey a dramatic self-change than do father-memoirs. One possibility is that mother-memoirs are more marketable within the current "nobody memoir" publishing boom, as described by journalist Lorraine Adams in the *Washington Monthly* and explored in depth by English and disability scholar G. Thomas Couser in *Signifying Bodies*. According to Adams, "nobody memoirs" are those that are written by people who have no "preexisting audiences," unlike, for example, politicians and celebrities, who author "somebody memoirs" (cited in Couser *Signifying* 1). Notably, of the memoirs under analysis in this dissertation, over half of the father-memoirs were written by men who were already accomplished and published authors; yet only five of the twenty-four mother-authors had been published previously as writers, columnists, and academics, and one mother had a successful acting career. Adams goes on to explain that memoirs about childhood, especially a tragic one, are the most popular of the "nobody memoirs"; followed by memoirs of "physical catastrophe—violence, quadriplegia, amputation, disease, death [;] … and [memoirs of] mental catastrophe—madness, addiction, alcoholism, anorexia, brain damage" (para. 8 qtd. in Couser *Signifying* 1). Couser explains that this rise in popularity of "nobody memoirs" is really an increase in memoirs about bodies, and disabled bodies in particular (*Signifying* 2). "The nobody memoir," he writes, "is often about what it's like to have or to *be*, to live in or *as*, a particularly body—indeed a body that is usually odd or anomalous" (*Signifying* 2).[8]

Couser contextualizes the increasing popularity of disability life writing to two related cultural phenomena: 20th century civil rights movements, and the rapid increase in diagnostic

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[8] Philosopher Drew Leder argues in *The Absent Body* that being a "no-body" is essential to the construction of the self, "Bodily absence" (2), he writes, or the ways in which the body executes functions and reactions without the mind's awareness, permission, or even understanding, should be foundational to phenomenological accounts of the bodymind ("integrated being" 5). Leder argues that it is a body's natural state to go unnoticed (to be absent); but it is in the moments that a body brings attention to itself (through ecstasy or pain, for example) that we are made to realize that the body was there all along. Leder calls this the "dys-appearance" (87) of the body, meaning that states of "dys" or abnormality are what actually bring the body into presence and perception. It follows that these bodily absences — the body's normal, unnoticeable state — actually constitute the self. Leder's work intersects with Couser's nobody-but-some-body figure and asks us to understand all bodies as no-bodies prior to any sort of noticeable bodily experience.

labels for an ever-growing number of identified human variations (*Signifying* 4-5). Just as U.S. anti-racist and anti-sexist activism in the 1960s and 1970s yielded a number of autobiographies by previously marginalized voices (e.g., African Americans, women), the disability rights movement has been accompanied by life-writing that "has responded to, and helped to create, greater opportunity and access to public life" (*Signifying* 5). At the same time, increased pathologization of human variation has led to the proliferation of niche markets and communities united around a diagnosis, and sometimes, the diagnosis' related identity category (e.g., Deaf; Autistic/Neurodiverse; Mad). We can understand the rise in disability life writing as a response to the marginalization, and indeed, erasure, of disabled experiences in popular and political discourse, as well as a pushback against the medicalization of the disabled subject in diagnostic and treatment texts (see Frank "Rhetoric" 50 footnote 4).

We can also understand the popularity of mother-memoirs in the same way. Autobiography has historically privileged a "master narrative of the sovereign self" (Smith and Watson 3) and thus implicitly favored life-writing produced by autonomous, self-interested subjects. The increased popularity and relevance of memoirs from the margins—including life writing by women, people of color, and disabled people—evinces broader cultural shifts in understanding of who counts as an experiencing subject. Moreover, as Nancy K. Miller explains, the particular favoring of the term "memoir" in the current moment demonstrates an increased critical acceptance of self-reflexive, highly personalized narratives (cited in Smith and Watson 4). Miller situates the popularity of *memoir* as emerging from a postmodernist recognition of the instability of division between public and private spheres (cited in Smith and Watson 4). Mother-memoirs about children with disabilities capture these multiple shifts; they are written by women and almost centrally concerned with caretaking and child-rearing; they are about disability and the experience of living with an odd or anomalous body; and as the historical keepers of the private (or domestic) sphere both the publication of their memoirs and their critical reception capture the ongoing deconstruction of the division between public and private lives. Moreover, as I will argue below, mother-memoirs (and their popular reception) can be further contextualized to the current dominant ideology for motherhood in the U.S., and the neoliberal imperative to make a project out of one's own life.

As with childhood and disability narratives, the available narratives of motherhood are culturally and historically limited. Motherhood, like disability and childhood, is a set of social relationships that are embodied. Like disability and childhood, the notion of motherhood is regulated by dominant ideologies. It is important to maintain the distinction between the social practices of mothering and the biological capacity of many people to conceive and gestate a fetus, give birth, and lactate. It is also imperative to remember that dominant meanings of motherhood are encoded by class, gender, race, and sexuality normativities. In the analysis below, I address notions of motherhood in the United States while refusing to essentialize the bodies, experiences, or practices of individuals that mother.

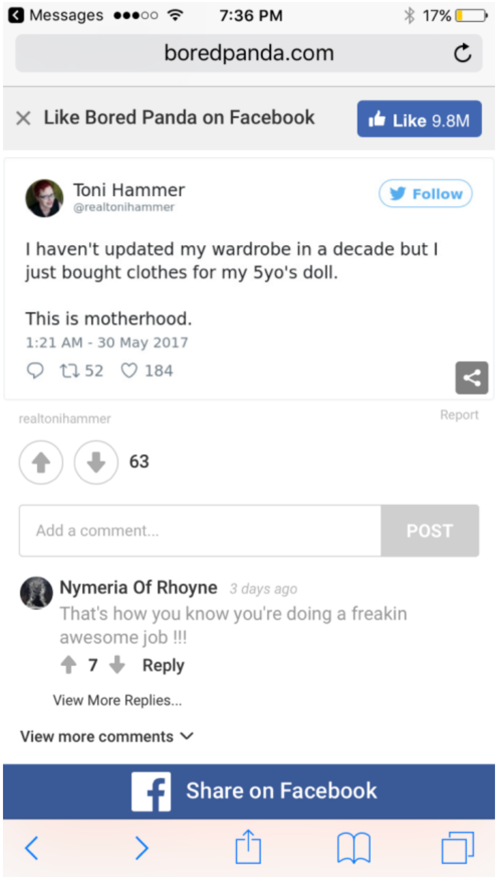
In her influential book, *The Cultural Contradictions of Motherhood*, Sharon Hays argues that that in the contemporary U.S., the prevailing ideology of motherhood is that of intensive mothering. Intensive mothering instructs good mothers to "invest vast amounts of time, money, energy, and emotional labor in mothering" (Elliot, Powell, and Brenton n.pag), and is characterized as child-centric, time consuming, and emotionally involving, albeit satisfying for the self-sacrificing mother (Arendell 1194). Because of what intensive mothering requires in terms of time, money, and reproductive labor, it is "entwined with idealized notions of the family, preserving the institution and image of idealized white, middle class heterosexual couple with its children in a self-contained family unit" (Arendell 1194).

The origin of the intensive mothering ideology has been debated within the existing literature. Some scholars locate it amidst broad scale social, political, and economic shifts beginning in the seventeenth century that redefined the meanings of sex, sexuality, and childhood. Lindal Buchanan, for example, writes that the unsettling of the single sex model (or, the dominant Seventeenth Century idea that females were imperfectly formed or inverted males) engendered a number of gender fictions, among them a notion of feminine sexual disinterest, and by extension superior moral standing, and by further extension the innate ability of women to guide and properly care for children (15). Others argue that the contours of motherhood shifted with cultural understandings of childhood, coincident with industrialization (Ehrenreich and English 208; Hays 32-33; see also Welter). During this period, gendered labor divisions became more fixed, especially for middle class workers and families. At the same time, childhood became increasingly understood as a special and important life stage. Children were beginning to be seen as future adults, and their care and development took on new importance in a eugenicist, progress-obsessed era. Women's primary labor activities were restricted to the domestic sphere, which contributed to the emergence of domestic and child-rearing sciences and the professionalization of mothering (Ehrenreich and English 173; Bassin, Honey, and Kaplan 5).

Elliot, Powell, and Brenton locate the origin of the ideology in more recent history. They write, "the seeds of [the ideology of intensive mothering] were planted during the 1980s and early 1990s when the conservative Reagan and Bush administrations stripped a number of child and family support systems even while valorizing family and motherhood" (365). While Elliot, Powell, and Brenton do not directly name these as neoliberal policies, the ideology of intensive mothering can be situated neatly within the compulsory neoliberal social and political order in the United States. As Wendy Brown argues, neoliberalism refers not only to economic and political policy, but also to the extension of market rationality into extra-economic spheres of life. It is better understood as form of governmentality, or a mode of governance that produces subjects and organizes the social realm (*Undoing* 47). In his work on governmentality, Foucault explored how biopolitical governing regimes call upon individual citizens to regulate and discipline themselves to attain an order of health, happiness, wisdom, and morality. Neoliberalism — neoliberal social and economic policies, and neoliberalism as rationality — operates in precisely this way to mandate citizens to "invest" in themselves, and bear sole responsibility for their health, well-being, and future outcomes.

While on the surface neoliberalism's demands for self-investment may seem at odds with the ideology of intensive mothering and the demand to invest in *another* person's well-being, our contemporary governing regime insists that subjects "make a project out of their lives" (Cossman 456), and full-time motherhood is one such project that invents the self. Moreover, a mother's investment of time, energy, and finances in her child's life can be, and often is, easily rationalized by existing cost-benefit schemes. The investment in the *child's* future has been understood popularly as a commitment to the future of the nation itself and to the reproductive family. And, for women, it works to consolidate femininity through the enactment of idealized motherhood. The payoffs are indeed significant. The embeddedness of intensive mothering ideology in neoliberal rationality can be further illustrated by the way the ideology works to rationalize other narratives of self-made motherhood. For example, in her famous 2003 essay "The Opt-out Revolution," Lisa Belkin argues that when faced with a precious, magnetic, and altogether demanding baby, women often find their jobs to be suddenly dissatisfying, unfulfilling, and easy to reject. "Opting out," or choosing the make motherhood a full-time project, resolves the conflict between work and family and produces motherhood as a site of self-governance through the very act of negotiating that choice (Cossman 466).

Thus, as a discursive formation, intensive mothering produces mothers as subjects that, emerging from a "common cultural matrix," share ideas about standards of behavior and appropriate narratives (Buchanan 6). As ideology, intensive mothering delimits what it means to be a good or responsible mother, according to the terms by which it is understood. Indeed, the good mother *is* the one who mothers intensively. A child with disability presents atypical conditions by which their mothers establish the terms and practices of intensive mothering. Understood as an obstacle to overcome, disability in effect justifies and makes meaningful intensive mothering practices and the discursive and material investments made by families into their children's development. The practices of intensive mothering, and indeed the very process of writing and publishing a memoir and claiming discursive, material, and cultural space for one's experiences, which interestingly take away from time for mothering, are strategies aimed at restoring mothers and their disabled children themselves into the normative regimes of motherhood and childhood. These memoirs, then, evince the process of contesting and complying with available narratives to make one's life, childhood, mothering practices, meaningful in a social environment that excludes and denies recognition.



Toni Hammer
@realtonihammer

I haven't updated my wardrobe in a decade but I just bought clothes for my 5yo's doll.

This is motherhood.

1:21 AM - 30 May 2017

Nymeria Of Rhoyne 3 days ago
That's how you know you're doing a freakin awesome job !!!
7

Image: screenshot of tweet describing motherhood

We can see this at work in Kristine Barnett's memoir, *The Spark; A Mother's Story of Nurturing, Genius, and Autism*. Barnett's son Jacob has autism and is intellectually gifted. When Jake was three years old, his mother decided against sending him to prekindergarten, a free program made available for children with disabilities, but in which Jake seemed bored, restless, and developed behaviors Barnett found “alarming,” like becoming non-responsive to her verbal requests (55). Barnett decided to pull Jake from the public school and begin homeschooling, with the goal of placing Jake in a mainstream (regular education) kindergarten class. This meant taking over the therapies (occupational, social, and speech) that the public school provides. In order to meet her goals for Jake’s development, she familiarized herself with therapeutic techniques and tools, and learned what Jake could expect during the course of a day in a typical kindergarten classroom. Then, twice a week, Barnett led a “kindergarten boot camp” for autistic children in her garage (which she and her husband had previously converted into the daycare center that Barnett ran). Barnett allowed Jake’s interests to determine his therapies. For instance, when Jake three, he loved string. Barnett let him create webs of yarn throughout the entire house for months (47). When Jake wanted to study alphabet, she bought him pack after pack (3); when he wanted to spend hours doing puzzles and tangrams, Barnett would sit with him and watch him work (62). When he became interested in astronomy, Barnett purchased a college-level textbook that had absorbed Jake’s attention for over an hour inside a Barnes & Noble (85). The book became three-year-old Jake’s “constant companion” (85).

Jake’s brilliance earned him admission to a master’s program in theoretical physics at age fourteen, but when he was a child, his mother felt Jake’s autism and above-average intelligence threatened to compromise his access to typical childhood experiences. So, she addressed it:

> I wanted Jake to have friends, but I knew I couldn't send him out to play football with the neighbor boys.... Jake's physical delays made him clumsy and slow.... What if I made our house... the kind of place that a boy couldn't help but gravitate toward, so that those other boys would come to him?... I went shopping.... I bought...cool fuzzy

> rugs and beanbag chairs...big screen TVs... Play Station... video games... every kind of flavor-blasted Doritos.... In short, I created...a boy cave. (122)

In this example, we can see what Barnett feels Jake is missing out on: a typical social life for a young boy. Relying on gender norms of boyhood, Kristine ushers Jake not only into the physical space of childhood (the "boy cave"), but also into a typical childhood narrative, one that is marked by happiness and play. Jake's autism becomes negligible. Disability is contained and then overcome through claiming access to gendered childhood.

Later in the memoir, Jake's mother decides to start a sports program for kids with autism. Barnett reflects on how despite Jake's progress, including mainstreaming into a regular education classroom and making many friends, he lacks access to the typical "childhood experiences [of] missing a goal, catching a fly ball, [and] nailing a free throw" (152). Her program, Youth Sports for Autism, meets every Saturday on rented space at a local church. They play baseball, soccer, hockey, basketball, and bowl on homemade lanes away from nightmarishly noisy and poorly lit bowling alleys. The governing rule for the program is "no therapy," just play (155). Barnett is never explicit about the sexes of the kids in her program; however, a gendered profile of Youth Sports for Autism emerges from the narrative almost immediately. She notes that Saturday's activities brought the "dads" out in droves; dads, she writes, "in sweatpants and baseball caps, playing with their kids … an experience many of them never thought they'd have" (154). The kids she mentions are Max, who is low-functioning; Jerod, who made a touchdown; Adam, who sleeps with his toy medal; Christopher, "a really good basketball player" (156); and an unnamed "her" who "brought down a single bowling pin while holding her dad's hand" (155).[9] Barnett's sports project, and the narratives by which she envisions and describes it, allow her to claim for Jake

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[9] These dads and kids do not comprise a group from which Barnett and Jake are excluded. Though her enthusiasm for athletics (expressed throughout the memoir) deviates slightly from feminine gender norms in the U.S., her intensive mothering practices reinstate Barnett under the rubric of normativity.

the mundane, discursive space of normative, able-bodied boyhood via the baseball diamond. Jake and the other boys are doing nothing more extraordinary than playing sports on a Saturday afternoon with (mostly) their dads. At the same time, her investment of time, resources, and energy into Jake's success enables her to situate herself squarely among expectations for ordinary mothering.

In yet another memoir, *Seeing Ezra*, Kerry Cohen articulates the pressure she feels to "make [her son Ezra] normal" (135) and how her failure to do so makes her a "bad mom" (e.g. 86). Ezra has autism. To be a good mother, Cohen must help her son (28), be selfless and deny her own wants (49). "A lot [of parents]," she writes, "feel those same hazy pressures that I do: We must do everything we can to make our children normal…. We're afraid that we really are failing our children if we don't follow the path handed to us" (135). But Cohen does not want to make Ezra "normal." She does not want to spend Ezra's entire childhood in therapy or chasing after one autism treatment or another (e.g., chelation—removing heavy metals from the body [85]—or communicating with dolphins [252]). She writes, "I want Ezra to just be a kid, to not have to constantly work on something that others need from him" (218). She connects her unwillingness to invest her resources into normalizing interventions with her status as a mother: "He does a lot of things differently from other kids his age. But there is nothing wrong. … Unless I hate the things that make him different from other children, I will always be considered a wayward mother" (33). It is worth knowing that, despite her resistance, Cohen does invest a great deal of time and energy into "helping" Ezra. She seeks Early Intervention services (24) and Ezra receives speech and occupational therapy (25). She spends hundreds of dollars on supplements prescribed by naturopaths through an organization called Defeat Autism Now! (DAN!), which promise to eliminate autism from Ezra's "system" (84). She sends urine samples away to test Ezra for heavy metals (94). She agrees to put Ezra on antidepressants (220). She enrolls him in a private school for autistic children that costs them as much as college tuition (257). Despite these efforts, which can be read as attempts at normalization, Cohen's ultimate wish is for "a world that will welcome [her] autistic son" (253) as he is. She maintains that this wish, and her decision to "do nothing" and "let Ezra be who he is" is the true accomplishment in their story (278), and argues that truly "good" parenting means loving one's children unconditionally.

When Cohen refuses to live up to the intensive mothering ideology and wrestles with the ways this renders her a "bad mother," she conveys the pervasiveness of the ideology in the contemporary U.S. and how it is both a moral imperative and the dominant mode of recognition. Her refusal can be read as resistance, which, while destabilizing the normative expectation, also attends to its power, especially when we consider that her memoir—subtitled "A mother's story"—concludes with Cohen becoming a good "parent" (280), rather than a good mother. Unable to embody the gendered expectations for motherhood, Cohen is, perhaps, neutered. "Perhaps," because, at the same time she fails at motherhood, Cohen's narrative is still one of becoming, and can be read as a life project, a means to create the self. In this sense, Cohen's narrative aligns with those characteristics that dominate special needs memoirs, especially those written by mothers. She is like Beth Kephart, who over the course of *A Slant of Sun* learns "who she must somehow be, to be [Jeremy's] mother" (245). She is like Gillian Marchenko, who shifts from being a "mother of a child with special needs" to a "mother of three girls" (122). She is like Vicki Forman, who "comes to be" her children's mother only over time and only through acknowledging and accepting devastating losses.[10] Cohen's memoir evinces both the generic imperative (making a project of one's life) and the cultural expectation that one's status as "woman" should and will be transformed into "mother" upon becoming a parent.

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[10] Forman's memoir, *This Lovely Life; A Memoir of Premature Motherhood,* is discussed in Chapter 3 of this dissertation.

We can contrast Barnett's, Cohen's, and Marchenko's narratives and concepts of motherhood, with the picture of motherhood that emerges in Helene Brown's memoir, *Yesterday's Child*, published in 1976 when her daughter, Karen, was in her twenties. Karen had cerebral palsy, intellectual disability, and was deaf. Brown institutionalized her daughter when Karen was around ten years old. She explains, "I wasn't going to be overcome by my child. We were both going to have lives of our own…. I was already living in a future in which I was liberated from the tyranny of a kind of motherhood I had never expected and did not want" (45). Brown expresses nothing suggestive of the kinds of pressures articulated by late-twentieth- and early-twenty-first-century mother memoirists to mother intensely; indeed, Brown's goal is to "separate herself … emotionally and physically [from Karen], so both of [them] can live" (208). Like other parents, Brown makes a "new life" for herself after Karen, but the change depends on accepting the "burden" of a disabled child (209) but refusing to let her child define her.

This dissertation analyses memoirs published predominantly since the year 2000 and are about children born between the late seventies and early part of the twenty-first century. They can (and I argue, should) be contextualized to the ascendancy of neoliberalism as rationality, as the means by which to make sense of one's life and self. They are as much about becoming an ordinary mother as they are about engaging in a project of self-creation. Of course, it is not possible to generalize the narratives of the special needs memoirs published before the 1990s because there are only three: *The Child That Never Grew*, by Pearl S. Buck; *Yesterday's Child* by Helene Brown; and *And Say What He Is: The Life of a Special Child* by J. B. Murray and Emily Murray. So, while Brown's memoir of escaping the "tyranny of motherhood" makes for a compelling counter-narrative, it is perhaps the paucity of memoirs published prior to the rise of neoliberalism that more convincingly conveys the cultural imperative to make a project of one's life, as well as the limited cultural scripts by which such narratives of self are constrained.

Conclusion: compulsive hetero-ablebodiedness

In Tom Fields-Meyer's narrative we see the way gender works to reclaim Ezra's identity as a child on the brink of adulthood. In his childhood, Ezra's autism is an obstacle to social inclusion. It also creates obstacles for his parents, who find themselves at once without any available narratives to guide them and make sense of their experiences of parenting a disabled child, and at the same time without narrative recourse to make their experiences, and their child himself, recognizable to others. Penning a memoir allows parents to make these claims, and memoir's increasing saliency in the contemporary moment (Couser *Memoir* 3) generates potential for shifts in paradigmatic understandings of childhood and disability. It is important to consider, however, that the challenges to ableist exclusion (and the effects these memoirs might have on cultural common sense) happen at the expense of perpetuating gender normativity and heterosexism. So, while claiming normative gender can be liberating for parents and children who find themselves excluded from dominant social narratives on the basis of ability, on the other hand, inclusion is contingent on perpetuating a system of recognition that has, historically, been itself exclusionary.

Narratives of ordinariness push back against exclusionary discourses and related practices. For example, "ordinary" refuses to be "special." "Special," and especially "special needs," is a popular way of distinguishing disabled bodies, their spaces, and their accommodations. Indeed, the subgenre of memoirs under analysis in this dissertation is commonly referred to as "special needs memoirs." In everyday use, "special" confers value, suggests something is treasured, important, and distinct because of its qualities that "surpass what is common" (Linton 15). However, Simi Linton explains that "when applied to education or to children … special can be understood only as a euphemistic formulation, obscuring the reality that neither the children nor the education are considered desirable" (15). Amy Shuman suggests that the emphasis on the specialness of disabled children "refuses their place at the table" (156), or, in other words, limits their full inclusion based on their differences. Claiming ordinariness and familiarity, indeed, demanding recognition, challenges the exclusions of both stigma and exceptionalism.

In a sense, these are narratives about how children with disabilities (and their parents) "fit in." In *The Cultural Politics of Emotion* feminist cultural theorist Sara Ahmed argues that fitting in—to both normative expectations and normative spaces—is like a body "sinking into a comfortable chair" (148). Ahmed writes about how queer bodies are oriented in heteronormative spaces, but her argument has significant implications for disability studies because the "fitting" is as much about the chair (for my chair, molded as it is to my body, may not be comfortable for you) as it is about the body (for my body may not sink comfortably into your chair). Bodies that are atypical—bodies that look differently, move differently, sense differently, and think differently—are oriented in unexpected and unfamiliar ways to spaces and cultural narratives; or, as Rosemarie Garland Thomson argues, fitting occurs when "a generic body enters a generic world" ("Misfits" 595). The failure of both queers and disabled people to "orient" correctly not only generates feelings of unrest and discomfort, but is moreover a threat to social order. They are misfits in both senses of the word.

Ahmed's point about queer discomfort can be further applied to disability experiences when we recall that disability is already queered by the failure to enact normative gender and sexuality. Stereotypes of disabled people as either asexual, non-reproductive, or sexually perverse situate disability outside the privileged space of heterosexuality. As such, they are excluded from the idealized, sentimentalized scripts of heteronormative love, marriage, and family that are not only broadly familiar, but also inform legislation, policy, the distribution of resources, and a national identity. The assumption of heterosexuality—the systematic privileging of heterosexuality and the institutionalized socialization of men and women (boys and girls) into heterosexual lifestyle—is, as Adrienne Rich argues, that which renders it compulsory, and, as Ahmed argues, what gives heterosexuality a quality of "everydayness" (147). The everydayness of heterosexuality, I contend, is essentially, the everydayness of ability in that heterosexuality is contingent on able-bodiedness. The failure to achieve able-bodiedness, then, can be understood as an inability to embody an "ordinary life."

The effect of narrative appeals to normative gender and sexuality is to reduce the significance of disability to a child's identity and thereby to challenge exclusion. However, these narratives evince a continued discursive and material investment in the elimination of disability that can be traced to eugenicist practice of the early twentieth century (as discussed in the introduction). They speak to unabating cultural anxiety about health and ability that undergirds ongoing efforts to develop technologies that will eliminate disability at the genetic level (discussed in greater detail in the conclusion). They reinforce taken-for-granted assumptions about gender and sexuality and thereby are complicit in the reiteration of compulsory hetero-able-bodiedness. In these ways, narratives of ordinary life, premised as they are on claiming normative sex and gender, reproduce familiar cultural scripts that are limited and limiting, even as they challenge them.

Chapter 2: Teachers, Gifts, And Gurus: (Re)Valuing Disabled Childhoods

> "But I have to admit, if we're stuck with the sensitivities and challenges of autism, we might as well get something cool out of the deal.… So, when he taught himself negative numbers at age seven and started to beat me at chess at age nine, I admit that I bragged just a touch"
> (Alison Auerbach 195).

Kelle Hampton always wanted to be a wife and a mother (Hampton 22-23). Her daughter Lainey was born within a year of Hampton's wedding to her husband Brett, and shortly before Lainey turned one, Hampton was ready to give her a sibling (21). Her husband had two sons from a previous marriage, and Hampton wanted another daughter so Lainey could have a sister. "I wanted to say 'my girls,' reuse bonnets and tights, read *Little Women* to two bodies snuggled under rosebud sheets, overhear gossip about boys, and break up fights over clothes and curling irons" (35). When the ultrasound revealed little developing female genitals, Hampton was overjoyed (36-37). Lainey was going to be a sister, and everything was going to be perfect (31).

As her due date neared, Hampton prepared. She packed her hospital bag with a pretty, black, lace-trimmed and polka-dotted nightgown for herself, and stacks of pink baby clothes for Nella Cordelia, her unborn daughter (61). For the hordes of visitors she expected, she put together party favors wrapped in small, pink, cupcake-sized boxes adorned with a pink satin ribbon and a pink sticker that read "Nella" in cursive script (4). Hampton made a T-shirt and a crown for Lainey that said "Big Sister" (28, 13, 106), and her mother hurriedly finished Nella's coming-home outfit, a hand-crocheted lace sleeper with matching ballet slippers and bonnet, each with shiny, thin, white satin ribbons woven throughout (102). She packed flameless candles and lavender oil for her recovery room and cued up her birth music for the delivery (62, 3). Friends toasted Nella's arrival holding hand-painted miniature champagne glasses that read “Nella,” while Hampton looked on from her hospital bed, upon which she had placed colorful afghans and pillows from her home (7). And while some readers might find it difficult to imagine a pregnant person staging her labor, delivery, and recovery so meticulously while at the same time caring for a toddler, the proof is in the hundreds of full color photographs that fill Hampton’s memoir, at least one on every page of the three-hundred-page book. There is almost no room to wonder if Kelle Hampton has not planned and color-coordinated every living moment of her life. In the recovery room, Hampton is pictured in her pretty nightgown, hair blown out and makeup applied, wearing a large tiara and holding newborn Nella, who is wrapped in a pink blanket (13). Lainey arrives, wearing her “big sister” shirt and a large flower in her hair that is the exact color of the tights under her pink skirt (13). The scene is well put together: a beautiful mother, lipstick perfectly applied, with her pretty little daughters, all nicely dressed for the camera (14-15).

But Hampton writes that she hardly felt perfect. Shortly after her birth, Nella’s pediatrician told Hampton that Nella had features consistent with Down syndrome (8). Hampton was overcome with grief, wishing that she could close her eyes and wake up and be pregnant again, wishing that Nella would be “normal” (6). And she was plagued with guilt, feeling that she had let Lainey down by not giving her the sister she had promised her (70). She cried the entire night after Nella was born, and writes that her eyelids were so swollen the next morning that she could not manage to curl her lashes (61). Hampton’s perfect family and future did not include a disabled child. Hampton found herself unable to cope with her shattered expectations, unable to be alone with Nella in the hospital recovery room (59), unable to look at her body or the decorations she made to celebrate Nella’s birth without thinking that only days prior these things were imbued with a happiness that was now absent (61). In her words, she was in a crisis (79). She mourned the child she did not get to have, writing that this baby had “died” the moment she learned Nella had Down syndrome (11).

She wept, with self-pity, for the *type* of family she felt they had become (87): a family that was no longer "perfect." The distress was so severe and the disappointment so intense, Hampton struggled to bond with newborn Nella and wondered if she even loved her, or was capable of accepting her (7; 11).

Later in the memoir, Hampton writes that her initial sadness over Nella's diagnosis was due to "social conditioning" (88). Her distress about the disappointment she anticipated Lainey would feel over having a disabled sister, for example, was shaped by the widely held assumption that disabled people do not live meaningful lives (Shakespeare 220) and that cognitively disabled people are incapable of forging sincere (and appropriate) emotional bonds with others.[11] Hampton found herself unable to imagine Nella filling the sister and daughter role that she had desired and expected, demonstrating the way in which Hampton sensed the limits disability places on normative gender enactment. She found it hard to imagine (indeed, impossible on that first day of Nella's life) because of the utter scarcity of disability narratives that would challenge these stereotypes. Faced with a newborn that did not fit into her existing expectations, and no narrative recourse to an optimistic alternative, Hampton was distraught.

By the following evening, however, drinking beers in the hospital recovery room with her sister Carin and best friend Heidi, Hampton began to rapidly reconstruct the narrative. Carin initiated the shift by telling Hampton: "this makes so much sense to me. You were made for this role. I truly believe you were chosen for this" (86). Hampton, who, twenty-four hours prior, wished she would wake up from what seemed like a bad dream, found herself crying,

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[11] This assumption is expressed in memoirs and scholarly literature in a number of different ways. Memoirist Martha Beck, for example, worries that her son Adam will engage in sexually inappropriate behavior with strangers (248), and Susan Zimmermann writes in her memoir, *Keeping Katherine*, that her daughter Katherine neither loves her mother (219-223) nor would know the difference if Zimmermann, or someone else, treated her unkindly (153). People with intellectual disabilities have historically (and persistently) been understood to be either innocent, asexual, and fragile, or morally depraved, instinctual, and hyper-sexual (Desjardins 69). Kittay and Carlson explain the significance of these stereotypes of cognitive disability on the lives of disabled people, exploring in depth, among other topics, the assumption that intellectual impairment forecloses on one's ability to exercise agency (e.g., 13) including the expression of attachment (e.g., Donna Thomson 65).

eyes closed, and agreeing, "*Yes, yes I know*" (86). Carin told Hampton how lucky she was, and that raising a child with Down syndrome "would be the most special thing in the world" (17). Hampton began to re-imagine Nella: no longer a disappointment, Nella was a gift that Hampton was specifically chosen to receive—by God, the Universe, Coincidence, and/or Science (163). Hampton was going to be changed for the better (163), and by knowing and raising Nella, Kelle Hampton would gain an understanding of the true meaning of life, "what life is all about" (87), the things that other people (i.e., people with typical children) would never have the opportunity to know (97). Instead of imperfection, Nella would bring insight; instead of despairing, Hampton began to see herself as "lucky" (18; 231). She explains later in the memoir that during those first twenty-four hours of Nella's life, she "just didn't know" (231) that Nella was a precious gift and that being her mother was a privilege (18) because of the ways it would enable her to transform into a new, better version of herself (65).

"Extraordinary" narratives and neoliberal logic

Many parent-authors of special needs memoirs describe their children as "giving back" to them in a profound way. In these narratives, which I categorize as "extraordinary," parents explain how their disabled children teach them about the limits—and limitlessness—of love, or about the value of diverse human experience or embodiment, or some esoteric truth about the world or universe. In these narratives, children show their parents something they could not previously see, or else they cause their parents to reflect on their own shortcomings and to become better people: kinder, more loving, and more gracious. Sometimes, like in the section above about Nella Hampton, disabled children are described as gifts. By doing nothing more than existing, they enrich their parents' lives and initiate positive changes and opportunities for growth (Hampton 163). Other times, disabled children occupy the position of guru or spiritualist in their parents' narratives, connecting their parents in some way to a higher power or a spiritual realm. Often, disabled children in memoirs do a combination of these things. These narratives of giving back challenge the widespread assumption that disabled children seriously compromise their parents' quality of life (Piepmeier "Saints" n.pag; Saxton "Why Members of the Disability Community" 148). They are narratives that ascribe value to disabled children in its perceived absence (Parens and Asch 23). In all of these narratives, parents challenge the way atypical embodiment and neurodiversity are seen as worthless attributes, and how disabled people are understood to be under- or non-productive members of society (McRuer *Crip Theory* 8). By claiming that their children bless them and elevate them, they challenge the stereotype that disabled people are nothing more than burdens on society (Piepmeier "Choice" 160).

These particular narratives of value are not necessarily unique to parents of disabled children, as many parents of able-bodied and neurotypical children also say that their children bring into their lives measures of joy and happiness beyond what they had previously imagined possible, and even that their children teach them about love, patience, and perseverance in life-changing measures. Indeed, one might argue that by narrating their experiences in these ways, parents of disabled children are writing their children into a typical childhood script. The similarities notwithstanding, three important distinctions must be made between narratives that ascribe this sort of value to able-bodied and neurotypical children and those that do so for disabled children. First, in many special needs memoirs, the narratives depend on a common narrative "shape," in which the story's protagonist experiences some sort of hardship, and in overcoming the challenge find their life has improved in significant ways: they are better off. It is a culturally resonant story, one to which many people can relate, and which structures countless popular films and novels. But it is a story that departs significantly from a typical script for childhood and the expected experience of raising a child. While many parents might describe the early years of childrearing as challenging for both their children and themselves, "tragedy" is not as frequently used to describe sleepless nights and bouts of colic. Parents of disabled children, however, often use precisely this language. Tragedy, hardship, grief, pain, fear, anger, and confusion are among the more common sentiments and experiences represented in special needs memoirs following a disability diagnosis (Piepmeier, "Saints" n.pag). This is because disability is popularly understood to compromise the quality of life of the disabled person and the lives of everyone around them (Saxton "Why Members of the Disability Community" 156). So, while parents of typical and atypical children alike may describe the experience of childrearing as enriching, the shapes of those narratives are distinguishable by the degree to which hardship is measured and overcome.

Second, the narrative arc that moves from burden to value, or tragedy to blessing, hinges on the parents' sense of having gained an advantage in life simply through proximity to their disabled child. In other words, the value of disability is contingent on an improvement in the parents' moral and or spiritual standing, and not necessarily because their child has "improved," become a better person, or been "cured" of their disability.[12] This is striking given that narratives of "improvement" are fundamental to the way we understand childhood and how we describe childhood development. As explained in the introduction, childhood is understood in relation to adulthood and the distinction between the two life stages is a matter of development. Children are dependent, lack skills and abilities, and are seen as *developing* towards adulthood. Children embody expectations for adulthood when they "overcome childhood" through the mastery of skills, learning and gaining emotional intelligence, and becoming independent. Disability in childhood disrupts this teleological narrative of childhood because of the way disability seems to arrest, or at the very least place significant constraints on, development. (This also works in reverse, where delays in development are

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[12] Contrast this to the narratives described in chapter one, where children "overcome" their disability by achieving normalcy in gender and the life course.

pathologized and signal disability.) Disability is considered a trait that perpetuates the childish state of dependency. There is an assumption, then, that a disabled child's potential is limited in a way that an able-bodied child's potential is not. When parents write that their disabled children make them better people, this narrative actually does nothing to restore disabled children to a typical childhood narrative. On the contrary, the emphasis on the parents' betterment actually brings into relief a sense of stasis, an unchanging quality assumed to be inherent to the disabled child's life and being. The parents improve because the child remains the same. This narrative has little to do with developmental achievements actually made by disabled children, because it emphasizes the child's essential, inherent specialness that over-determines the child's existence and life course.

This last point relates to the third distinction that can be made between narratives about disabled children and those about able-bodied children, which is that in the former, disabled children are reduced to their disabilities. In many special needs memoirs, disabled children are special, or have remarkable abilities, or are ultra-spiritual beings *because* of their disabilities. In their parents' eyes, Down syndrome, Rett Syndrome, or autism make these children who they are, which is extraordinary, even super-human. Many parents write that to take away the disability would be to take away their child (e.g., Becker 225). While this can read as an affirmation of acceptance, this recurrent expression dehumanizes disabled children. Not only does the sentiment deny the child's complexity or any sense of personal identity, it positions them as "exceptions to human capability" (Thompson "Seeing" 341), permanently displaced from the realm of the ordinary and thus excluded by virtue of their essentialized specialness. Parents of able-bodied children may deny their children complexity, and often do so in terms of gender or life stage (e.g., "boys will be boys," or "your average teenager") but the distinction is that those narratives do not necessitate the reduction in order to construct the story. "Extraordinary" narratives of childhood disability rely on an equation: “disability makes my child special, which makes my life better.” Take away the source of specialness, and the self-improvement narrative is compromised, making both the parent and child vulnerable to the unpleasant alternative narratives mentioned above (e.g., tragedy, burden, imperfection).

Reducing the child to their disabilities dehumanizes them and reinforces mechanisms for social exclusion. Moreover, “extraordinary” narratives commodify disability because disability confers value on the children through the moral and spiritual advancement of their parents. Parents write that a child’s disability can yield valuable returns like intellectual, moral, and spiritual growth. But at the same time, these narratives gesture towards inclusion in an even more culturally salient way than simply making claims to typical childhood experiences. By commodifying their child’s disability, parent-memoirists appeal to a common-sense notion that all relationships can be—and should be—understood in terms of value and exchange (Harvey 3). Their love and care for their children is rationalized as an investment in self-betterment, and the disabled child is valued as a catalyst for others’ self-improvement. Extraordinary narratives thus reflect what Hall and O’Shea describe as “common sense neoliberalism,” or the permeation of neoliberal values to every stratum of society and human interaction. As explained in the introduction, common sense neoliberalism, or neoliberalism as rationality, refers to the extension of market logics into extra-economic spheres of life, and the ascendancy of entrepreneurialism, self-improvement, and productivity as the dominant modes of conduct for both persons and states. Harvey explains that neoliberal rationality has exceeded political and economic spheres to code all behavior in terms of the market: investment, profitability, and utility (41), and Wendy Brown describes neoliberal rationality as the governing mentality in the United States (“Neo-liberalism” n.pag). It is the primary logic by which we make our lives and experiences meaningful to and comprehensible by others. By writing their children into narratives that align with neoliberal rationality, parents attempt to elide the ableist exclusions that operate at the level of market value. They challenge the assumption that disability is strictly a financial, emotional, and time-consuming burden by foregrounding the ways in which they benefit from caring for a disabled person. These narratives argue that people with disabilities can contribute to society in ways we may not have previously imagined. In other words, disabled people can be re-conceived as "productive" in an economic sense, because of how disability functions as the "price" for others' personal enrichment (and in the case of memoir publication, potential monetary profits, too).

There is another way these narratives evince the prevalence of neoliberal rationality. In *The End of Normal* Lennard J. Davis writes that the "the essence of [the] transformation of citizen into consumer is that identity is seen as a correlate of markets, and culture becomes lifestyle. One's lifestyle is activated by consumer choice—and this kind of choice becomes the essence of one's identity" (2). In other words, identity is both chosen and purchasable. Subjectivity, by extension, is understood as unfixed and flexible, and the diversity of the citizenry with regard to race, gender, class, or sexuality is operationalized to make us all the same in the sense that we are all consumers (Davis *The End* 2-3, 7). Disability, in contrast to this model of diverse, purchasable subjectivity, is understood as "not choose-able" (Davis *The End* 7), and "fixed" (Davis *The End* 6). Davis explains that in this way, disability is the "exception to the rule" of neoliberal diversity: disability brings into relief the "suppressed idea of a norm" against which the celebration of difference can be articulated (*The End* 9). Disability is not a viable identity category in this schematic.

Except, of course, that it increasingly is. Besides claiming the identity Autistic-with-a-capital-A (and the growing possibility of being recognized as such), or as a person of short stature or Little Person, of being "differently-abled," not to mention the long-standing Deaf culture and identity, the increasing accuracy and commonness of prenatal diagnosis, advancements in prosthetics, adaptive communication devices, and disability-related bio- and medical technologies have all shifted disability more and more into the realm of choice. This is because prospective parents can more easily decide if a child with disabilities will be born, and because growing identity categories and advancing technologies broaden the scope of possibility for "doing" disability. (These hypothetical prospective parents and people with disabilities are, of course, those for whom such choices are made accessible by class and racialized status; this is explored in the conclusion.) For example, cochlear implants, which allow deaf people to "hear,"[13] create a number of choices: parents of deaf infants must choose whether or not to implant their child (the cost of implants is covered by most insurance), which will largely determine if they will or will not learn sign language (through private lessons) and if they will send the child to a Deaf school (private and funded for deaf children) or hearing school (public or private). For non-implanted deaf children of Deaf adults and Deaf adults themselves, a cochlear implant will remain an option for life, and with it, a number of considerations about the relationship between language and identity, culture and ability, and the meaning of deafness.

The narratives examined in this chapter demonstrate other ways disability can become individualized and brought under the banner of diversity. Extraordinary narratives claim and celebrate the difference of disability by arguing that disability makes children special in an important way, and importantly, in the salient and familiar terms of individualism and consumerism: parents, and by extension, readers, are quite literally getting something wonderful in return for their investment (in the child; the cost of the book). These narratives do not seek to normalize disability in childhood by minimizing the difference of disability, as seen in the narratives discussed in chapter one. Rather, they reflect the cultural salience of

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[13] Cochlear implants do not allow a deaf person to perceive sounds exactly as they are produced. Rather, cochlear implants send sound signals to the user's brain. These signals quickly become coded by the brain to translate to meaningful words and sounds.

individuality, the importance of the differences that unite us as consumers of identity, at the same time that they perpetuate the reduction of human interaction to cost and benefit through the explicit exchange of investment of time and resources with self-improvement.

In these ways, narratives of extraordinary childhood disability are good examples of what Lauren Berlant describes as "a relation of cruel optimism," or an attachment to or desire for a thing that actually inhibits one's flourishing (*Cruel* 1). At the individual level, parent-memoirists are addressing their own personal crises: shattered expectations about their child, fear for their child's future, challenges securing accommodations in school and the community, and obstacles to full inclusion for their children and themselves as parents. At the collective, perhaps generic, level, these memoirs demonstrate a shared historical sense[14] of threat to health and happiness engendered by decades of neoliberal economic policy, reflected in the awareness of vulnerability that comes with a subordinated racial, gendered, economic, sexual, or ability status. Berlant explains that intensifying "class bifurcation, downward mobility, and environmental, political, and social bitterness that have increased progressively since the Reagan era" (*Cruel* 11) have made more people keenly aware of just how out of reach the "good life" really is. The "good life" names an expectation of "upward mobility, reliable intimacy, and political satisfaction" (*Cruel* 10). It is the expected outcome of life in the U.S.; in reality, it names what we think of as "normal," or ordinary existence under capitalism. For parent-memoirists—who are almost uniformly white, heterosexual, and middle to upper-middle class[15]—the birth of a disabled child brings into relief the structural contingencies that threaten achieving a "good, normal" life. Writing disability in terms of benefit, rather than cost, contains the threat and allows parents to remain optimistic that the

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[14] Berlant discusses how consumers/readers of a thematically similar literature and culture shared worldviews that derive from common historical experiences in *The Female Complaint*. She calls this an "intimate public," a receiving audience made intimate though a sense of shared identity (viii).

[15] This is explored in detail in the conclusion.

promise is still theirs. Their optimism is cruel (Berlant), however, because it both relies on and perpetuates the idea that disability is wholly tragic unless it yields extraordinary benefits to those in its proximity.

Extraordinary narratives evince an attachment to the ideals of neoliberalism, especially its rigid expectations for productivity, self-management, and self-improvement, despite the way these ideals and expectations are incompatible with widely held assumptions about disability. These narratives intend to be liberating, and indeed, affirming, yet they do little to challenge the existing rationality that measures a person's worth in terms of their market value alone. Thus, while special needs memoirs challenge the ableist notion that disabled people are strictly burdens on their families, the community, and the state, they do so in a way that reaffirms, rather than challenges, the very schematic that devalues disability because of its assumed foreclosure on the individual person's potential for productivity. To construct a narrative of benefit and yield does nothing to challenge the way human value is linked to productivity under neoliberalism. In other words, extraordinary narratives fail to challenge the system of value that excludes disability in the first place; they simply shift abjection onto bodies and ways of being that are unable to be recuperated according to these terms.

Teachers, gifts, and gurus

This chapter will look at several memoirs to discuss how parents construct narratives of extraordinariness and challenge the assumption that raising a disabled child is strictly a burden. Like the narratives examined in chapter one, gender normativity is both taken for granted in extraordinary narratives, and/or used to articulate the parent's sense of loss or grief, as seen above in Kelle Hampton's memoir. For Hampton, Nella's disability compromised her gender status. Hampton was unable to imagine a child with Down syndrome filling the role of sister and daughter according to the strict, gender-normative terms Hampton had plotted out during her pregnancy with Nella. Hampton assumed that Nella would grow up to be a straight, ciswoman. She had hoped that Nella and Lainey would walk in each other's weddings and share the joys of motherhood (70). After the diagnosis, she doubted Nella would ever commiserate with Lainey about lazy husbands and rude children (37), because as far as Hampton understood, people with Down syndrome do not grow up to be parents or spouses. This is the pain that Hampton describes feeling most acutely. She felt that the heteronormative sister she had promised Lainey had been replaced by a disabled sibling who, instead of providing companionship, would require care (70, 155), and instead of becoming Lainey's confidante and co-conspirator, would require protection and would cause Lainey to be shamed and teased by others (153).

Hampton eventually overcomes her grief and lets go of her guilt. Part of this process is recognizing that Lainey, only two years old at the time of Nella's birth, neither shared Hampton's sense of disappointment about the "kind" of sister Nella was nor Hampton's expectations for the sister Nella might be. But the process was also motivated by the shift in how Hampton imagined Nella. As she began to understand herself as lucky, "chosen" to be Nella's mother, she began to see how the benefits of Down syndrome—namely, to improve the lives proximal to it—would extend to Lainey as well. Lainey might not get the sister Hampton had promised, but she would get "so much more" (152).

Kelle Hampton's memoir is an example of how neoliberal logic contains disability's threat to normalcy. Hampton also clearly shows how disability's threat can be imagined and understood largely in terms of gender failure. In the examples below, we can see the way the entanglement of gender and ability manifests in normalcy. This entanglement denies disabled children access to normal childhood because of the ways in which childhood itself is made intelligible by gendered ability. The exclusion of disabled children from normative childhood narratives is difficult to overcome because of the way gender depends on able-bodied enactment, and the way ability is understood in terms of gender (as explained in the introduction). By claiming inclusion via neoliberal narratives of value and exchange, parent memoirs elide the narrative exclusions that operate along the gender-ability axis.

The benefits of raising a disabled child take different forms in the memoirs under analysis in this chapter. Susan Zimmermann, author of *Keeping Katherine*, learns to love less conditionally. Paul Collins is able to place his son—and himself through proximity—in the company of geniuses in his memoir *Not Even Wrong*. Amy Julia Becker and Martha Beck both gain profound, life-altering insights about spiritual truths from their children Penny and Adam. In other memoirs (not reviewed in this chapter), a child's disability inspires their parents to change careers in ways that bring them deep satisfaction and a sense of purpose (*Melanie, Bird With a Broken Wing*; *Dana's Legacy*). In *Jesse, A Mother's Story*, Marianne Leone transforms into a "warrior mother" who battles grief, fear, and school districts, inspired and led by her "warrior boy," Jesse.[16]

In writing a memoir, parents are engaged in creating, and/or recreating, identities for themselves and their children in response to disability's disruptions to typical expectations for the life course. Disability "demands a narrative" (Couser *Signifying* 16) in the sense that difference compels an explanation, but also because disability and illness are recognized as paradigmatic forces for self-change (Frank "Rhetoric" 39). In other words, there is an expectation that disability and illness have a profound effect on a person's sense of self. As Arthur Frank explains in his work on illness narratives, the onset of disease or disability creates a different self—an ill or disabled self—but one that is tethered by memory to the previous (healthy and able) self (43). Narrating this change is a means to re-recognize the

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[16] Jesse's story is discussed in chapter three of this dissertation.

self. The new self emerges in narratives as either truly unchanged (the person I have always been, but did not realize, (Frank 43), or radically new (Frank 44).[17]

Disability operates differently in parent memoirs than in autobiographies (including the illness narratives discussed by Frank) because parents narrate both the creation of their children's identities and the re-creation, or the terms of re-recognition, of their identities as parents. These are intertwined: the memoirist constructs their self in relation to how they have come to understand their child's self. To validate their narratives—to be recognized by readers—parents draw on familiar cultural scripts for gender, ability, and development, and existing rhetorical schemes. G. Thomas Couser writes in *Signifying Bodies* that the most preferred narrative of disability is the story of triumph over adversity (33). Extraordinary narratives satisfy the demands of the literary marketplace by adhering to the preferred plot in which disability is not only overcome, but the new selves that emerge in the wake of its disruptions are better off than they were before, or better off than they were expected to be. The memoirs discussed in the previous chapter triumph over adversity by claiming ordinariness and minimizing the difference of disability. The memoirs discussed in this chapter triumph through claiming exceptional difference. In both articulations, these memoirs comply with neoliberalism's expectations for self-improvement.

Of the thirty-eight memoirs I have read for my dissertation research, fourteen can be categorized as "extraordinary" narratives. The shape of these narratives emphasizes a profound improvement in the parents' lives that results from their child's diagnosis. The children in extraordinary narratives are described as teachers, who show their parents how to become better, braver, or wiser. They are described as gifts to their parents, bestowing privilege through proximity (as Nella does). Or, they are gifts to the world because of their genius, or because they inspire others to see beauty and goodness where they assumed it was

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[17] The child that has "always been the same" is a theme of the "ordinary" memoirs analyzed in chapter one of this dissertation; the "radically new" parent is the theme of this chapter.

absent, and in doing so experience joy themselves. These children are also described as gurus or spiritual guides. Their disabilities connect them to a spiritual realm and through this connection, they possess spiritual knowledge that they share with others, and others are blessed and enlightened. Often, disabled children in extraordinary narratives are described in a way that combines these categories. In every case, extraordinary narratives frame disability in terms of the benefits gained by those proximal to the disabled child, and in doing so, do little to challenge or deconstruct harmful stereotypes and narratives of disability.

Keeping Katherine

Katherine Zimmermann was born in 1981 to Susan and Paul Zimmermann, in Denver, Colorado (Zimmermann 21-22). Katherine has Rett syndrome, a neurodevelopmental disorder marked by intellectual disability, loss of purposeful hand use, seizures, and mobility limitations (Rett Syndrome Fact Sheet). The onset of Rett syndrome occurs after a year or two of typical infant development (ibid). It is caused by a gene mutation on the X chromosome, and affects females almost exclusively (ibid).[18] Katherine developed as she was expected until she was approximately six months old, though her developmental delays were not addressed until after her first birthday (Zimmermann 37).

In medical terms, Katherine’s disability would be categorized as profound (DSM-5). Her intellectual disabilities and mobility limitations compromise Katherine’s independence and her ability to care for herself almost totally. She is completely non-verbal. In Katherine’s mother’s terms, Kat “*does* nothing” but “simply *is*” (140). Zimmermann was devastated by Katherine’s disabilities. As Katherine began more and more to exhibit symptoms of Rett

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[18] A mutation in MECP2 causes Rett syndrome. Due to X-inactivation, about half of all X chromosomes are “turned off” at random throughout the body of genetic females (XX). This means that females with Rett syndrome still have a half-set of functional X chromosomes, which mitigates the expression of the Rett mutation. XY fetuses (typically boys) have no such protection. In XY fetuses where the X gamete carries the mutation, every cell will be affected. This proves to be almost totally fatal (Rett Syndrome Fact Sheet).

syndrome her mother quit her job and devoted herself full-time to intervention therapy (60-64). She enlisted dozens of neighbors as volunteers into a home-based therapy practice based on the idea of "imprinting the developmental stages of a normal child onto the brain of an injured child" (59). "Patterning," as the regime was called, required continuous therapy "from dawn until dusk" (59). The Zimmermanns and their neighbors practiced patterning 365 days a year for three years (61). Katherine made little developmental progress but Zimmermann struggled with the decision to seek other options for Kat. Zimmermann described "despair and darkness" descending on her home and family (12). She felt unlucky (103), burdened (50), bitter, resentful, and angry (83; 80). She wished for her own death (73), and prayed for Katherine's death (159). She describes Katherine throughout the memoir as a "hurt child," and also likens her to "a dimwit, a retarded thing … a drooling idiot" (50), unable to have a normal life (96), and sentenced to a life of pain (39).

Early in the memoir, Zimmermann describes looking over photos of two-year-old Katherine and writes that she was unable to reconcile Katherine's beauty with her disability. She could not grasp how Katherine could be so gorgeous and yet, at the same time, profoundly intellectually disabled (46). She describes Katherine's delicate features and writes that she had never seen a lovelier creature (22). She clothes her in dresses, tying her silky hair in bows, hoping the "pretty clothes would banish her vacant look" (42). Nurses, Katherine's siblings and their friends, and children in Kat's care center all describe her as pretty (27; 197; 98); and of her four children, three of whom are girls, Zimmermann writes, "Kat was the pretty one" (146). Katherine's beauty and femininity are used to articulate the incompatibility of gender and disability and provide a framework for Zimmermann to articulate her grief. But Katherine's gender also proves the severity of her disability— "she can't talk, can't tell us what's wrong or how she feels ... but look how beautiful and gentle she is. Isn't that enough in this life, to just be?" (228). It is this reduction of Katherine's personhood to mere, beautiful existence that catalyzes Zimmermann's personal journey. It took Katherine's entire childhood for her mother to finally accept her (217), nearly two decades for Zimmermann to move past her pain to a place where she felt she could fully love her daughter (221). And when she does accept Katherine, and is able to love her, she explains that it is because Katherine, silently and passively, has taught her to overcome her expectations and to love unconditionally. Zimmermann explains that Katherine "possesses a haunting reflected life," which means that she enables those around her to see the world through "a different lens," and to see their own "inner weaknesses" (127). Zimmermann's weakness was her initial inability to love her daughter in light of the "inescapable sorrow" of her disability (223). When Zimmermann does realize her love for Katherine, she describes it as a "pure love" (221), one without dreams, nor promises, nor a future (223). In her mind, these things are irreconcilable to disability. By merely existing—and by being reduced to mere existence—Katherine showed her mother how to love without expecting anything in return. Katherine's inert "being" propels action, a "becoming," in those around her. Dehumanizing Katherine in this way allows Zimmermann, and others, to be more fully human.

The idea that intellectually disabled people "reflect" the complex personhood of able-bodied people is a narrative mechanism for asserting able-bodied privilege. It relies on the assumption that an intellectually disabled person does not have an interior life or a sense of self, nor hold opinions or feel desire, and even if they did, their expressions of self and agency are seen as suspect, possibly irrational (Kittay and Carlson 13). Describing intellectually disabled people as "mirrors," or as living "reflected" lives (literally lives that reflect others' lives), refers to the way able-bodied people understand their own complexity in the perceived absence of personhood in the disabled Other. It demonstrates the degree to which personhood is understood broadly to be reserved for able-bodied and "rational" actors. Ability, rationality, and complex humanity are brought into relief against its denial.

Little has been written about using a mirror metaphor to explain the relationship between able-bodied people and the intellectually disabled people with whom they interact.[19] I would like to suggest that the mirror metaphor reflects the interplay of two discourses: first, the idea that children are a sort of "raw" humanity, and thus innocent, or pure of heart; and second, the infantilization of disability, especially intellectual disability (Robey et al.). As discussed in the introduction, there is no universal quality to childhood; rather, childhood is a socially constructed life stage (see Ariès). In the West, one of the prevailing notions about childhood is that children are "blank slates," uncorrupted by adult desires and concerns. This notion was shaped in part by enlightenment intellectuals John Locke and Jean-Jacques Rousseau, who in the seventeenth and eighteenth centuries (respectively) wrote that children were like "white paper" upon which rules of society could be inscribed (Dailey 145). Rousseau likened the nature of childhood to that of the "noble savage": innocent, intuitive, and unconstrained by civilization (Cunningham 113; Gupta 50).[20] Because of the way intellectually disabled people are, to varying degrees, dependent on caregivers and aides, they are often described as childlike. In the instance that an intellectually disabled person is also non-verbal, like Katherine, not only might they be imagined as child-like, but in failing to express their own thoughts, they are imagined to be without an interior life or sense of self. They are seen as embodying the "pure" state of humanity, uncompromised by civilization, and adult concerns. The able-bodied person then, sees in the non-verbal, disabled child, a truth about the human condition, and thereby a means by which to draw a comparison with their own humanity.

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[19] In my research on parent memoirs, the metaphor has been used to describe intellectually disabled people who are also non-verbal. In addition to Katherine, Paul Collins describes Peter the Wild Boy as "a mirror held up to the great men of his time, reflecting their thoughts and dreams and revealing none of his own. All who gazed at Peter's averted eyes discovered something about themselves instead—and about what it means to be human" (10). Ian Brown describes his "severely disabled son" Walker as like a mirror, reflecting much, including Brown's own choices and perceptions (286).

[20] While Locke and Rousseau agreed that children were "blank slates," Locke described the processes of education and socialization as training a child in the way of a rational adult, while Rousseau saw these processes as destroying the goodness and freedom that is innate in children.

This is an active, albeit perhaps unconscious, denial. For example, while Zimmermann insists throughout her memoir that Katherine "does nothing," the narrative is punctuated by incidences when Katherine expresses desires and emotions. In her last chapter, for example, Zimmermann describes her moment of confession, when she admits to Katherine that "it has been hard" to love her, but that she is finally able to do so (220). Katherine responded by staring into her mother's eyes, moving her mouth "trying to mold words that wouldn't come," smiling "the most pained smile" Zimmermann had "ever seen." Katherine had "been waiting all those years for [Zimmermann's] words" (220). In another instance, we learn that Katherine's younger sister, Alice, has made Kat a drawing of teddy bears and hearts, to "keep [her] company when [she's] alone" in her room (215). Zimmermann propped the framed picture against the wall next to the bed in Kat's room, unconcerned that Katherine would roll off her mattress into it. The following morning, Zimmermann found that Kat had not only rolled off her bed towards the picture, but was lying on the floor next to it, staring at the yellow bear (215).

In between these two passages, Zimmermann has written, "Katherine has no wants. She can do nothing. She is defined entirely by her being" (218). Katherine clearly has desires. She desires her mother's attention, at the very least, and derives pleasure, or at least is stimulated by, visual imagery. Zimmermann's narrative, however, depends on denying Katherine complexity and personhood so that Zimmermann can articulate her own personal growth and self-improvement. By insisting that Katherine is nothing more than an empty shell—a child with no future and no promise—Zimmermann is able to overcome the ways her ability to love is limited, and to declare, by the memoir's end, that she is able to love anyone, any*thing*. This makes Zimmermann a better person, and it also compensates for what felt to her like wasted time and effort trying to cure Kat of Rett syndrome.

Feral boys to "eccentric" geniuses: an autistic lineage

Sometimes the personhood of a disabled child is not only recognized, but also exoticized, especially when doing so yields unique rewards to those proximal to the child. At the start of this chapter, I included an epigraph from Alison Auerbach's essay, "Sound, Noise, Music," from the anthology *Monday Coffee & Other Stories of Mothering Children with Special Needs*. Auerbach writes that while autism is challenging for her family to manage, in her son Gabriel's case it has its up-sides, too (190-196). For example, like many people with autism, Gabriel is extremely sensitive to auditory input, and loud noises or cacophonous settings can cause him to become upset and withdrawn. At the same time, this sensitivity is accompanied by what his mother calls an "innate" and remarkable gift for learning and playing music. Alison Auerbach describes Gabriel's experience of sound and music as two sides of the same coin, meaning that his precocious musical ability is inextricably linked to his hyperactive auditory input process (190-191). And though Auerbach dislikes the often-made assumption that all autistic people are savants and that her son Gabriel has a "trick" of his own, she also clearly enjoys the awe Gabriel's musical ability inspires in those around him, especially in his guitar teacher (194-195). For Auerbach, Gabriel's gifts are autism's plus side, and as his mother, she has bragging rights.

Auerbach may be basking in reflected glory. But unlike the glory that results from standardized assessments of, for example, academics or athletics, Gabriel's accomplishments are entangled with his disability. In publicizing and celebrating Gabriel's gifts, Auerbach not only constructs the narrative equivalent of a "My Child is on the Honor Roll" bumper sticker, but also challenges the stigmatization of autism by emphasizing its benefits.

Paul Collins uses a similar narrative to structure his memoir, *Not Even Wrong; A Father's Journey into the Lost History of Autism*. The title comes from Wolfgang Pauli, a theoretical physicist who used this phrase to describe colleagues that disagreed with him (Collins 86).

Pauli argued that his colleagues were "not even wrong" because they were so completely off-base to start with; in other words, "only a person working from the same shared set of expectations" could be wrong, or in disagreement with Pauli (86). Collins writes that we should remember this when trying to understand autism. He explains that autistic people use different parameters to solve problems and understand their environments than those of neurotypical people. They live, he argues, in an entirely different world (86). According to Collins, we cannot be right or wrong about autism until we shift our expectations to align with the rules that govern what he describes as the autistic mind and world.

Collins' book maps this autistic world. It is a genealogy of sorts that traces the history of autism over centuries by examining the lives of individuals who were singular and strange, as well as the research and writings by those who studied and cared for them. In doing so, Collins erects a kind of archetypical Autistic Person, a figure that embodies the distinction of the autistic mind and "otherworldliness" of autism. Collins uses this figure to justify his retroactive autism diagnoses of various historical figures who were either very eccentric, very brilliant, or both. His narrative establishes his autistic son Morgan as heir to a rich history of talent and giftedness, and as the embodiment of autism's legacy and potential. Collins does this by creating parallels between Morgan's traits, behaviors, interests, idiosyncrasies, and atypical abilities and the same characteristics of a number of people assumed by Collins and others to be autistic. Part history, part auto-ethnography, and part memoir, *Not Even Wrong* attempts to understand autism, autistic people, and Collins' son, Morgan. As a result of his research and reflection, Collins learns about himself and what it means to be human (10).

The first part of the memoir, "The Wild Boy," interweaves an introduction to Morgan with the biography of Peter the Wild Boy, a "feral" child found in 1725 in Hanover, Germany and brought to London in 1726 by order of King George I. The section begins with a visit to Morgan's pediatrician, which yields a concerned recommendation for a developmental evaluation. Like Morgan, who can talk but “chooses not to” (7), Peter the Wild Boy “refused to speak” (48). Peter also proved difficult to civilize, preferring to eat nuts and roots instead of the luxurious fare of King George’s court, and he rarely adhered to social mores (12). He was, however, baptized (23), and thus his civility—and by extension, humanity—was secured.[21] Morgan, on the other hand, whose humanity is arguably assured in both law and custom, can scarcely tolerate being bathed (23), a point Collins contrasts with Peter’s successful baptism.

At the conclusion of “The Wild Boy,” Collins is in a library researching feral children and stumbles upon a brief passage in sociologist Werner Stark’s *The Social Bond*.[22] In this passage, Stark discusses sociality and the degree to which individuals raised in (or who have spent a great deal of time in) isolation can achieve appropriate and typical social behavior. He uses cases of “wolf children” and feral men (Stark 109, 105) to support the discussion, and briefly engages with Bruno Bettelheim’s 1959 paper “Feral Children and Autistic Children,” in which Bettelheim argues that *all* feral children were actually autistic, abandoned to nature by their families because of their autistic symptoms (Stark 114).[23] Collins claims that for Stark, Peter the Wild Boy presented “an early case of autism” (Collins 57). Upon examination of Stark’s text, however, one finds that Stark is in fact critical of Bettelheim’s assumption, arguing instead that the isolation endured by abandoned children more likely resulted in autistic characteristics (Stark 114, 116). In addition, Stark does not actually

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[21] There are clear links in colonial discourse regarding the less-than-human status of “uncivilized,” “savage,” colonial peoples. Forced participation in European commerce was accompanied by forced conversion of colonized people (e.g., McClintock; Said). Once baptized, the soul of the human could no longer be denied, since by Christian doctrine it was recognized by God. This was not, however, a universally held belief in the 18th century. Rousseau, for example, argued the opposite: that man was most truly human in the “uncivilized” state before language, morality, and knowledge. For Rousseau, the divine (the Christian God) was in nature itself (cited in French 1429).

[22] Collins mistakenly describes Stark as an anthropologist. Werner Stark was a sociologist and an economist. Collins cites *The Social Bond: An Investigation into the Bases of Lawabidingness.*

[23] Bettelheim was a self-educated psychoanalyst who established and ran a clinic for autistic children in Chicago during the 50s, despite having no training or education in developmental psychology or the treatment of disabled children.

comment on Peter the Wild Boy, but focuses his discussion on Victor, the Wild Boy of Aveyron, and Kamala and Amala, feral girls found in Midnapore in the early Twentieth Century (Stark 109).

Though the connection is flawed, Collins nonetheless uses Peter's story to catapult the rest of his autistic genealogy. In the next section readers meet the boys who "[fell] from the sky" (Collins 64) and landed in Dr. Hans Asperger's Vienna clinic in the 1930s, boys Dr. Asperger described as "talented eccentrics living among us, albeit in a sphere of their own" (87-88). In Bruno Bettelheim's clinic in Chicago,[24] autistic behaviors led Bettelheim to conclude that autists live within "a protective shell" (71). Collins learns from Asperger that autism's chief characteristics include being born male, preferring "solitary pursuits," a habit of focusing deeply on a single task, and possessing a "fascination with logical systems matched only by social awkwardness" (90). In Cambridge and the office of leading contemporary autism researcher Dr. Simon Baron-Cohen, Asperger's characterization of autism is confirmed. Baron-Cohen informs Collins that "'the paradigm occupation for [the typical autistic] cognitive profile is engineering,'" and that autistic boys figure disproportionately among the children of engineers and mathematicians (Collins 90).

Asperger, too, noted that the boys in his clinic were remarkably good at math (64). And indeed, Morgan was counting double digits and doing simple arithmetic before his third birthday (Collins 7). Collins connects the theme to two of recent history's most notable mathematicians, Sir Isaac Newton and Alan Turing (92, 214; 106-109), men Collins describes as extraordinary (92) and curious (107). But rather than pigeonhole his precocious progeny, Collins expands the range of autistic giftedness and brilliance. He describes the life and perspective of well-known autist and advocate Temple Grandin, whose expertise lay in

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[24] Collins rightly points out that Bettelheim was not actually a doctor. His doctorate was in art history. Collins also notes that after Bettelheim's death his methods were scrutinized and his theories largely rejected by the psychological and medical communities.

animal science (179-80).[25] George Fields and Septimus Piesse were famous nineteenth century synesthetes who published works on the colors of sounds and the sound of odors, respectfully (123-128). Brothers James and William Pullen were talented artists who made drawings, engravings, sculptures, and lithographs, all with astonishing detail, from within the asylum where they were institutionalized in the 1850s for being "ineducable" (134). And Henry Darger, a reclusive janitor who lived alone in a Chicago tenement from 1930 until his death in 1973, produced the longest unpublished work of fiction "in human history," a fifteen-thousand-page epic accompanied by hundreds of drawings, some spanning twelve feet in length (204). Darger also kept detailed records of the weather in his diary (210).

While their talents and interests were diverse, these figures shared an atypical way of being in the world that registers to Collins, and others, as special: Peter was perhaps "infinitely more happy" than his "better taught fellow Brutes" (Defoe cited in Collins 40); "Asperger's charges were capable of feats of incredible brilliance" (Collins 67); James Pullen was called the "Genius of Earlswood Asylum" (Collins 132); Temple Grandin's slaughterhouse designs have "done more to reduce suffering in the world than any other person who has ever lived" (Newkirk, founder of People for the Ethical Treatment of Animals (PETA), cited in Collins 180); and Turing, of course, saved the world from the Nazis during World War II (Collins 106). Morgan, the "happiest child" Collins has ever seen (175), the precocious reader (7) who associates shapes with colors (119) and tends to avoid conversation (148), figures in Collins' narrative as next in the long line of eccentric geniuses. The problem with Collins' narrative, however, is that aside from Temple Grandin, the children in Asperger's and Baron-Cohen's clinics, and Morgan himself, the people comprising this lineage were not diagnosed with autism.

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[25] Grandin is one of three females with autism mentioned in the text. The other two were girls brought from their homes to live in Bettelheim's clinic (Collins 79).

In 2011 historian Lucy Worsley and geneticist Phil Beale of University College London concluded that Peter the Wild Boy's symptoms were more characteristic of Pitt-Hopkins syndrome, a genetic disorder characterized by distinct facial features and cognitive delay, including profoundly underdeveloped language abilities (Kennedy n.pag). Collins' memoir was published in 2005, before Peter was re-retroactively diagnosed. Still, Peter the Wild Boy could not have been autistic, since the condition did not exist before Dr. Asperger and Dr. Leo Kanner both first used "autistic" to describe the symptoms presenting among the boys in their respective clinics in the 1940s.[26] Neither could Sir Isaac Newton, the Pullen Brothers, Fields, nor Piesse have been diagnosed, since each of these men lived and died before Asperger and Kanner's time. It has been popularly speculated that Turing and Darger were autistic, but these are posthumous diagnoses based on anecdotes about their mannerisms and habits (O'Connell and Fitzgerald 28-30; MacGregor 660-661).[27]

Why would Collins construct such a story? To what ends does he assume that unusual habits of concentration and attention to detail necessarily indicate autism? Collins' broad-brush strokes paint every quirky somebody who was exceptionally good at something as autistic; in doing so, anyone whose behavior might be described as idiosyncratic or strange can be assumed to be a genius. We see this in a passage towards the end of the memoir. Collins is dining alone in a café and is approached by a middle-aged man in a windbreaker who shares with Collins his vast wealth of knowledge about the effects of painting light bulbs

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[26] Dr. Kanner's paper on "infantile autism" was published in 1943 in the United States, and Dr. Asperger's paper on "autistic psychopathy" was published a year later in Vienna. Communication between the two countries was cut off due to World War II. Collins calls this an "odd quirk of history" (66). Others have speculated their nearly simultaneous publications were a conspiracy, others have assumed coincidence, and yet others argue there was a middleman. See Baron-Cohen ("Leo Kanner") and Robison.

[27] Cornelia Dayton cautions against posthumous autism diagnoses in her article, "'The Oddest Man that I Ever Saw': Assessing Cognitive Disability on Eighteenth-Century Cape Cod." She explains, despite any constellation of symptoms resembling autism that emerges in the historical record the diagnosis is not truly applicable and positions the historian who makes such a diagnosis problematically as an "objective" researcher. Even so, Dayton argues for thinking historical cases of cognitive disability through the "prism" of autism, rather than a diagnostic label, allows us to make cross-cultural comparisons of treatments and understandings of disability.

different colors. Collins assumes the man is autistic, and also that he is brilliant, the “Isaac Newton of light bulbs” (211-214). Both may be true, neither is certain, but the assumption is pivotal to Collins’ project. If unusual social behavior *always* indicates autism, and autistic otherworldliness often conceals brilliant insight, then Morgan Collins is a very special boy, and there is nothing at all wrong with him.

Collins’ story is ultimately about is how the world benefits from people with autism. By emphasizing the good of autism, Collins challenges the stigmatization of neurological difference: “it’s as much an ability as a disability,” he decides (161). His narrative however, fails to honestly portray autism, not only because the figures he describes do not actually have autism, but also because he focuses almost entirely on high-functioning individuals (with the exception of Peter the Wild Boy). As such, *Not Even Wrong* contributes to a persevering cultural obsession with the autistic-savant like Dustin Hoffman’s character, Charlie, in *Rain Man*, the preferred style of disabled person that is not too difficult to manage, and whose skills, habits, or intelligence benefit others. Collins suggests that the key to unlocking an autist’s potential is simply to let them be themselves: to support their curiosity and allow them to be “guided by their own inner world” (214). To a degree, Collins’ suggestion represents a shift from the medicalization of autism spectrum disorder and the prioritizing of cure and “recovery.” Indeed, Collins circumvents any engagement with the mysteries of autism’s etiology and the cultural imperative to find its cure by rendering both discourses irrelevant in light of autism’s beneficial yields. Collins’ emphasis on the “otherworldliness” (91) of autism, however, is exoticizing and dehumanizing. His repetitious, awestruck references to autistic difference— “they are in their own world” (201; e.g. 13, 137, 66, 86), as “aliens among humans” and yet more human than humans (161)—exceptionalize high-functioning autism without actually challenging exclusion. Instead, autism becomes the key characteristic of some sort of club for extraordinary children, but in particular, extraordinary boys. Indeed, when Collins enters Morgan's all-boy autism class for the first time and remarks, "It's like a family reunion" (223), it becomes radically apparent to readers just how far Collins has taken his notion of an autistic genealogy.

Research does suggest that there is a genetic component to autism. Studies have shown, for example, higher rates of heritability among both mono- and dizygotic twins, and a significantly increased rate of diagnosis among siblings compared to the total population (Freitag n.pag). No studies to date, however, have demonstrated sex-specific genetic influence on the heritability of autism (Freitag n.pag). Boys, however, are diagnosed with autism at four times the rate that of girls (Rivet and Matson n.pag). In the 1940s, both Asperger and his U.S. contemporary Dr. Leo Kanner noted the gender disparity among their patients (Rivet and Matson n.pag). Building off Asperger's work and an assumption of innate, biological sex-based differences in neurology and cognition, Baron-Cohen has argued that autism is "the extreme male brain" (*Essential* 149). But, other studies suggest sexually dimorphic autistic phenotypes (Van Wijngaarden-Cremers, et. al; Hiller, Young, and Weber 75). In other words, the disparate prevalence of autism among boys and girls may have less to do with sex and more to do with existing diagnostic criteria and a bias towards male-typical presentation that overlook symptoms of autism spectrum disorder (ASD) in girls.

When Collins wrote and published *Not Even Wrong*, it was in the midst of rapidly increasing rates of ASD diagnoses (Centers for Disease Control),[28] and increased public awareness about autism and ASD. Autism Speaks, the largest autism advocacy organization in the U.S., was established the same year Collins' book was released. Andrew Wakefield's (now-retracted) article, which falsely claimed that autism was caused by the measles-mumps-rubella vaccine, had been published in the *Lancet* a few years prior (Wakefield et. al, 1998)

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[28] While prevalence has increased since the 1960s, several studies question whether what we are witnessing is an actual increase in the number of cases of autism or if the broadening of diagnostic criteria and more widespread recognition of ASD can explain the increased prevalence. See Fombonne 2009.

and had engendered a huge response from the media that reverberated for years.[29] *The Curious Incident of the Dog in the Night-Time*, a novel about an autistic child with a keen interest in train schedules and a gift for solving equations, was published in 2003 and received a number of book awards and a great deal of publicity.[30] Importantly, Christopher Boone, the novel's autistic protagonist, is a fifteen-year-old boy. Eleven of the twelve children in Wakefield's study were boys; the founders of Autism Speak established the organization after their grandson was diagnosed with ASD; and countless online and print news articles reiterated the refrain: "nationwide, autism strikes three to four times more boys than girls" (e.g., "6 Facts You Need to Know"). The fact that there are only boys in Morgan's autism class would come as no surprise for readers, and the link to masculinity, the thread connecting autism to being male that has woven throughout Collins' story becomes, at this moment, vibrantly clear.[31] As it does, Morgan's inheritance is secured. He is autistic, he is a boy, and his autistic forefathers were geniuses.

Collins' subtle emphasis on heritability and continuous appeals to autism as "another world" conveys that people with autism comprise a tribe of their own. In the end, his "journey into the lost history of autism" yields a phallocentric family tree, within which Morgan can be found and will blossom. Collins' last line in his memoir states that his story is "not a tragedy, it's not a sad story, it's not the movie of the week," but it's "his family" (229). Morgan's tribe of geniuses, it seems, is Collins' too, by proximity. It is not insignificant that

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[29] According to Ben Goldacre, writing for *The Guardian*, there were over twelve-hundred news articles published in 2002 about the MMR-autism link. Goldacre cites Tammy Boyce, *Health, Risk and News: The MMR Vaccine and the Media (Media and Culture)*, Peter Lang, 2007.

[30] Guardian Children's Fiction Prize; Costa Book of the Year; Waverton Good Read Award. The novel was also adapted for stage. It debuted in 2012 and has won numerous awards, including the Tony Award for Best Play.

[31] Temple Grandin is an obvious exception to the male-dominated lineage Collins constructs. It is worth noting, however, that Grandin is considerably gender non-conforming. In addition to her interests in livestock, ranching, animal science, and biochemistry, Grandin keeps her curly hair cut short, does not wear make-up, and dresses in non-formfitting clothes, usually denim pants with a big silver belt buckle, and western-style button-up shirts with a slim tie scarf. Some have speculated Grandin may be a lesbian. These rumors are based on Grandin's gender presentation and the depiction of her close relationship with her college roommate in the 2013 biopic *Temple Grandin*.

Collins notes that his father was an engineer, his father-in-law was a musician and math major, and his brother holds a doctorate in computing (96). Collins is conspicuously absent from the list of family members that have occupations typical of what Baron-Cohen calls “geek syndrome” (Collins 90). This is put right, however, in the pages immediately following: Collins may not be an engineer, but as a child he was removed from a mainstream classroom and placed in special education on account of his “fits”: episodes of hand flapping, clapping, and erratic movements, and at times being so lost in thought that his teachers wondered if he was deaf (102). It is perhaps in this—the narrative arc that bends toward a shared family history, even suggesting that Collins himself exhibited symptoms that one might find among autistic individuals—that we find a clue as to why Collins would go to such great lengths to raise this family tree, literally crossing continents in search of a story to make sense of autism and his son Morgan. The alternative to this lineage—the sensationalized depiction of autism as painfully detached, self-obsessed, anti-social, and unable to love—is a challenging prospect for a parent to face. Collins’ lineage not only connects Morgan to a network of inspiring, world-improving men (and Temple Grandin), but it connects Morgan to Collins himself, through masculinity, through their shared habits of concentration, and because Collins has solved a sort of puzzle: he has discovered something about the state of humanity reflected in these more-than-human-humans (10). What Daniel Defoe saw in Peter the Wild Boy, Collins sees in the light bulb painter (214). This allows him to see Morgan as not even wrong, challenging the assumption that autism is a tragic and life-ruining condition. Morgan is a gift. And while this is undoubtedly true for Collins, proving to readers that autism (and Morgan himself) is desirable depends on a narrative that privileges boy-geniuses at the expense of actually challenging systemic, ableist exclusions.

Penny and Adam: moving from tragedy to inspiration

Penny is a child with Down syndrome and the subject of her mother's memoir *A Good and Perfect Gift*. Like Katherine, Penny is a teacher, but what Penny teaches has implications that exceed the moral economy typically invoked in memoirs. Like Morgan and Nella, Penny is a gift to her parents, and makes their lives better in profound ways. Penny's parents, Amy Julia and Peter Becker, are religious Christians. Becker was trained in seminary (39) and her memoir reads like a testimony to her faith as much as a reflection on parenting a disabled child. Belief in God's providence, belief that every human life is "created in the image of God" and bears "the mark of God's goodness and light," and belief that "brokenness," in mind, body, and human relations, or "everything that [is] wrong in the world," is "a consequence of sin" (46), are fundamental features of Becker's worldview and the measures by which she understands her experiences. Upon Penny's birth, Becker finds herself unable to reconcile the idea of "brokenness" (40) with her beautiful child (46-47). Eventually, parenting Penny brings Becker and Peter to new depths in their spiritual lives, causing them to better understand God and their faith. By teaching her parents that disabled people can be beautiful and lead satisfying lives (57; 140), Penny causes her father's "heart [to] become more open" (38) and she shows him "a whole new world" (140). Penny answers her mother's prayer "to become more real," a process that involves being "broken of [her] pride" (113). And Penny's extra chromosome brings Becker to the understanding that although the "brokenness" of people with disabilities is "more easy [sic] to see," *all* people are equally, albeit differently, broken (127).

Early in the memoir we begin to sense just how Penny fits into this spiritual economy. Becker writes that while still pregnant, and experiencing a somewhat typical ambivalence about the timing of her first pregnancy, she hears a voice in her head telling her that "*this* child" is the one she was intended to mother (emphasis in original, 68). Penny's special importance is continually referenced throughout the memoir. As Becker's sister Kate explains, Penny's extra chromosome "sets her apart," from everyone else, and gives Penny something "more to offer" than anyone in their family (164). Over the course of Penny's first two years, Becker begins to understand that conceiving and bearing a child with Down syndrome is part of God's divine plan to teach her about the limits of her own faith and her own imperfections. Becker resists this idea, writing that she was "angry at the thought that Penny had Down syndrome because [she and Peter] needed to be taught a lesson" (134). At the same time, Penny's parents continuously reflect upon their gratefulness for a child who would "be a blessing," in the sense that she would "minister" to others (79). In Christianity, having a "ministry" refers to being "led" by the Holy Spirit (the third person in the Christian Trinity after God and Jesus) to care for others. Individuals "minister" to others using their particular gifts, interests, or characteristics (e.g. being a woman and leading a women's ministry; being a musician and ministering through music); they may also be "called" by the Spirit of God to minister (care for) a particular population (e.g. a "homeless ministry"; or a ministry for ex-convicts). Penny's parents see Penny "ministering" to others (i.e., everyone) simply by having Down syndrome. Penny is inherently "special," and her ministry will not be limited to any particular population or identity group.

Penny's ministry—which it seems she neither chose nor could avoid due to its biological basis—situates her in God's economy, where value is measured by a different set of terms. In "God's economy" the ultimate purpose is the global dispensation of the knowledge of God in exchange for lives lived in faith and religious devotion (Witness Lee 7-8). Becker binds Penny's ministry to Down syndrome because Penny's "imperfections" cause her mother to realize the degree to which she and her husband value perfection, high intelligence, overachievement, and competence. To drive this message home, Becker begins her memoir with a reflection about herself. Even as a small child, she writes, she refused to pronounce a word unless she was sure she could do it correctly (16). She was a precocious reader and a student at a private boarding school before attending Princeton University and Princeton Theological Seminary. She struggled with an eating disorder and compulsive exercising in high school (57) and described herself and her husband Peter as “well dressed, good looking, in shape” (84). They live in, and Peter runs, a prestigious boarding school not unlike the one they both attended as high school students (56). Readers get the sense that Becker and her husband Peter are cut from a fine cloth, and understand why she expected a healthy and precocious child, a “little version of herself” (33). These descriptions frame the sense of despair she felt upon receiving Penny’s diagnosis and set up Becker’s transition. Penny’s birth and diagnosis are shrouded in a sense of loss. When newborn Penny was taken to the NICU, Becker writes, “she was gone” (23). Readers know that it’s the “perfect,” non-disabled child who is gone, and Becker cries over the child Penny is not (29).

Over the course of the memoir, Becker wants readers to understand that Penny is a rebuke—from God—against her perfectionism, her obsessions with overachievement and intelligence, and her impatience. Penny’s “existence” forces her mother to “recognize the ugly parts of [her]self” (134). She contrasts these ugly parts with her last thoughts in the memoir, where she explains how Penny has caused her to understand the true meaning of “perfection” as “wholeness” (237). This understanding is based on a translation of “perfection” from the Greek word “telos,” found in in the New Testament: Matthew 5:48, “Be perfect [τέλειοι], therefore, as your heavenly Father is perfect [τέλειός],” where elsewhere “telos” is translated as “complete” (e.g. Matt. 19:21[32]), and “the end” (e.g. Matt. 24:13[33]). By letting go of her expectations of perfection—for both her daughter and herself—Becker comes to a deeper understanding of “true perfection” (237), which is the universal broken state of all humanity (40).

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[32] Matthew 19:21 “Jesus answered, ‘If you want to be *perfect*, go, sell your possessions and give to the poor, and you will have treasure in heaven. Then come, follow me.’”

[33] Matthew 24:13 “But the one who endures *to the end* will be saved.”

In this memoir, Penny's specialness is inextricably bound to disability. Penny's specialness, however, has almost everything to do with the positive changes it inspires in her parents and her extended family, and little to do with changing perceptions of disability. Penny's parents have such low expectations of Penny when they learn of her diagnosis, a diagnosis that rocks this overachieving couple to their cores. But Penny surprises them by meeting developmental milestones within normative time (196). Becker's sense of surprise in turn causes her to self-reflect, to ask, "why are my expectations so low?" She encounters her perfectionism, which is ugly to herself and to God. In one and the same narrative arc, Penny is rendered as having a sort of extraordinary Down syndrome that does not significantly delay her development, and which is doubly extraordinary in that it serves as a catalyst for her mother's spiritual growth. Penny is special *because* she has Down syndrome. "To take away Down syndrome," Becker writes, "would be to take away my daughter" (225). Penny-with-Down-syndrome makes Becker a better person. Though she writes that she sees Penny "as a child," as a complex person who "also has Down syndrome" (198), Penny's complexity is recognized through a dehumanizing process in which Becker benefits from having a disabled child. Becker defines Penny's subjectivity in terms of disability, wherein Down syndrome is some sort of vector for divine instruction. Moreover, while Becker concludes her memoir by writing that "true" perfection refers to the messy, imperfect, human condition, it is somewhat ironic that she herself has become a "better" person over the course of her narrative.

A strikingly similar story can be found in *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic* by Martha Beck. Like Amy Julia Becker, Martha Beck is an Ivy League-educated (Harvard), self-described perfectionist (8-9). Her son Adam has Down syndrome, like Penny. Penny and Adam both elevate their parents' spiritual lives in their mothers' memoirs. But whereas Penny is a passive instrument of God's instruction, Adam is a knowing conduit and active participant in his mother's personal and spiritual growth.

As an undergraduate and then doctoral student at Harvard, Martha Beck was obsessed with perfection. Her husband John, also a Harvard grad, was the picture of self-discipline. Beck explains that she was “the kind of person who made elaborate and detailed plans for [her] life several years in advance” (11), and that academic excellence and having a high IQ were among the most important things in her life (127). She provides lengthy descriptions of her studying and teaching loads as a Harvard student and Teaching Assistant (e.g., 151-153); stories about the professors who told her and John that delivering their first baby was not an acceptable excuse for turning an assignment in late or missing class (12). She recounts working through the night, night after night, complaining not about the pressure to be perfect but about her body’s annoying demand for sleep. She writes that admitting to her husband how much she feared failure was the most intimate moment they had shared (9). Beck helps readers to understand just how much she valued high intelligence by admitting—and reiterating—her view that intellectual disability and any “birth defect,” is a tragedy (137). She writes that she had always found “retarded [sic] people” to be revolting (15). When her doctor called her with the results of her amniocentesis, Beck looked at the phone in her hand as “an instrument of destruction” (194), and described the news as “a sack of headstones” (199). Beck thought disabled children were terrifying (31), and expected her son Adam to be ugly (323). Beck felt her pregnant body was “freakish, monstrous, grotesque. The baby inside it was broken. He was substandard” (202). He was the “wrong kind of baby” (198).

Beginning with Adam’s conception, Beck and husband John’s lives began to “slip” out of their control. Like Penny Becker, Adam is living proof of an unseen spiritual force, somewhere between an angel, deity, and clairvoyant, and his connection to “another realm” (e.g., 343) or “the other side of the veil” (3-4) ushers a host of hard-to-explain, miraculous events into his parents’ lives. While still in utero, and long after his birth, Adam communicates telepathically with Beck and her husband, with other clairvoyants, with friends, family, and strangers. He is accompanied by spiritual beings or guides that Beck calls "rescuers" (100) and "puppeteers" (15). The puppeteers orchestrated Adam's conception (11), overriding Beck's good sense and free will. They intervene in the Becks' lives when they need help or are struggling. They send uninvited friends to her door with food when Beck is sick and too weak to grocery shop herself (52-53); they physically save her from a burning building—literally carrying her pregnant body down the stairs and out the door (89-97). The spirits save Beck's and unborn Adam's life after she wakes up in a pool of blood caused a placental abruption and decides, against her doctor's instructions, not to go to the emergency room (163-169). The puppeteers instruct her on how to perform CPR on a child who has drowned in a bathtub (160). The magic that comes with Adam causes a spot to open up at a local daycare that only minutes before had a three-year waiting list (41). The guides send Beck visions, sometimes of other people in real time (48; 109-110). Beck and her husband hear their voices and are told separately by the spirits that their unborn child's name is Adam.

Beck describes surrendering her "common sense" to the enchantment of expecting, and living with, Adam, this child "between worlds" (4). In return, Adam gives Beck "a new set of eyes" (231), the ability to see the truth of the world, other people's true feelings (230). Her new perception causes her to understand that what is good and valuable in the world is the ordinariness of life (74). This means the unimpressive, the unremarkable, and the over-looked, rather than the brilliant, genius, ivy-league level perfection for which she had previously strived. She writes, "Adam has slowed me down to the point where I notice what is in front of me, its mystery and beauty, instead of thrashing my way through a maze of difficult requirements toward labels and achievements that contain no joy in themselves. Adam … is the one who taught me to appreciate rainbows—not only in the sky but also in lawn sprinklers and dish-soap bubbles and patches of oil. He is the one who stops, and makes me stop, to smell the bushes" (327). Adam sees beyond the outward ordinariness "to the magic … inside" (197-198).

Conceiving and raising a disabled child causes Beck and husband John to encounter their own fears of failure and to adjust their perspective on what is and is not valuable. Adam caused them to reconsider their goals in life, to let go of the urgency to "get ahead" they had felt for so long (112). In *Expecting Adam* Martha Beck constructs an image of herself before Adam as someone who has it all wrong, and who is after the wrong things in life. Adam changes that, and causes Beck to see the world differently, in a way she describes as better and more joyful. To maintain her integrity, Beck narrates this radical shift as outside the realm of control. She describes Adam's conception as orchestrated by invisible puppeteers, and the hard-to-explain events during her pregnancy as miracles that happen to her. Again and again she sets up scenarios in which the odds are against her: the daycare waiting list is three years long; she needs desperately to eat, but is too weak to leave the house; the loss of blood is so severe during the placental abruption that she nearly loses consciousness on the phone with her doctor. Again and again, the puppeteers, who guide and surround Adam, intervene and make her life better. And so, she starts to believe in magic, and she begins to understand Adam as magical, of possessing a certain vision, of knowing truths about the human condition and beauty in ways Harvard cannot teach. Beck learns from Adam, and in the process of deconstructing her old identity and value system and surrendering to irrationality and joy, Beck becomes a better person.

Adam also undergoes a change. He figures initially as a great disappointment, "a tragedy," but he transforms into a teacher and a conduit of good fortune. Penny Becker undergoes a similar shift from a subject that inspired fear and grief in her mother (24; 29) to one that promises to bless and edify her parents and community. In this way, Penny and Adam embody two different and broadly familiar ways of imagining disability. Like Nella and Katherine, they figure first as tragic. Later, they are become inspirational. Both are narratives that produce stereotypes about disability that, in turn, actually prevent the full inclusion of disabled people into their communities and broad understandings of what it means to be human.

The understanding of disability as tragic can be located most recently in the eugenicist notion that some bodies are “defective” (Snyder and Mitchell 79). The eugenics movement advocated for the elimination of “unfit” through encouraging reproduction among the “right” kinds of citizens (positive eugenics) and preventing reproduction among the “wrong” kinds of citizens (negative eugenics) by means of forced sterilization and involuntary institutionalization (Snyder and Mitchell 30). The parents of infants born with birth defects or visible impairments were advised to abandon their children to care facilities, a practice which prevailed through the middle of the Twentieth Century (Rose and Michel 242). As late as the 1980s infants with severe disabilities were sometimes denied medical care and allowed to die from minor infections, or else were starved to death (Saxton “Disability Rights” 90). The idea that birth defects or disabilities were tragic was reinforced in the early part of the twentieth century through the circulation of images of disabled children by charity organizations, which used these images to raise money for disability prevention (Longmore 36). “Poster children,” as Paul Longmore has called them, drive home the notion that disability and misfortune are intertwined, and give the impression that even disabled people themselves wish they had never been born disabled. In the contemporary moment, the tragedy of disability is sustained through discourses that question the quality of life of disabled people. It is consistently reinforced through the increasing normalization of prenatal genetic diagnosis and selective abortion of fetuses with impairments, practices which some disability rights advocates call “neoeugenic” (see Tremain 46).[34] Increasingly sophisticated prenatal diagnostic technology

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[34] While the exact rate of selective abortion of fetuses with Down syndrome is difficult to pin down, researchers put it between sixty and ninety percent. See Jaime L Natoli, et al. (2012), “Prenatal Diagnosis of Down

heralds an era in which many disabling conditions could be prevented pre-conception or detected earlier in pregnancy. Moreover, an unrelenting cultural investment in progress and improvement (in health, wealth, and technology) not-so-subtly suggests that disability *should* be detected and prevented.

The sense of tragedy that accompanies the birth of a disabled child is why Rachel Adams' writes that a baby with Down syndrome "demands a story" (108). Rachel Adams means that society demands an explanation for disabled babies' existence. Existing explanations are hardly satisfactory: if parents do not opt for prenatal testing, they are seen as Luddites and irresponsible. If prenatal testing results in a positive disability diagnosis and they choose not to abort, they are regarded scornfully as burdening taxpayers with their child's long-term care and security. Both sets of parents are chastised for inflicting a life of pain and suffering on their children (Piepmeier "Choice" n.pag). These criticisms seriously deny the humanity of disabled children, framing them instead as accidents of birth. Given the existing cultural exceptions surrounding reproduction, including the notion that science and medicine should be able to prevent disability and that expecting parents should play their part in hastening a disability-free future, it is no wonder that many parent memoirists experience feelings of grief upon learning their child's diagnosis. Indeed, as Alison Piepmeier has argued, grief is overrepresented among parent memoirs, even when unhappiness is not the dominant emotion in the families' experiences ("Saints" n.pag). These parents, and their children, have let the nation down.

For this reason, the narrative shift from tragedy to inspiration, or, less abstractly, from a child who is seen as a burden to one who contributes, provides a more satisfactory explanation for the existence of disability. The inspirational disabled person—also called the "supercrip"—frames the distinction of disability in terms of wonder (Thompson "Seeing"

Syndrome: A Systematic Review of Termination Rates (1995–2011)." *Prenat. Diagn.*, 32: 142–153. doi: 10.1002/pd.2910

340). This is the disabled person who overcomes “their limitations,” by exceeding the expectations set for them, which are often very low. In doing so, the disabled person is not seen as pitiful or suffering, but rather someone to be admired for their achievements. The presence of disability and the widespread belief that people with disabilities are faced with too many obstacles to lead satisfying lives makes almost anything disabled people do seem remarkable. The underlying assumption of the supercrip narrative is that disability is so tragic, so defeating, that a disabled person must have an astonishing inner strength to carry on with living. But while a disabled person’s achievement may be as banal as having a sexual partner or buttoning their own shirt, the inspirational narrative is also reinforced through the viral circulation of images and stories about disabled people accomplishing difficult things that seem distinctly at odds with their impairments like being a wheelchair user and a dancer, or graduating from Harvard Law School.[35] (Never mind that graduating from Harvard Law School is an impressive achievement for anyone, of any ability status.) Together, the idea that we should celebrate when a disabled person simply gets out of bed in the morning, and the cultural obsession with stories of “overcoming” disability (doing what the impairment would seem to foreclose), do little to humanize disabled lives. Rather, these figures are positioned as “super” human, extraordinary in the most literal sense. They alleviate the discomfort able-bodied people feel around disabled people by making them into objects of wonder rather than of pity. Furthermore, unlike the “tragedy of disability,” inspirational disabled people embody the (eugenicist) promise of progress through the reiterative act of overcoming their limitations. This makes the inspirational narrative the most preferred representation of disability (Couser *Signifying* 33).

Tragedy and inspiration narratives both reinforce the medical model of disability, which locates disability in the person’s body, rather than in the physical, social, and relational

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[35] “Deaf-Blind Harvard Law Grad Slays Every Expectation, But Don’t Call Her An ‘Inspiration’.” *Oxygen Official Site*.

obstacles to inclusion they experience. The alternative model is called the social model of disability, or sometimes the social-relational model of disability. The social model of disability "is a distinctly materialist structural analysis that sees the experience of social oppression as the common feature of disability" (Scully 38). According to the social model, disability is located in the loss or limitation of opportunities to take part in the life of the community. These losses and limitations are the results of social processes, including stigmatizing representations of disability, rather than atypical embodiment or neurological status (Kafer 5; Piepmeier "Saints"; Piepmeier "Choice"; Longmore 34; Siebers 279). Importantly, the medical model depends in the first instance on understanding disability in terms of loss, limitation, reduction, dysfunction, disorder, or defect, terms and descriptions that convey brokenness, invoke pity, and reinforce the belief that disability is *not good*. The medical model of disability motivates research for cures or methods to eliminate disability. In the absence of a cure, the medical model favors rehabilitation and other interventions that will minimize the difference of disability; or in other words, that aim to normalize the disabled person. Normalization (to any degree) is framed and celebrated as overcoming the limits imposed by the "impairment," and thus reassures our cultural faith in medicine and science to improve the health and wellbeing of the population. The understanding that disability is inherent to the body, rather than the social environment, creates the necessary conditions for the disabled person to embody this preferred narrative of overcoming.

Furthermore, while "overcoming" refers to achieving some degree of normalcy, including any measure of independence in self-care, developing personal interests and pursuing them, or developing a sexual identity and desiring sexual partners, inspirational disabled people are in no real way considered "normal." Framing disabled people as inspirational puts them on a pedestal, which as Amy Shuman and others have argued, actually does nothing to increase inclusion (156). Instead, it perpetuates the idea that disabled people are irrevocably different from able-bodied people and brings into relief what a privilege it is to embody the banal and predictable scripts for normalcy. Some parents may indeed want to "opt out" of normalcy, they may in fact desire to purchase exceptionalism that the commodification of identity offers. But the exceptionalism they claim through extraordinary narratives perpetuates the fundamental exclusion of people with disabilities through the *denial* of ordinariness and banality. What is more, extraordinary narratives depend on a system of exchange that naturalizes disability and renders it static, permanently and essentially exceeding the boundaries of normality, and useful for furthering able-bodied privilege.

Recuperation

The existing cultural scripts for disability are limited, and limiting. At the level of discourse, stereotypes of disability and the circulation of only a few representations of disability reinforce narrative exclusions that have material effects, including the denial of access to education, community, meaningful occupation, relationships, and use of space. The available narratives maintain that disabled people exceed the limits of normalcy and that this is a static, essential quality of the disabled condition.

Little is done to challenge this discursive exclusion in extraordinary narratives, which far from claiming access to privileged narratives of normalcy, position disabled children as super-human, exceptional, otherworldly, and even, "not quite human" (Beck 74). Extraordinary disabled children elevate their parents' moral and/or spiritual lives simply because they are disabled, and because their parents actively shift their understanding of disability from something tragic to something that has moral and spiritual significance. But, at the same time, extraordinary narratives can still be read as attempts to recuperate access to narratives of normalcy, problematic as these attempts may be. While these narratives reinforce ableism in the way they categorically deny disabled children complex subjectivity or the opportunity to embody an identity that is familiar or banal, in writing disabled children into extraordinariness, parents attempt to foster inclusion. They do so via neoliberal rationality and the logics of exchange that over-determine the worth of all bodies and relationships.

These narratives attempt to imagine disabled children in a "good life," one in which they will surely thrive. The conditions of this fulfilling present and future are based on a narrow (and normative) interpretation of goodness and value, one that aligns with neoliberal mandates for self-improvement and upward mobility, autonomy, and the ability to participate in the market in a prescribed way (Berlant *Cruel* 10; Harvey 3). As argued above, market logics over-determine not only how we, in the U.S., conceptualize our abilities and relationships, but inform us as to what we should desire, and where to find and how to achieve fulfillment. In relation to disability, neoliberal logics reinforce the medical model as a framework for understanding disability as an obstacle to be overcome on the path to a meaningful existence.

In *The Four Walls of My Freedom,* Donna Thomson articulates her desire to provide a good life for her son, Nicholas, in explicit terms: the good life, she writes, is having "family and friends, a place of one's own, financial security, choice, and the ability to make a contribution to society" (Thomson 51). From Thomson's perspective, "caring relationships are the key to a good life" but not enough to sustain it (51). For this reason, Thomson, along with other parents of children with disabilities, initiated a program in 1989 called Planned Lifetime Advocacy Network (PLAN), to support their children into adulthood through privatized networks of care financed by families and charitable contributions (50-51). PLAN "network members" are volunteers—family friends and community members—who contribute time and resources to advocate for the disabled person and offer other help and supports (52-53); network members are quite literally volunteer friends (53). Fundraising and volunteer recruitment and commitments are solicited on the basis that people with disabilities, no matter how severe their impairments, are contributing members of society and, importantly, that their status as contributors reserves them all the benefits of citizenship (52) (albeit the delivery of benefits is understood as best removed from state hands). As a non-governmental organization, Thomson points out that children of PLAN families would be protected from cutbacks in state funding over the course of their lives (51).

Thomson's approach to advocacy is informed by Amartya Sen's capabilities model for understanding poverty and assessing its impacts. The capabilities approach, developed in the 1980s and since used in a variety of means to measure growth and development, offers an alternative framework for evaluating whether or not one is living a fulfilling life. The framework measures inequality by the distribution of "capability sets" among people (Burchardt 738). Capabilities are opportunities to achieve desired states of being, which depend not only on ability and practical means, but also on accessible resources. In this way, the capabilities framework accounts for the social, political, and economic environments that affect an individual's "practical opportunities" (Mitra 238) to achieve desirable states. One of the key distinctions between Sen's capabilities approach and other approaches to measuring deprivation is that the capabilities approach takes into consideration one's ability to transform resources into activities. At its core, the capabilities approach measures an individual's freedom to make choices to engage in activities and achieve the lifestyle they find valuable; or, as Sen explains, "the freedom to live a life you value and have reason to value" (qtd. in Donna Thomson 37).[36]

While typically used to assess well-being in circumstances of deprivation, Thomson applies Sen's model to her family's experiences, which include a great deal of privilege (her spouse is a high-ranking Canadian diplomat, 33), as well as the limits Nicholas' disability

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[36] Freedom in Sen's capabilities approach is negative, meaning it refers to freedom from government intrusion.

places on his opportunities for engaging in appealing and meaningful activities (37). Thomson explains that her family illustrates how the capability to “live a life worth living” is truly “dependent on one’s physical and mental characteristics as well as one’s social opportunities and influences” (37). Because Sen’s model is concerned with equity, not equality, each person’s “good life” must be measured within the context of their existing conditions and the degree to which they can “function freely” within them (40). There is “true equity,” Thomson argues, when “individuals are free to convert *all* the aspects of their lives into good (or bad) living” (40). For Nicholas, who has cerebral palsy and chronic pain, and is cognitively typical, this means, among other things, living an adult life with the same access to community, medical care, comfort, entertainment, space, privacy, engaging activities, and stimulation that he received growing up in his parents’ home and continues to value.

Scholars have argued that the capabilities approach is a useful tool for assessing a disabled person’s well-being. It works well in tandem with the social model of disability, which frames the environment (natural, social, political) as the most disabling factor in the lives of people with impairments (Burchardt 735). Economist Sophie Mitra writes that the capabilities approach may even be useful for defining disability (240), because it gives us a framework to assess whether or not impairment yields a deprivation of capabilities (opportunities to exercise choice), or a deprivation of functionings (actually being able to do what one values) (Mitra 241). In Nicholas’ case, his impairments do not uniformly prevent him from exercising choice, because among the factors that contribute to his capability sets are wealth, influential parents, and his own ego (93). However, Nicholas’ capability sets do not necessarily allow him to live entirely pain-free. For Thomson, pain—however sporadic—is an injustice (92) because it prevents Nicholas from living the life he values.

The capabilities approach, as conceived by Sen and operationalized by Mitra and Burchardt, and as a framework adopted by Thomson by which to measure the goodness of one’s life, may provide a model for assessing value that exceeds the limits of neoliberal schemas. If, at the core, the capabilities model is about an individual’s freedom to thrive in their circumstances, this presents alternative value scales in which one might thrive. Specifically, if equity refers to each individual’s freedom to convert all their capabilities into good living, the measure is conversion opportunities, rather than achieving an established set of functionings (e.g., personal autonomy and the ability to self-manage). This, in turn, creates the possibility for embracing dependence and interdependence, and disability as just a few of the myriad characteristics that comprise one’s capability sets. And this potential of the capabilities approach for understanding disability is what makes the “good life” narrative in Thomson’s *The Four Walls of My Freedom* so engrossing. For Thomson, the most way to secure Nicholas’ well-being and his practical opportunities to living a life of value is by shielding him within PLAN, a privatized organization to advocate for Nicholas and act on his behalf if and when necessary, funded by family and charitable contributions. Thomson unambiguously applies Sen’s capabilities approach to assessing Nicholas’ well-being within the existing neoliberal political economy. Nicholas’ practical opportunities to thrive are his, and his alone. Thomson does not deny the injustices of stigma against disability, or lack of access, or an ableist social world; but neither does PLAN do anything to improve the lives of people with disabilities less privileged than Nicholas, nor does the privatization of care challenge the neoliberal economic policies and rationality that perpetuate the devaluation of disabled bodies.

Chapter 3: Hetero/Able Futures and Crip/Queer Discontinuities

Jeremy and the Not-Queer Hat

On the cover of Beth Kephart's memoir *A Slant of Sun* is a black-and-white photograph of a tiny child sitting on a wooden-slat porch. The child, presumably Kephart's son Jeremy, looks out towards an empty suburban street, back turned to the camera. There is a stuffed animal to his left, and on his head is a large hat that has been tinted bright green, the color of key lime pie. It is a "ladies' hat" (Kephart 37): soft, with velvet trim around the wide brim. Early in Kephart's memoir, we learn that shortly before his second birthday, Jeremy becomes obsessed with this hat. He refuses to take it off, even wearing it to bed and in the bath. Kephart's husband demands that she return it to the store, or at the very least forbid Jeremy from wearing it outside the house. Both Kephart and her husband are alarmed and she laments, "the writing [was] on the wall" (38). What the wall says, however, is not immediately clear. Kephart elaborates over the next few pages, beginning with how Jeremy's obsession thrusts both the mother and child into a new, conspicuous cultural space. Walking around town, Jeremy is mistaken for a girl. Neighbors tell Kephart "not to worry"; the child is "definitely in a phase" and that "worse cases have been solved" (39). She interprets the stares from "muscular men in sleeveless ribbed shirts" as a mark of her failure to "raise a man's man" (40). Fretting that people in her community will think her little knowledgeable of fashion or gender, she tries to coax Jeremy into foregoing the hat. Nonetheless, when boys at the playground exclude Jeremy on account of his "sissy hat," she leads him gently away and rallies around his passion (41). "Set your kite high," she tells him, "and hold on" (42).

Jeremy eventually lets go. He loses interest in the green hat, which, after this brief passage, Kephart never again mentions in the memoir. The hat remains pivotal to the narrative regardless, functioning as a sign of Jeremy's yet-to-be diagnosed disability, suspected due to his compulsive behaviors and intense fear of change. Surmounting his obsession with the hat, and the myriad obsessions that precede and follow it, is part of Jeremy's narrative of "overcoming" disability. As G. Thomas Couser writes in *Signifying Bodies*, the preferred story of disability is one of triumph over adversity, figuring disability as inherently compromising to the quality of life (33). Disability thus becomes a "personal defect that must be compensated for" by disabled people themselves (Thomson "Feminist Disability Studies" 1568), who are made responsibility for managing and transcending disabling obstacles.[37] Our cultural preference for that story of overcoming disability (of performing what the impairment would itself seem to foreclose) does little to humanize disabled people, instead perpetuating ableist ideals about what counts as a meaningful life. Indeed, particularly instructive about the hat episode is how it catapults Jeremy towards normalcy: by the memoir's end, he has moved past many compulsions and fears that previously controlled him and is doing well in a mainstream classroom, alongside neurotypical children in the process of becoming his friends. Soon after the hat brings Jeremy and his mother precariously close to gender transgression, a diagnosis of autism spectrum disorder (ASD) makes "the writing … on the wall" legible (38). Jeremy may be abnormal in some ways, his mother wants us to know, but from her perspective, he is *not* queer. The not-queer hat remains a marker of Jeremy's difference—albeit of his atypical neurology, not atypical gender—a symbolic and material obstacle that he must overcome. It emblemizes the denial of queerness that sets Jeremy up for a heteronormative and disability-free future—that is, according to his mother's narrative anyway. After all, by the memoir's conclusion, Jeremy is only seven years old.

The final page of the book features a short dialogue between Kephart and Jeremy. He

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[37] Overcoming narratives rely on the medical model of disability, which sees atypical bodies and neurodiversity as defective and in need of a cure. In contrast, the social model of disability sees impairment as a feature of human diversity and environments as what disables individuals, especially through lack of access and stigmatizing attitudes.

tells her, “Mommy, I know what’s going to happen when I grow up. … I’m going to drive to the church and get a wife. ... Then my wife and me will drive to the hospital and pick up our kid. ... A boy with my same hairstyle” (249). Jeremy goes on to explain that in his future life, his primary role will be “daddy,” to which Kephart replies, “Sounds just right” (249). And, of course, Jeremy’s fantasy does sound “just right” because that is how the story of normalcy goes. This story is perhaps one of the most familiar that we tell ourselves about children and sexuality, and about the future, a story that begins with an ordinary, sexually innocent child and concludes with the heterosexual, reproductive adult. It is a story about a privileged past and future, in which disability and queerness are, as Alison Kafer describes, “out of time” (66).

In the preceding chapters, I trace the entangled narratives of gender, and ability that shape this story of childhood and argue that the logics that govern dominant ideas about childhood are distinctly ableist and heteronormative. I explore how a typical child—or more specifically, a cisgender, able-bodied child—becomes a straight adult, and how disability in childhood disrupts that narrative of maturation. Race and class are also essential components in the construction of normalcy and, importantly, in the production of a “typical” childhood narrative. This chapter explores the entanglements of gender, sexuality, and ability with time, specifically, but it is important to note that access to a “normal” childhood greatly depends on a child’s racial and class status—hence all of the memoirs under review in this chapter, and the vast majority of published special-needs parenting memoirs, concern white middle- and upper-class children. The racialized exclusions of the genre are explored in greater detail in the conclusion. I draw on a number of memoirs to demonstrate how parents write their children into the normative script. I maintain that for the parents of these children, narrative constructions of ordinary heterosexuality or gender-normative extraordinariness attempt to mitigate the discursive and material exclusions engendered by the disability, but do so at the cost of perpetuating heterosexism and ableism.

In what follows I foreground the entanglement of gender, ability, and sexuality with time. Because the cultural construction of childhood is dependent on both nostalgia and future autonomy (as discussed in the introduction), normative childhood is bound by temporal logics that produce and recapitulate a privileging of hetero-ability. I draw on Lee Edelman's concept of "reproductive futurism," which links all politics to heteronormativity and the figure of The Child, ultimately positioning (and celebrating) queerness — in its rejection of heteronormative reproduction — as futureless. In tandem, I use Anna Mollow's "rehabilitative futurism," a phrase offered by Mollow to replace "ableism" because of the way it emphasizes neo-eugenic cultural, political, and sentimental investment in the elimination of non-normative bodies. Similar to the figuring of queerness within reproductive futurism, rehabilitative futurism asks disabled bodies and disability theory to resist "getting better": to resist the so-called better future and the disability identity politics that welcome it. Holding these two concepts together, and exploring the ways in which each is in fact deeply implicated in the production of the other, this chapter ponders the potential for destabilizing childhood narratives and temporalities through appeals to gender fluidity, queerness, and a critical perspective of disability that refuses to see disability as a tragedy or only tolerable to the degree that it can be rehabilitated. Moreover, I consider the construction of gender (or lack thereof) in narratives about children with disabilities who seem, to their parents, to have no future. To do so, I highlight narratives of resistance to medicalization, narratives that question gender and the value system in which parents find themselves negotiating a place for themselves and their child, and narratives that reject the future, or due to illness and death, cannot imagine it. I moreover demonstrate that by disentangling the narratives of gender, ability, and sexuality from time, parent memoirs might point to new possibilities for imagining children and adults atypically positioned within hetero-able normativity.

The Entanglement of Gender, Sexuality, Ability, and Time

As Judith Butler argues, coherent, "intelligible" gender identities privilege a heteronormative alliance of sex, gender, desire, and sexual practice (*Gender Trouble* 23), implicating compulsory cisgender identity in compulsory heterosexuality (Butler *Gender Trouble* 30; see also Rich 27). Robert McRuer contends that however much compulsory heterosexuality "masquerades" as the "natural order of things," able-bodiedness is more naturalized, more normal and normative, than is heterosexuality (*Crip Theory* 1). The material body that bears the conditions of this naturalization is gendered, heterosexual, and able-bodied, with each identity made intelligible only in and through the others (Siebers 175). Meanwhile, "incomprehensible" queer and disabled identities proliferate in the margins (McRuer, "Compulsory Able-Bodiedness" 372; Butler *Gender Trouble* 23).

The normative regime of able-heterosexual identity is also bound to the adult body—not simply because childhood figures as a site for developmental ability and identity, but also because we prefer to imagine children and childhood itself as sexually innocent, even asexual.[38] If not denied completely, childhood sexuality is tolerated only when "innocent of sexual desires or intentions" (Bruhm and Hurley ix). Children who express "interest in sex generally," not to mention in non-heterosexual sex, are seen as deviant (Bruhm and Hurley x). For example, in the memoir *Jesse: A Mother's Story*, Marianne Leone views her son's pre-teen crush on his beloved, beautiful blonde-haired aide Brandy as confirming his gender identity while propelling him toward a paradoxically asexual heterosexuality. Jesse had

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[38] The narrative of childhood sexual innocence represents sexuality as latent, an extension of gender, and virtually incomprehensible to children themselves. See, respectively, Steven Bruhm and Natasha Hurley introduction to *Curiouser: On the Queerness of Children* (ix); Eve Kosofsky Sedgwick's "How to Bring Your Kids Up Gay" (140-41) and J. Jack Halberstam's *In a Queer Time and Place* (211); and finally, Lauren Berlant's "Live Sex Acts (Parental Advisory: Explicit Material)" (67). The pathologization of childhood sexuality is a rich site for research at the intersection of disability and childhood studies, but beyond the scope of this chapter.

cerebral palsy, a seizure disorder, and was almost entirely non-verbal due to muscle spasms. He passed away at age sixteen. Leone's narrative constructs a gender-normative Jesse, preserving the asexual purity of the disabled child's infatuation by portraying his relationship to Brandy without erotic overtones: Brandy appears as "a girl in a fairy tale" (168) whom Jesse's friends had crushes on and Jesse himself "loved with all his heart" (168). Her youth, beauty, and gender conformity consolidate Jesse's boyish masculinity and structure Leone's fantasy of Jesse's future heterosexuality. In one passage, when Jesse, his parents, and Brandy are vacationing at a hotel, Leone writes, "Eight-year-old Jesse and twenty-two-year-old Brandy are wrapped in white terry cloth hotel bathrobes, both wearing sunglasses, both lounging on a chaise by the pool, taking in the sun, Jess [sic] looking for all the world like a tiny mafia don next to his gorgeous girl babe" (163). Later in the memoir, Leone notes that Jesse said "I love you" to Brandy "in actual words," despite his difficulties articulating recognizable speech (162). In this way, Jesse overcomes his disability through the otherwise mundane narrative of heterosexuality. His boyhood crush affirms his gender and promises to deliver on his adult heterosexual able-bodiedness.

The interpretation of children's gendered behaviors provides apparent clues about their latent sexuality to reveal the underdeveloped sexual self that will manifest in the able-bodied, sexually active adult body of the future (Bruhm and Hurley ix). While children like Jesse may "do" normative gender (boyhood and girlhood), their heterosexual identities often remain in limbo. The temporality of an able-bodied, heterosexual adult self originating in a sexually pure child abides to what queer and disability studies theorists call "straight time." Drawing on Judith Halberstam, Kafer writes that "normative narratives of time presume a linear development from a dependent childhood to an independent adulthood defined by marriage and reproduction" (35). Since these narratives take the normative development of human experiences and embodiments for granted, framing them as "natural, common-sense"

(Kafer 35), time is a key factor in producing normalcy (Halberstam, *A Queer Time and Place* 152). Unlike the common-sense, heteronormative temporality of straight time, "queer time" is not subject to the "paradigmatic markers of life experience—namely, birth, marriage, reproduction, and death" (Halberstam, *A Queer Time and Place* 2). Queer temporalities offer alternative modes of living, loving, having sex, and making families, all which defy the logics of straight time.

Given that straight time entails normative development, queerness and disability manifest as overlapping categories that have "no future,"[39] or at most have a future pictured (and tolerated) in curative terms alone. In "The Future is Kid Stuff," Edelman argues that all politics, no matter the regime, seeks to affirm a particular social order and to actualize a social reality to pass on to future generations. For this reason, the figure of The Child is the privileged figure of politics and political futurity and the "emblem of futurity's unquestioned value" (cited in Burman and Stacey 232). Children symbolize the future and the fulfillment of the evolutionary promise through achieving normative development in body and ability. Centering the child as the harbinger of the "better future" naturalizes heterosexual coupling, and thus Edelman argues the symbolic realm of the political is inherently implicated in reproductive heteronormativity: every political vision, in other words, is a vision of heterofuturity. Anna Mollow draws on Lee Edelman's work in order to forward her concept of "rehabilitative futurism." Whereas Edelman argues that queerness – with its rejection of heterosexual reproductive sex – threatens the future imagined in terms of The Child, Mollow argues that "rehabilitative futurism" likewise shapes fantasies about the social order in which the figure of The Child plays central role because justifying technologies to eliminate disabilities in addition to heteronormative regimes (Mollow 288). Rehabilitative futurism speaks to the legacy of the eugenics movement as it infuses current day understandings of

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[39] See, respectively, Lee Edelman's "The Future Is Kid Stuff" (29) and Kafer's *Feminist, Queer, Crip* (28).

disability: the broad, often unquestioned response to physical, intellectual, sensory, or neurological atypicality, and the underlying motivation behind well-meaning but harmful expressions of pity or sorrow: “Oh, she’s disabled? I’m so sorry.” Eugenics is essentially about controlling the future, which is why the eugenics movement was centrally concerned with reproduction and producing genetically fit children. Disability reminds us of the terrifyingly slippery slope by which we might regress to primitivism and away from our perfected, civilized future (Snyder and Mitchell 31).

While after World War II the eugenics movement lost favor with the American public, for many parents, caregivers, and medical practitioners, atypicality and neurodiversity continue to be viewed under the framework of defect, disorder, or disease. As many scholars of disability have argued, the pervasive medicalization of disability positions atypical individuals as in need of a cure or rehabilitative intervention. As an individual “problem,” disability entails treatment, by means of postnatal (if congenital or genetic) or post-onset intervention strategies, drug therapy, and rehabilitation. The medical model is also seen by many disability activists and scholars as the supporting logic of “neoeugenic” efforts to eliminate disability at the genetic level by means of prenatal testing and selective abortion (see Roberts). Indeed, some scholars suggest that the very purpose of genetic counseling and prenatal testing is to decrease the number of babies born with impairments or physical difference like Down syndrome, spina bifida, muscular dystrophy, and sickle cell anemia (cited in Bérubé “New Genetics” 105). In addition, as Alison Piepmeier notes, nearly ninety percent of fetuses identified with having Down syndrome are in fact terminated (“Inadequacy of Choice” 159; see also Natoli, et al., 2010). These are recent figures, despite over thirty years of semi-inclusive education for atypical children and more than twenty years since the passing of the Americans with Disabilities Act (ADA 1990), which prohibits discrimination on the basis of disability. Discrimination persists, nonetheless, and does so in the name of

The Child. The figure of the *disabled* child, however, communicates a failure to actualize rehabilitative and reproductive ideals and thereby threatens the onward march of progress.

Pushing back against normative regimes, Edelman and Mollow respectively articulate a politics of negativity, an oppositional positionality that refuses to be on “the side of the child” (Edelman “The Future” 18-19). Queer oppositional politics, Edelman argues, must tend toward redefining a civil order divorced from the concept of futurity. In the same way Edelman theorizes queerness as fundamentally negative, destructive, and in opposition to the creative, Mollow theorizes disability by means of identity disintegration, lack, and suffering. She argues that disability is inextricably bound with the cultural politics of queerness in the way it too threatens the “better,” future and in the way disability and queerness are disciplined in tandem by reproductive- rehabilitative logic. Moreover, Mollow writes that she takes “seriously” Edelman’s definition of queers as universally “stigmatized for failing to comply with heteronormative mandates” (cited on 291). From this she argues that queerness is the available and appropriate figuration for all those subjects “our culture abjects” (291). Edelman’s is a post-identity apolitical figuration of queerness, one that allows for queers to say “fuck reproduction, and fuck the future.” Extending to disability theory and the abject figure of the disabled body, Mollow writes that a post- (or even anti-) identity politics of disability will problematize the goals of disability advocacy that seek (merely) to enable access or achieve workplace accommodations, and, instead, will rally around the cry: “fuck employability.”

What would it mean, and what would it look like, for a parent of a disabled child to write a narrative in this way? How can a parent construct a story that refuses to abide by the dominant temporal paradigms when doing so requires the embrace of a negative identity, a refusal of hope in progress as manifest in hetero-able futurity, and a resistance to pursuing employability, when “contributing to society” is understood to be *the* most relevant modern-day characteristic of the subject-citizen? Below, I analyze three memoirs that depart from the conventions of the genre in the sense that they claim neither a recognizable childhood nor imagine their children in a "productive," let alone reproductive, adulthood. *The Boy Who Loved Tornadoes: A Mother's Story*, *The Still Point of the Turning World*, and *Schuyler's Monster: A Father's Journey With His Wordless Daughter* each demonstrate the limits of the existing narrative templates. In *The Boy Who Loved Tornadoes* by Randi Davenport, the disabled child Chase's psychiatric disability and long-term hospitalization are so profoundly atypical of childhood that his mother's memoir, while inclusive of his birth and the entirety of his life up to the moment of publication, begins and ends with his psychotic break (age 15-19), circling continuously, erratically, through the years before and up to the initial moments of his recovery. *The Still Point of the Turning World* by Emily Rapp sustains an engagement with the present moment through a repetitive, rhetorical refusal to imagine the future and a narrative structure that attempts to slow time. Rapp writes in this way because her son, Ronan, has Tay-Sachs and will not live past early childhood. The memoir moves incrementally forward in time through a collection of linked essays, each a deep reflection from that moment of Rapp's life with Ronan. Both Rapp's and Davenport's memoirs, and the children about whom they are written, are without futures. Chase and Ronan's childhoods — so unlike what childhood is understood to be — preclude development, futurity, or adulthood, and with these, gender and sexual identity. In contrast, while *Schuyler's Monster* similarly deviates from normative narratives, Rummel-Hudson writes his daughter Schuyler's future as open, queer, and disabled. In other words, Rummel-Hudson's memoir both exposes the limits of the existing narratives while allowing for new futurities to emerge.

Diagnosis NOS (not otherwise specified)

No one really knew what to call this thing that was wrong with Chase. Each moment

> brought with it a new set of words, and those words did not pin down truth. Those words destabilized all meaning: global developmental delay, severe ADHD, pervasive developmental disorder, Tourette's syndrome, obsessive-compulsive disorder, complex partial seizure, Asperger's syndrome, atypical autism, psychosis, absence seizure, epilepsy, mild mental retardation, bipolar disorder, affective disorder, grand mal seizure, seizure disorder, Capgras syndrome, schizophrenia, schizoaffective disorder, movement disorder, movement disorder not otherwise specified, affective disorder, moderate mental retardation, autism, psychosis not otherwise specified. (Davenport 31-32)

When Chase was fourteen, he began to believe he was being targeted for execution by a death squad. He called them "profilers" and was convinced they watched him from rooftops and ceiling vents. Afraid of being poisoned, he often refused food. After a short time, he became unable to recognize anyone with whom he was previously familiar, including his mother and sister. Randi Davenport's memoir, *The Boy Who Loved Tornadoes: A Mother's Story*, chronicles her experience raising a child with severe psychiatric disability. She narrates the years with Chase's father, Zip, before Chase was born; Chase's development and the incremental, and then abrupt, intensification of his mental illness; and the years during which he was psychotic and living in various hospitals. At the memoir's conclusion, Chase is in recovery and lives in a residential care facility for adults with developmental disabilities. At first glance, Davenport's memoir paints a picture of a boy "transformed by illness" (138) yet imminently returning to himself and his mother. However, as Davenport explains, the boy who loved tornadoes, "who loved to dance and read comic books and who always, in [Davenport's] mind, had a future," became only "a dream" (138) after Chase became psychotic. Davenport's narrative admittedly fails to present a picture of wholeness and return, constructing instead a portrait of a child disconnected from his childhood and his future. This is in part because Chase's symptoms lack diagnosis, etiology, or prognosis, and in part because Davenport uses non-linear narrative discourse to mediate her story.

As the passage at the start of this section conveys, Chase was not under-diagnosed. From the age of four, when his mother began seeking care and intervention following Chase's first (apparent) seizure, Chase's doctors diagnosed him with one condition or another. "There's something different about your son" (136), specialists would say, but what it was, exactly, was unclear. As a child, Chase had "symptoms of things but didn't really have those things" (117); and when Chase is a teenager, a doctor explains "[Chase's] psychosis is very severe but he doesn't quite meet the diagnostic criteria for schizophrenia" (135). Davenport wonders if by seeking a diagnosis, "naming things," she had "secured Chase's future" (115), but goes on to write that "it was a nameless thing" that affected Chase, reminding readers that his future remains entirely uncertain (200). Chase's pediatrician hoped an appropriate diagnosis would "clarify over time" (32). One does not; but later, Davenport comes to know Chase *as* his not-specified disability: "[I] saw him as he was … beset with the unseen, the unknown, the unnamable, but arrived into himself completely, as if all of this had been hardwired, preordained from the start" (359). And, while on the one hand, she comes to recognize similar, albeit "milder" symptoms of Chase's fully-bloomed psychosis in Chase's father, Zip (200), she nevertheless insists on the unpredictability of this "thing"; its "start," actually impossible to locate; its end, elusive. In his influential work *The Normal and the Pathological*, Canguilhem writes that it is the very identification, or location, of a disease that allows us to articulate normalcy (40-41). Chase's diagnosis *not otherwise specified* is significant in that it represents the failure of medicine to deliver on its promise to fully know and understand the body and thus undermines hegemonic normality. "Diagnosis" translates from the Greek as "to know apart" or "distinguish"; the addendum "NOS," however, is a catch-all designation for those syndromes, conditions, and states that yet evade naming, constellations of symptoms that have not been mapped and that cast doubt on medical authority.

Medicine's promise to know the body has a relatively recent history in the west, a result of the institutionalization of medicine Michel Foucault identifies as part of the shift from sovereign power to biopolitical governmentality. For Foucault, hospitals are but one several regulating state apparatuses that objectify and bring the subject under biopower; along with prisons and schools, hospitals (the medical establishment) monitor and discipline the body to make it knowable and docile (cited in Sullivan 30). In *Fantasies of Identification*, Ellen Samuels clarifies what this looked like on the ground in the United States. She writes that beginning in the mid-Nineteenth century, a "crisis of identification" emerged in the U.S., demonstrated by an increased effort by scientists and the state to determine knowable identities (2). With the mid-century consolidation of the categorical designation "normal" and the establishment of the American Medical Association in 1845, anxiety intensified around embodied identities, especially those which differed from the "recognizable subject of democracy" (1); namely women, people of color, and disabled people. This led to the development of scientific and medical techniques to definitively identify bodies. One of the earliest procedures to fix identity was fingerprinting; today, our identities are imagined to be reducible to and fully explainable by our DNA (Samuels 186). Medical and scientific identification procedures exist alongside state authentication and state-issued documentation, which Samuels calls "biocertification" (9), that fix identity in public realms of law, security, and health. As Samuels explains, biocertifications are powerful interventions and regulatory controls (161). They determine who is included in a marginalized group and thereby who is deserving of the benefits and protections of related social policies. It follows that biocertification makes moral claims, which further invest the social in the stability of these categories. But the anxiety that circulates around categories of "difference" – including the constant efforts to claim, specify, and measure them – demonstrate the instability of the terms themselves.

Importantly, both biocertification and the diagnostic regimes on which it is based are temporal in two registers when we understand difference as relational to normalcy. Canguilhem explains that in the evolution of medical ideas the pathological state emerged as relationally distinct from the "normal" (read: healthy, 228) state and as such, diagnosis is a mechanism to provoke cure and return to normal function. Disease thus has an inherently temporal quality, in that the movement between states is one that happens over time (however brief or prolonged) and that it motions to future return. This is true even in the case that a condition is congenital: the temporal location of onset (stage of fetal development) is contrasted to what would have "normally" happened at that same stage; then, the characteristics that distinguish the condition from the "normal state" are framed by developmental paradigms indexed by time. The temporality of disease is made further apparent by the language of disease: "etiology," or "cause," refers to the origin of the disease; "prognosis" refers to the likely future outcome of the disease's effects (from the Greek for "before" and "knowing"). As such, both biocertification and diagnostic regimes rely on linear, normative developmental paradigms and mark bodies in normative (or nonnormative) time.

Moreover, biocertification and diagnosis proceed from the idea that our identities are embodied and objectively knowable, and in this way, echo the eugenicist logic that reduces personhood to bodily characteristics. Eugenicists used sex, race, and ability not only to organize groups in a social hierarchy, but also to argue that non-white and non-able-bodied individuals were evolutionary throwbacks.[40] As Douglas Baynton explains, normality (read: white, male, able-bodiedness) "was intimately connected to the western notion of progress,"

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[40] It is also important to note that non-white groups and women of all races were already considered disabled. See Baynton.

and disabilities (including the diagnoses of defect or feeblemindedness given to racialized groups) were understood by eugenicists as “reversions to earlier stages of evolutionary development” (19). Today, eugenicist evolutionary classification of racialized and disabled bodies has been debunked as pseudoscience. At the same time, however, the idea that our identities are embodied and knowable persists and, importantly, the categories fixed by biocertification maintain the regulatory quality of biopower discussed above in the way that they sort citizens into groups worthy or unworthy of state protection. As a result, biocertification draws boundaries around who is, and who is not, a responsible citizen, who does, or does not, embody the ideals of the state. Because, as discussed above, all politics are about realizing an idealized future, biocertification and diagnostic regimes work quite explicitly to classify which subject’s (or group’s) characteristics align with “progress.”

Chase’s diagnosis NOS positions him outside narratives of progress in that he fails to embody the role of the responsible, productive citizen-subject. Chase’s diagnosis NOS means “to not exactly know” and lacks both etiology and prognosis and, as such, is atemporal. Moreover, in his mother’s narrative, Chase *exists* as “diagnosed” in the present moment. He is “set apart,” or “known,” as both language and the memoir convey, by what amounts to be almost fundamental difference. This totalizing atemporal construction emerges clearly, for example, when Davenport writes that the healthy “boy who always had a future” is only a dream (138), but when she awakes, she and Chase “live in a world apart” (1). By foregrounding Chase’s psychiatric disability, entangling it with his identity, and doing so within the medical, scientific, and eugenicist contexts that claim the body is knowable in terms of normative temporality, Davenport’s narrative renders Chase himself as atemporal.

Davenport also destabilizes normative temporality by constructing her memoir in a nonlinear way. She alternates between Chase’s time in the hospital and the years leading up to his psychosis, though also writes non-chronologically even within these temporal sets. In other words, *The Boy Who Loved Tornadoes* is not comprised by two neatly alternating pre- and post-psychotic break narratives, but rather two nonlinear, intertwined narratives. To demonstrate, the memoir begins with the onset of Chase's psychosis at age 14, followed by reflections of Davenport's own young life before meeting Chase's father. By Chapter 8, it is April, Chase is fifteen years old and has been in the hospital for five months; in Chapter 9, Chase is four years old; in Chapter 10, Chase is psychotic without diagnosis; in Chapter 11, Chase is six years old; in Chapter 12, Chase is between six and seven; in Chapter 13, Chase is fourteen again and hospitalization seems imminent; in Chapter 14, Chase is seven and obsessed with tornadoes; and in Chapter 15, Chase has been in the hospital for three months. In Chapter 17, it is April again.

Written in this way, Davenport asks the reader to construct the story of Chase's life up to age nineteen from non-chronological discourse. H. Porter Abbott explains that narrative discourse—how the events of a story are represented—is not bound by temporal logics (17-19). Rather, narrative discourse can "expand and contract, leap backward and forward" (17). We construct the story (the sequence of events) from the information we receive from the discourse. In *The Boy Who Loved Tornadoes*, the story is Davenport's experience of parenting from a few years before Chase's birth until he was nineteen; the discourse, in contrast, bookends Davenport's experiences by Chase's psychosis (ages fourteen to nineteen). At nineteen, the narrative concludes. The memoir's structure is significant to Davenport's framing of childhood and ability in two ways. First, the relationship between narrative and time cannot be understated. As Abbott argues, "narrative is the principal way in which our species organizes its understanding of time" (3). Citing Paul Ricoeur, Abbott explains that narrative allows events to create order, and thus, "human time," as opposed to abstract, "non-narrative" organizations of time dependent on (for example) seasons, the sun, seconds, minutes, days, etcetera (4). These are measurements of time, to be sure, but which provide the framework within which we "locate events"; to compare, Ricoeur writes, "Time becomes human time to the extent that it is organized after the manner of narrative" (quoted in Abbott 4) meaning that the events of our lives, ordered, gives us our sense of time. In turn, "narrative…is meaningful to the extent that it portrays the features of temporal existence" (Ricoeur, quoted in Abbott 4). And so, when Davenport uses a discursive structure that contrasts with the sequence of events that make up her story, she causes, and indeed allows, readers to think of her experiences on two temporal planes: a familiar human story of parenting and the passage of time; and as an unfamiliar series of intertwined moments that resist being framed as "beginning, middle, and end." Combined with the rhetoric of unknowability and futureless-ness, the narrative discourse that mediates *The Boy Who Loved Tornadoes* conveys that Chase is outside of time. His disability disconnects him from the time-bound, biocertifiable stories of childhood and identity that are broadly familiar and easy to locate via pre-existing diagnostic categories. Chase is disconnected from normative temporality, and as such, we encounter narrative foreclosure on imagining Chase in his, or any sort of, future.

The Still Point of the Turning World

"Future, future, future" (Rapp 13).

Emily Rapp's memoir, *The Still Point of the Turning World*, also combines an atypical narrative chronology with the language of futureless-ness, albeit under profoundly different terms than *The Boy Who Loved Tornadoes*. Rapp's son, Ronan, has Tay-Sachs, a rare, fatal, degenerative nerve disease (Genetics Home Reference). Tay-Sachs destroys nerve cells in the brain, causing weakness, blindness, hearing loss, inability to swallow, intellectual disability, seizures, and paralysis. Few children with Tay-Sachs live beyond their third birthdays. Ronan was diagnosed at nine months old. Having so little time left with her child, Emily Rapp wonders "How do you parent without a future, knowing you will lose your child, bit by tortuous bit? Could it even be called parenting, or was it something else, and if so, what?" (11). Rapp asks readers to consider the degree to which both parenting and childhood are teleological and constructed within a specific temporality. Rapp poses this question directly, but the structure of her memoir furthers her point. Originally a blog, the memoir reads like a series of essays, each a narrative of its own. Her twenty-three chapters are linked and move (mostly) forward in time from Ronan's diagnosis until his death; however, each chapter also follows its own internal arc, most often shifting from an update, or report, on Rapp and Ronan's daily life to more abstract, lengthy reflections on the meaning of life, death, time, parenting, writing, and love. Writing in this way, Rapp tries to slow time. Deepening each moment and simultaneously reflecting on Ronan's present-ness underscores Ronan's atypical lifetime at the same time constructing him in a non-normative, reluctantly onward temporality.

The memoir begins with Ronan's diagnosis. We learn in the Afterword that Ronan passed away two years and one month later, shortly before his third birthday. The chapters in-between span the nine months immediately following Ronan's diagnosis, concluding with Rapp's vision of Ronan's afterlife, in which she meets his spirit off the foggy, rocky shores of Ireland (250-51). The nine months before the diagnosis and the nine narrated months create a kind of symmetry that pivots on the diagnosis. Before January 10, 2011, Rapp invested in Ronan's development and imagined future-Ronan. She explains, "I devised an ambitious list that I hoped would lead to important development outcomes for him: I would talk to him in different languages (language development); pick him up when he cried (attachment issues are crucial in the first year of life); breastfeed exclusively for a properly developing brain (I took herculean and often expensive and painful measures to do this)" (16). After Ronan is diagnosed, she writes "Ronan would never benefit from any of Rick's [Ronan's dad] and my efforts beyond what he received *in the moment*" (emphasis in original, 15). With this statement, she primes readers early in the narrative to recognize that a shift has occurred and that her understanding of parenting as "future-directed" (13) has been dramatically altered.

Rapp's narrative is at once chronological and out of time, beginning in January and concluding in September but moving through the months in increments, loops, jumps, and sometimes not at all. For example, most of the memoir (chapters one through eighteen) creeps slowly through the winter and spring months of 2011. Chapters six and seven begin in February, and chapters eight, nine, eleven, twelve, and thirteen weave through March. Chapter ten stands alone in this sequence and the memoir in its entirety as a poem; it begins "Grief is:" and pulls readers into the unrelenting presentness (the "is") of Rapp's pain and Ronan's illness. Almost every chapter begins in time: "Opening my eyes on that January morning" (41); "January felt endless" (50); "Ronan and I began the first day of February" (56); "At the beginning of March" (77); "Throughout the month of March" (96); "In those winter and early spring months of 2011" (120); "At the end of March" (130); "Spring arrived" (152); "On a warm afternoon in April" (159); "On Mother's Day" (195); "On a sunny and cool late September afternoon" (236).[41] Few chapters, however, end on any particular moment, most culminating rather with meditations, questions, weak conclusions, and reluctant resignations: "This is the time to be *fierce*" (95); "writing would not save Ronan. *But*, I thought, *it might save me*" (129); "learning how to live with death … was also about learning how to *live*" (135); "I realized that I'd been thinking, all that time, that Ronan would always be, in some way, right in the other room…. Wouldn't he?" (158); "My son was being destroyed, every minute of every day…. What had not yet happened was already happening" (185). Often, a chapter's connecting thread is difficult to identify, and Rapp often cycles through similar sets of questions (How to write [e.g., 42; 124]? What is healing [e.g.,

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[41] Seventeen out of twenty-three chapters begin with a phrase that marks the time of year.

112; 143]? What is grief [e.g., 40; 116; 121; 178]?). The movement from daily experience to contemplation feels, at times, formulaic; and indeed, Rapp sometimes repeats phrases (e.g., parenting “without a net” [13, 246]), and other times reverses her ideas, for example when she writes “I began to understand that the story of my son’s life would end but that what he had to teach me was as epic and mythic as a creation story” (20), and later “The meaning of Ronan’s life is not to teach me” (114).

This narrative circularity, both structurally and through repetitious phrases, allows Rapp to slow time through reiterations and do-overs. Simultaneously, in returning to questions and mediations explored earlier in her memoir, Rapp invites readers to experience the “unraveling” she names as Tay-sach’s effects. Ronan was unraveling (5; 178), being “unmade in some bizarre reversal” (88), each moment of his development becoming undone, unstitched, even as his hair and teeth and fingers continued to grow (181). “The traditional milestones turned on their heads….” Rapp explains. “We no longer wondered ‘What if he starts talking today?’ but ‘What if he stops smiling, cooing?’” (52). Rapp emphasizes this ongoing unraveling, this undoing-despite-onward progression, by grounding Ronan and her experiences as a parent “in the everyday” (12). In contrast to the paradigms and tactics used by parents of well children, “planning for the future, looking forward, tracking change” (75), Rapp writes, “for Ronan … there was no potential to actualize” (35), but also that one must “feed and wash the baby, even if you know it will die in the morning” (246). And while Rapp is certainly grieving deeply throughout this time, she also writes that there was a sort of liberating effect to parenting in the present (58; 97) and she wondered if Ronan existed in an almost-Nirvana, “a perpetual state of being in the now that people tried to achieve on expensive retreats” (88-89).

Essential to the narrative that at once resists progressive temporality and constructs freedom, peace, and comfort in the present moment is the absence of Ronan’s future. When

Rapp writes, “Ronan had, literally, no future” (53), she means that Ronan would not grow up, would not meet normative expectations for development, would not experience and understand the passing of time. She also means that Ronan’s life-story has “no narrative anchor” (42) that allows her to create order and meaning from something so utterly unfamiliar as the death of a baby (35). Ronan’s prognosis (death), his present unraveling, and Rapp’s narrative and narrated resistances to normative temporality underscore the ways in which a future-less childhood is unintelligible. And it would seem that childhood-without-adulthood is beyond recognition even in terms of other familiar narratives like those of hegemonic gender and sexuality, for neither Rapp (nor Davenport) engage gender or sexuality beyond articulating the ways these are relevant to normative childhood but not to them nor to their sons. When she describes, for example, the hopes she harbored for Ronan’s future before learning about his condition, Rapp writes, “he would be generous and gorgeous. Women or men would be falling all over themselves to go out with him” (16). This statement alone comprises the entirety of Rapp’s narrative exploration of Ronan’s existence as a gendered and sexual being.[42] Similarly, beyond making the speculative connection between Chase’s and his father’s conditions, Davenport does not gender Chase’s childhood. In contrast, she writes about trying to give her daughter, Chase’s younger sister Haley, a “normal girlhood” (311) in the face of so many atypical experiences and time-consuming concerns, but neither “boyhood” nor manhood (or adulthood) inform her construction of Chase’s life. The absence of gender schemas in both memoirs does not imply that Rapp and Davenport understood their children to be without gender; indeed, both parents write about their “sons” and use masculine pronouns to do so (he/him/his). Rather, the omission demonstrates the mutual constitution of normative gender, ability, and temporality. In other

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[42] This statement is also completely unique in the subgenre of special needs memoirs in that Rapp allows for the possibility that Ronan might have grown up to be queer. This raises interesting questions about the relationship between queer possibility and death.

words, these memoirs are instructive, in that the legibility of "future" depends on other familiar, entangled, normative scripts.

Narrating Normalcy

Normativity is a discursive regime, a regulated way of knowing and producing "truth." The truth about gender, sexuality, or ability intertwines with other truths about which bodies are good, what sorts of living are valuable, the meaning of progress, and the bearing of that progress on our social world. Normativities translate into narratives that become highly recognizable in and meaningful to our lives. The normative discourses that circulate in contemporary North American culture are not universal, but their ubiquity across multiple domains (e.g., medical, cultural, political) makes them register as common sense. Many in the U.S. presume that children "develop" towards cisgender, heterosexual adulthoods; that disability is an undesirable characteristic in children; and that it is irreconcilable with normal gender and sexuality— "hence the 'tragedy' of a 'beautiful woman in a wheelchair'" (McRuer and Mollow 23). People with disabilities are frequently seen as sexually queer, asexual and non-reproductive (Siebers 174-75; Mollow 296).

Some memoirs stand out by breaking the conventions of the special needs subgenre and destabilizing the discursive regimes of gender and ability. In doing so, they remind readers that normativity and narrative have limits, and point to the possibilities for reimagining and reassigning the meaning of disability (Wilson and Lewiecki-Wilson 3-4). Robert Rummel-Hudson's memoir about his daughter's first seven years, *Schuyler's Monster, A Father's Journey with His Wordless Daughter*, is one such memoir. Rummel-Hudson offers a possible alternative to the narratives of overcoming disability, narrowly eliding the pathologization of disability that plagues the special-needs genre (see Ferri 2269). Schuyler's "monster" is bilateral perisylvian polymicrogyria, a rare neurological condition characterized by atypically profuse folds (gyria) on the surface of the brain (Rummel-Hudson 122)—in Schuyler’s case, located primarily in the region responsible for speech. This condition is not linked to language, and Schuyler understands spoken and written English as well as her able-bodied peers; rather, Schuyler’s “wordlessness” results from an atypical motor function preventing the articulation of many consonant sounds, however capable she is of communication through various vowels and tones. Schuyler’s intellectual progress is standard for her age at the time of the memoir’s publication (205), but her father was then uncertain whether she would develop a seizure disorder (267), which often accompanies the condition along with problems in cognition, swallowing, and respiration. Schuyler begins to communicate through assistive technology during her fifth year, using a device slightly larger than a first-generation iPad that “voices” input from either keyboard typing or words arrayed on multiple screens. Affectionately portrayed as a strong-willed child who does not like being told what to do, even from a very young age (79), Schuyler employs her speech device to tell jokes and to roar like a dinosaur (225), and relies on her voice to howl at the children disparaging and excluding her on account of the disability (263).

Few parents articulate a future orientation in special-needs memoirs as explicitly as does Schuyler’s dad. Early on, Rummel-Hudson writes that after Schuyler’s birth, “the future stretched out before [them] with nothing but promise” (50). This promise shifts to a “nervous hopefulness for the future” as Schuyler begins to miss the developmental milestones of normative time (113). Upon her diagnosis, Rummel-Hudson encounters the narrative limits that disability places on the teleological model of childhood; he remarks, “I cried for the future, for the life I had always imagined for my little girl, a life that would never ever be what we’d imagined it to be” (118). Other adults likewise grieve for “the little girl they had always imagined [Schuyler] becoming” (129). For them, disability compromises the future of promise and replaces it with a future of uncertainty. Schuyler transitions from a person who is "becoming" to one who "might have been" (156), the fulfillment of her potential no longer imaginable or inevitable (165, 177).

Rummel-Hudson's memoir nevertheless demonstrates how competing discourses (e.g., childhood as becoming; disability as unbecoming) can operate side by side in a new temporality, one that pivots on gender fluidity. Like Jeremy, the boy with a fondness for ladies' hats discussed above, Schuyler is a bit queer, a tomboy in pink camouflage pants (254). She is "pretty like her mother but also a little troublemaker like [her dad]" (47). This "sweet little girl" (82), a "fragile flower" (71), loves dinosaurs, King Kong, and insects (144, 82), and prefers to keep her hair chin length. Though she looks "like a ballerina" (144), she plays hard: "Her full lips and long eyelashes kept [her] from looking terribly boyish, but most days she came home from school covered in scratches or bruises, her jeans grass stained and worn. ... She loved mermaids and ponies and princesses [and] even in her most feminine of phases, … always loved monsters" (144). In another passage, Rummel-Hudson describes Schuyler as having a "little girl crush" on her best friend Samantha (258).

As with Jeremy, the queering of Schuyler's gender and sexuality does not translate into a narrative of non-normative adulthood. On the contrary, Schuyler's father writes that Schuyler will one day be "a lovely young woman" (36), a future "heartbreaker" and "boy killer" (258), who will "move away and fall in love" (87). While Rummel-Hudson repeatedly muses on the adult, gender-normative Schuyler, he does so without writing his daughter into a narrative of overcoming as does Jeremy's mother with Jeremy. Instead, he holds disability in tension with a positive narrative of empowered womanhood. One of his most disjointed passages reads "I couldn't see her living independently one day, a young woman who couldn't speak but who had the world's ass kicked anyway as she made her way through it" (165). Rummel-Hudson knows that Schuyler will always require accommodations in one form or another; as to whether she will kick the world's ass, however, this father has no doubt. He imagines Schuyler as a permanently dependent *and* self-possessed adult woman, vigorously navigating her world.

The memoir holds these two discursively antithetical possibilities together because Rummel-Hudson constructs Schuyler's identity as at once normatively feminine and gender transgressive, unraveling the narratives of gender that engender normative temporalities. Nonetheless, it is not Schuyler's gender transgression alone that upsets these normative temporalities. Halberstam has argued that tomboyism is commonly a part of a girl's trajectory toward adult heterosexual womanhood. Tomboys, when more androgynous than queer, "represent … a resistance to adulthood, rather than to adult femininity" itself (Halberstam, "Oh Bondage Up Yours!" 194). Unless, of course, all children are already queer. Kathryn Boyd Stockton considers this possibility, noting that from the standpoint of adults, children are queer insofar as they possess the "normative strangeness" of sexual naiveté and are "not yet straight"— qualities that estrange them from adults (296, 283). Though children are those "for whom, we imagine, sex itself seems shockingly queer" (296), their being "not yet straight" demands a loss of innocence in pursuit of adult heterosexuality. If "all children are Q" (Stockton 278), childhood—strangeness, queerness—would permit what Rebekah Sheldon calls "the proliferation of lateral potentialities" (n.pag), rather than the supposedly inevitable smooth progression towards normative adulthood. This most certainly is the case for "strange," disabled children, whose bodies and experiences may not "grow up" according to the existing developmental paradigms. Many children with disabilities embody the "strange temporality" that Kafer and others term "crip time," a temporality that not only refuses normative linearity (from dependent childhood to independent adulthood), but also accommodates atypical, interdependent forms of maturation and living (Kafer 34-40).

Halberstam's alternative teleology allows for a less disruptive queerness; gender transgression vies against adulthood without completely upsetting the dominant temporality.

This strange alliance between child and adulthood queerness accords with the straight-time/queer-time binary of Halberstam's *In a Queer Time and Place* (1), yet each is based on the assumption of ability. Schuyler complicates Halberstam's alternate temporality as much as the dominant temporality because of the way in which her disability makes her gender incoherent regardless. Indeed, Schuyler estranges the narrative limits of normative life so much as to render them meaningless; Schuyler's future is, in a way, already open. Rummel-Hudson, in constructing a narrative of her tomboy disability, introduces a new temporality for Schuyler's disabled adult femininity, for while Schuyler's path to maturity cannot be imagined in terms of normative temporality (straight-able time) due to disability, it *can* be imagined as not exactly crip, and not exactly queer, but as queer*ish*, en route to an impaired yet empowered straight adulthood. The memoir reflects an expectation of development, but not necessarily an ableist or heterosexist one, with heteronormativity competing with other rhetorics embracing queerness and disability. This, I would like to suggest, is what Eve Kosofsky Sedgwick would call reparative work.[43] Schuyler's father, in narrating the tomboy stage as a stepping point to adult heterosexuality, without necessitating that Schuyler overcome her disability, claims a meaningful future for his daughter, disentangling her ability from her gender and sexuality.

Conclusion: An Open Future

When Kephart writes about Jeremy abandoning his obsession with his queer little hat, she opens a narrative channel for him to overcome his disability, though at the cost of perpetuating heterosexism. Queerness, like disability, figures tragically in Kephart's memoir: as an unwanted status threatening to compromise Jeremy's open future, as an obstacle for him to overcome. This memoir enlists readers into adopting Kephart's worldview as true, at

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[43] See Sedgwick's chapter "Paranoid Reading and Reparative Reading, or, You're So Paranoid, You Probably Think This Essay Is About You" in *Touching Feeling: Affect, Pedagogy, Performativity*.

least for her life, because that is in part what memoirs serve to do in locating individual experiences within broadly recognizable narratives. Some readers may feel differently about queerness and disability—might find Kephart's dismissal of them painful, unjust, or harmful—while still perceiving little about the narrative unfamiliar. Even if we take seriously Stockton's assertion that "all children are Q," their seemingly universal strangeness masks the estrangement of children with disabilities from the story of childhood itself.

The appeal to gender and sexual normativity in "special-needs" memoirs makes disabled childhoods seem ordinary, an attempt at restoration to familiar scripts and paradigms. Gender normalcy compensates for disability or, at the very least, contains it. The parent narrators, in claiming this normalcy for their children, declare, in effect, "See? We are the same. (Just ignore that disability over there.)" Perhaps some healing results from that gesture. Jacqueline Rinaldi suggests, for instance, that writing can heal, if we understand it to include not just interpersonal exchanges, but also "intrapersonal" inner speech yielding sympathy for the writer (832). Imagining such inner dialogue for parents of children with disabilities—who face daily, pervasive, painfully exclusionary ableism—is not difficult. It explains why Leone verbalizes her son's affections for Brandy and, in doing so, pictures herself an ordinary mother of a pre-teen boy with a crush. Once disability enters the plot, it must be overcome because it's *too* disruptive, too contrary to the natural order of things, and parent-memoirists have little other recourse to claim a privileged, cherished story of childhood. Given that no real narrative can normalize the disabled experience, who can blame these parents for trying to normalize it by other means? Normativity is, after all, a utopia, "an aspirational site of rest and recognition in and by a social world" (Berlant, *Female Complaint* 5). Most of us want to belong and to be recognized.

But perhaps queerness, too, is a utopia. In *Cruising Utopia*, José Esteban Muñoz argues that queerness is a "potentiality" (21), a way of seeing and feeling "beyond the quagmire of the present" (1). Muñoz's complaint is with the anti-relational approach that came to characterize queer theory in the 2000s. The anti-relational approach, especially as articulated by Bersani (1999) and Edelman (2004), distances sexuality "as a singular trope of difference" from other social "contaminants" like gender and race (Muñoz 11), and at the same time seeks to disconnect acts of sex from reproduction, futurity, progress, seriousness, even life (Halberstam "The Anti-Social Turn in Queer Studies" 140). Muñoz, however, envisions queerness as "collectivity… primarily about future and hope" (11) and critiques the presentist queer investment in pragmatic political gains like gay marriage. Muñoz wants to honor Edelman's critique of reproductive futurism (Halberstam's "straight time"), but re-conceive queer negativity as first, a rejection of the reiterative character of presentism, which can only reproduce "majoritarian heterosexuality" (22), and second, a positive embrace of Shoshana Felman's theory of "radical negativity": belonging neither to negation, nor contradiction (Muñoz 13). Muñoz suggests that such a framework aligns with Sedgwick's "reparative hermeneutics" (12).

Thinking queerness as collectivity and potentiality maybe particularly useful for articulating a crip critique of anti-futurity. For example, when Halberstam writes that queer temporality resists straight time's incorporation of gender as among the "flexible" identity characteristics of the postmodern neoliberal subject (19), they might attend to the ways in which people with disabilities not only call attention to the embodiedness of "flexibility" (think: cerebral palsy's spasticity, Down syndrome's hypotonia), but also to the ways in which disability might prove the exception to the rule of identity choice, as argued by Lennard J. Davis in *The End of Normal* and discussed in Chapter 2 of this dissertation. Edelman might consider how queer disabled subjects, not to mention heterosexual disabled subjects queered by heterosexist-ableism, might seek to reproduce children that are both hopeless and unwanted.[44] Must such subjects inhabit an oppositional position to reproductive futurism when their Deaf, dwarf, and intellectually disabled offspring, beloved by their parents, are among the wretched of the earth? How can we persist in conceiving queer and disabled reproduction in collusion with normative heterosexual futurity when so much reproductive queer and disabled sex is community-based and orchestrated, as when lesbian couples get friends to contribute sperm, Deaf queers seek Deaf donors, physically disabled folks rely on aides to help coordinate sexual contact, and intellectually disabled people's sexual expression in many ways requires degrees of support from caregivers and the community?

Rummel-Hudson's memoir does not beholden its subject, Schuyler, to the wholesale anti-normativity sometimes informing queer and crip politics, and especially Edelman's *No Future*. Schuyler appears as a bit difficult to recognize, but not entirely unfamiliar: she is queerish, a tomboy both disabled and capable of increasingly complex expressive speech with the use of communication devices. At the conclusion, Rummel-Hudson admits that Schuyler's future is unknown: "With Schuyler, there's no such thing as typical, and there's no narrative" (266). Narrative eludes Rummel-Hudson because his daughter neither overcomes her disability, nor does gender along other normalizing lines. However, the lack of that narrative signals the possibility of writing something new, and with it the possibility of reassigning the meaning of disability. When disability, gender, and sexuality are destabilized, new narrative arcs and templates emerge.

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[44] See Kafer, "Debating Feminist Futures," in *Feminist, Queer, Crip*.

Conclusion

My dissertation addresses the cultural climate that grants recognition and inclusion to privileged identities, embodiments, and ways of being. The texts I have examined for this project are predominantly about white children (thirty-three out of thirty-six memoirs) from middle- to upper-class families. I did not deliberately exclude children or families of color from my analysis; rather, there are very few memoirs about raising a disabled child of color on the market. This is in part due to publishing bias (discussed below). The whiteness of the special needs genre, I argue, evinces not merely a white-centric readership, but rather a culture that sees Black bodies and bodies of color as not fully human to begin with, and hence unimaginable within recuperative disability life course narratives. In this conclusion, I consider the implications of this omission for social justice and intersectional feminist, anti-racist politics and scholarship. I focus on four structural obstacles: publishing bias, the criminalization of bodies of color, the whiteness of "childhood," and the cultural imperative to eliminate disability through genetic testing and prenatal diagnosis. I demonstrate how they intersect to exclude children of color from becoming the subjects of popular special needs memoirs.

Mostly white boys with autism

"Special needs" memoirs are a subgenre of a subgenre. As memoir, they are a kind of auto/biography (discussed in the introduction). Since the subject is about living with a disability, they are grouped together by retailers as a "special interest" subgroup. The memoirs I have examined for this project are even more specific to this subgroup because they written by able-bodied parents[45] of children with disabilities. On Amazon.com, "Special

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[45] With the exceptions of Emily Rapp, who uses a prosthetic limb but does not identify as disabled, and Paul Collins, who, over the course of writing his memoir *Not Even Wrong*, discovered that he probably has autism like his son.

Needs” is one of four subgenres of “Specific Groups” of Biographies/memoirs (along with Crime and Criminals, LGBT, and Women).

The memoirs used for this project were chosen based on whether or not they were perceived by buyers or organized by booksellers to be “memoirs,” and if so, their popularity (sales rankings, critical reception, etc., discussed below). To determine the former, I relied largely on Amazon.com’s subgenre organization. However, not every book listed under “memoir” on Amazon was also categorized by the publisher as a memoir. Michael Bérubé’s *Life as We Know It*, for example, can be found under Memoirs > Special Needs on Amazon.com, but the publisher’s categorization is “Parenting/Family.” Many other memoirs are categorized by publisher as “Memoir/Parenting” or “Special Needs/Memoir” or even “Memoir/Psychology.” Categorizations become even less cohesive at the Library of Congress subject level headings, which include “Mentally handicapped children,” “Parenting,” “Caregivers,” “Brain abnormalities,” “Mental Health,” “Fathers,” “Mothers,” and many more. Many of the memoirs discussed in this dissertation are catalogued under RJ, the Library of Congress heading for “Pediatrics” (under the general heading, “Medicine”). Others are catalogued under HQ for “The Family, Marriage, and Women.” (See Appendix for catalog and classification details for all the memoirs used in this project).

The popularity of any given memoir is not easier to determine than its categorization. As discussed in the introduction, sales data like Nielsen BookScan Ratings are neither accurate publicly available (nor do UCLA librarians have access; personal email). My emails to publishing houses yielded no information about sales. On Amazon.com, a book’s popularity can be determined at any given moment according to where it shows up on their “Bestsellers” or “Most Wished For” lists. The current most popular memoir list on Amazon usually correlates with lists found elsewhere, e.g. Goodreads.com, or by searching “special needs memoirs” through Google. This data, however, is imprecise and changes rapidly.

In January 2017 I stopped reading memoirs for this dissertation so that I might commence with writing.[46] At that time, the ten best-selling special needs memoirs (not including those that were co-authored by children and their parent/s) on Amazon.com were: (1) *Life Animated* (2016) by Ron Suskind, whose son has autism; (2) *The Edge of Normal* (2015 Kindle E-book) by Hana Schank, whose daughter has albinism; (3) *Don't Blink* (2016) by Brandon and Brittany Buell about their son, Jason, who has a rare brain malformation; (4) *Through the Eyes of Hope* (2017), a Christian inspirational book by Lacey Buchanan about her son's rare facial disfigurement; (5) *Love that Boy* (2017) by Ron Fournier about his son, who has autism; (6) *Expecting Adam* (2011) by Martha Beck, whose son has Down syndrome; (7) *Every Least Sparrow* (2017) by Carolyn Walker, about her daughter, who has Rubenstein-Taybi syndrome; (8) *The Spark* (2013) by Kristine Barnett, about her son Jacob, who has autism; (9) *Bloom* (2012) by Kelle Hampton, whose daughter has Down syndrome; and (10) *The Child Who Never Grew* (1950) by Pearl S. Buck, about her daughter, who was developmentally delayed.[47]

Of these ten bestsellers, six are about boys, four are about girls. Three are about children with autism (all boys), two are about children with Down syndrome (a boy and a girl), and each of the other five represent a different disability. All of the children are white. Based on this small sample, we might conclude that race, gender, and disability representation is slightly skewed among popular special needs memoirs to overrepresent white boys with autism. Looking at critical reception this picture skews further. Five of the top ten books received no critical reviews in major outlets like *New York Times Review of Books, Publisher's Weekly, Huffington Post,* or any others. *Life Animated* and *Love that Boy*, both about boys with autism, have each been reviewed by *The New York Times*. Both

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[46] At that time, at least 2 new parenting memoirs were being released monthly, and I realized I could add to my archive indefinitely or choose a stopping point. I chose a stopping point.

[47] Pearl S. Buck's memoir was published in 1950 and appears to be the very first of its kind.

memoirs were covered by all the major TV and news outlets, including *CBS, Fox, USA Today, The Atlantic, PBS, The New Yorker, NPR, LA Times, Rolling Stone, Good Morning America,* and *The Guardian*. *Life Animated* has since been made into a documentary. *The Spark*—book 8 on the top ten list—was covered by *Washington Post, CBS, BBC, 60 minutes, USA Today*, and Glenn Beck. The other books to receive a bit of Internet attention were *The Edge of Normal* and *Bloom*. *The Edge of Normal* author, Hana Schank, is a regular contributor to *The Washington Post* and *The New York Times*. *Bloom* was reviewed by Kirkus and a few personal blogs.

Taking this into consideration, it appears that the most popular, talked-about special needs memoirs are about white boys with autism. The whiteness of the popular stories is not particularly remarkable given the whiteness of the subgenre itself. Again, only three memoirs from this archive are about children of color: two are about half-white, half-Japanese children, and one is about a Black (Trinidadian) girl, Melanie.

This is important because of the stories "special needs" parenting memoirs tell. I have categorized the texts under analysis in this dissertation in one of three ways: some are narratives of ordinariness, in which the parents expect disability to prevent their child from having a "normal life" but they come to learn that their kid is just like any other kid. This normalcy is often highly gendered, so we have "boys being boys," "girls being girls," and proto-heterosexuality, otherwise described as "innocent childhood crushes." Or, the narratives are extraordinary. In these, the disability makes the parents' lives better, because they see their disabled child as a gift, or a teacher, or a spiritual guide, and they learn valuable truths about humanity and the world through their child and through parenting their child. A smaller number of memoirs completely reject narratives of childhood and narratives of normalcy. These are about a child who passes away, or one whose disability is so severe that they have almost no opportunities to participate in what most people think of as typical life.

All of the narratives are structured by neoliberal logics for self-improvement and self-governance.

The first and second narrative groups are recuperative; they claim access to a typical childhood, access presumed to be denied because of disability. Through this they access a future and community, in both senses of meaningful relationships and spaces. In both the first and second categories we find parent-memoirists reinforcing ableism by denying disability or by perpetuating the narrative of overcoming. Nevertheless, the narratives are attempts at inclusion. These parents want their children to belong.

Briefly, consider again the popular memoirs *Life Animated, Love That Boy,* and *The Spark,* each about a white boy with autism who is uniquely and remarkably gifted. Owen, the child in *Life Animated,* is a gifted illustrator with a remarkable memory. When Owen was little, he was non-verbal. His father, Ron Suskind, writes that Owen was “kidnapped” by autism (4). A few years after his diagnosis Owen began communicating with his family through Disney scenes and this became for Suskind a way to re-connect. By the memoir’s conclusion Owen is highly verbal and living independently in a supported living community. (In the documentary we learn he has a girlfriend.) Tyler, the boy of Ron Fournier’s *Love That Boy,* also has a remarkable memory for details. His interest is U.S. presidents. He, too, overcomes a number of obstacles over the course of his father’s narrative, most notably, learning how to behave typically in public.

Life Animated and *Love That Boy* were both hugely popular upon their release. Not coincidentally, both boys’ fathers were well-known journalists for high-profile media outlets. But this cannot be the sole reason for their memoirs’ popularity. *The Spark,* by Kristine Barnett, was comparably received, and prior to the memoir’s publication, Barnett was an unknown stay-at-home mom in Indianapolis, Indiana. Jacob Barnett has been considered by some to be a child prodigy. At age 16 he began a doctoral program in Theoretical Physics. In her memoir, Barnett explains that by nurturing her son's interests and by encouraging him to deeply explore the things that fascinated him, she supported a developing genius. Jacob still has autism, as do Owen and Tyler, but in his mother's narrative her efforts to give him an ordinary childhood work together with his genius to mitigate the social stigmatization and exclusion children with autism often experience.

In each story, disability has something to offer: to the world, to the parents, to knowledge. These white children—who 60 years ago might have been institutionalized—are described as valuable members of the community (however problematically), and the broad reception of these narratives supports G. Thomas Couser's claim that narratives of disability are limited, and that the reading public prefers narratives of overcoming disability (*Signifying* 33). These memoirs aim to recuperate lost access to dominant narratives and to community, to childhood, to gender; however, the subjects of these narratives represent an already privileged subset of the population. Children of color are missing from the bookshelves, which implies they are missing from the public imagination when stretched to include people with disabilities in humanity's scope.

Entangled bias

In 2012, Roxanne Gay systematically researched the racial background of every writer whose book was reviewed by *The New York Times*, and found that nearly 90% of the books were written by whites (cited in Hess). Gay writes that getting a book deal is hard for everyone, but "if you are a writer of color, not only do you face a steeper climb getting your book published, you face an even more arduous journey if you want that book to receive critical attention" (The Rumpus). Amanda Hess, commenting on Gay's article, notes that both systemic inequality in education as well as elitism in publishing contribute to the underrepresentation of people of color authorship.

Cécile Cottenet writes that historically in the U.S. the intermediaries (editors, publishers, agents, and reviewers) between texts and markets have been predominantly white. In 2015 Lee & Low Books conducted an industry-wide diversity survey and found that 79% of publishing personnel are white (this number jumps to 82% and 86% at the editorial and executive levels, respectively, JasonTLow). In a similar survey from 2014, *Publishers Weekly* found that 89% of publishing industry employees identified as white (Milliot). Respondents cited "entrenched leadership that includes few people of color, low starting salaries and unpaid internships that together discourage minorities from applying to entry-level jobs, and not enough effective outreach to minorities" as reasons for the lack of diversity.

These considerations notwithstanding, it is important to foreground that the publishing industry is white-majority in a social climate that discriminates against people of color and is particularly hostile to Black people, including those with disabilities. People of color face additional, and more intense discrimination for having a disability, and experience multiple, intersecting stigmatizations. This could possibly dis-incentivize publicizing one's status as disabled; I feel it is disingenuous, however, to name "publishing bias" as though it stands apart from the sense of white, able-bodied supremacy that shapes American culture.

Consider the criminalization of Black disabled people, including children. Beth Ferri and David Connor demonstrated in 2005 that children of color—especially boys of color—are overrepresented in special education classrooms (93-95), where they are sent for behavioral management or because English is not their first language. Nirmala Erevelles discusses the way the segregation of children of color in special education in many ways mirrors their overrepresentation in prison, as well ("Crippin' Jim Crow"). In their paper on the "special-education-to-prison-pipeline," Torin Togut writes that Black children with disabilities are three times as likely to be suspended and four times as likely to be "educated in a correctional facility" than their white disabled peers (178). A U.S. Department of Justice survey in 2012 found that 40% of state and federal prisoners had a disability. 40% of inmates in U.S. prisons are also people of color (Bureau of Justice Statistics). Both numbers are disproportionately large compared with population statistics (see Sakala). These data suggest it might not be in a person of color's best interest to *have* a disability, let alone disclose their disability status.

The criminalization of children of color is not reserved for disabled children, however. Indeed, Togut cites data showing that able-bodied Black students (boys in particular) receive harsher punishments for less serious behaviors than do non-Black students (177). These include suspension, detention, and segregation, all punitive responses meant to control the movement of Black bodies. Similarly, at the time of this writing, several hundred migrant children remain in shelters or foster care after being forcibly separated from their parents, who were sent to federal immigration detention centers under Donald Trump's "zero tolerance" immigration policy (Gamboa et al.). The policy, implemented in April 2018 (Farivar), led to the forced separation of over two-thousand children before Trump signed an executive order halting the practice on June 20, 2018 (Shear et al.) Meanwhile, reports of sexual abuse at an immigration detention center for minors (The Associated Press) and of toddlers exhibiting mental health issues, including anxiety and post-traumatic stress (Jordan), have begun to make headlines. The family separations were met with public outrage: *The New York Times*' readers wrote in and described the policy as "heinous," "cruel," and "unconscionable" (Opinion). As Shaila Dewan points out, however, child separation is a regular occurrence in the United States. Writing for *The New York Times*, Dewan notes that hundreds of thousands of U.S. children are separated from their parents because of incarceration (of the parents or the children) and through the foster care system, which often removes children from homes that are merely poor. These practices disproportionally affect children of color (Dewan), whose parents are more likely than white parents to be surveilled by police and social services, who are more likely to be punished for wrongdoing, and who receive harsher punishments for the same crimes committed by white peers (see Alexander; Roberts). In all of these ways, the State legislates, guarantees, and enforces the ongoing separation of families of color.

These practices stand in stark contrast to the State's agenda for children on paper: to promote economic and social well-being for all children, including those with disabilities, refugees, and migrants (Administration for Children and Families (ACF). Health and Human Services (HHS) pledges to "prepare children and youth for healthy, productive lives" ("A Family Centered Approach") as part of Trump's executive order to reduce poverty (Whitehouse.gov). HHS recommends regular childhood vaccinations to protect children against death and disability caused by a preventable disease ("National Immunization Awareness"). HHS's current website also features a personal story about a family who adopted an infant born addicted to opioids ("The Opioid Crisis"). The story tells us that babies and children deserve love, care, and protection, regardless of their life circumstances or their parents' choices. Elsewhere on Capitol Hill, The Senate voted to change a rule that barred children from the Senate floor so that Senator Tammy Duckworth could bring her ten-day-old daughter with her to vote (Stolberg). Baby Maile's arrival in the chamber was met with bi-partisan coos and compliments. The rule-change came only days after Attorney General Sessions announce the immediate implementation of Trump's "zero-tolerance" policy that initiated the border family separations. While the separations took place between April and June, Kansas, and then Oklahoma, passed a law allowing adoption agencies to refuse to place children in homes of eligible same-sex couples (Shorman; Kansas SB284; Oklahoma SB1140). Supporters of the Kansas bill argue that its passing will allow agencies to continue to serve needy children because, if forced to place children into same-sex homes, the agencies would themselves have ceased providing adoption services altogether (Shorman).

This collection of current events and recent legislation conveys that children are wanted, vulnerable, and deserving of protection, but compels us to ask, "which children" and "what is a threat?" At the heart, recent politics of the child evince a collective understanding of children as "innocent" but disunity over exactly who is covered by that innocence. In *Racial Innocence*, Robin Bernstein argues that the very idea of childhood innocence is historically constructed as white (8). Bernstein writes that childhood innocence, or "holy ignorance," was a performance of obliviousness to one's racialized (and gendered, and classed) status (6). Innocence, here, is innocence of the knowledge of difference; and in the performance of "not noticing" race (6), the power that comes with being un-marked by race (or other statuses) is consolidated. Bernstein goes on to argue that, in this way, children of color could never be "innocent," or ignorant, of the way they were racialized against whiteness. Importantly, childhood is more than simply innocent; "it is the embodiment of innocence itself" (Bernstein *Racial Innocence* 4; see also Ariès 106-127, Austin 83, Bruhm and Hurley xxxiv). By performatively constituting children of color as not-innocent through the performance of innocent white childhood, children of color are effectively not children at all, and thus not deserving of State protection.

The question, "which children?" brings us back to the subject of this conclusion. The disabled children that can be reimagined through their parents' narratives to occupy childhood and the life course can do so because of the discursive and material privileges of whiteness. Remarkably, they do so in a cultural climate that increasingly understands disability as avoidable and actively pursues technologies to eliminate disability, including selective abortion. Parens and Asch write that although the purpose of the genome project is to identify and correct sequences associated with disease and disability, in practice, the discovery of abnormal sequences has been used primarily in prenatal testing to identify fetal anomalies (3-4). Parens and Asch explain that prenatal testing occurs within a cultural environment that assumes the elimination and prevention of disability to be a good thing, and selective abortion is considered by many to be an extension of reproductive choice (7).

The general agreement that disability is bad is why Rachel Adams writes of her son, “a baby like Henry demands a story” (108). Adams is a white, able-bodied, cisgender, heterosexual, tenured professor at Columbia University. According to the back cover of her memoir, her “life had always gone according to plan.” When Henry was born Adams’ friends asked, “Didn’t you get tested?”; they imply: *this could have been avoided* (107). Adams did not get amniocentesis, and Henry has a story: he has Down syndrome; he learns from his brother to break household rules (139); he is a curly-haired four-year-old at preschool’s chosen future husband (158); he is the subject of his mother’s memoir about motherhood and disability. Adams writes that Henry is a miracle child (102), and compels readers to agree that her choice to forego amnio was a good one.[48]

Alison Piepmeier argues, however, that the notion of “reproductive choice” inadequately accounts for the ways in which reproductive choices are made within multiple, sometimes competing, social contexts. When faced with fetal anomalies, prospective parents consider dehumanizing representations of disabled people alongside their own beliefs and imaginations, their family’s opinions, and the accessibility of social supports (“The Inadequacy of Choice” n.pag). Piepmeier writes that the “choice framework” obscures these

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[48] Adams’ memoir received mixed reviews. Among the criticisms, Cristina Nehring’s complained that Adams’ memoir taught readers less about raising a child with Down syndrome and more about the “privileged lives of some New York City professors.” Nehring’s point is taken, but it is important to challenge the implication that Adams’ memoir harms Henry and people with disabilities *because* Adams is a person of privilege and writes about her personal experiences. To accept this would imply that only people who experience discrimination and/or other inequities are capable of fully comprehending the challenges of raising a child with disabilities. Such an argument traffics in a discourse that would equate wealth with moral depravity, and completely misses the point that ableism happens across class lines. Moreover, as I have shown in this conclusion, almost all special needs memoirs are written by parents with a great deal of social and economic privilege, and that is sort of the point: these are the stories the public is willing to hear.

complex negotiations and places the burden for responsible reproductive decision-making on the pregnant person alone. Writing along similar lines, Dorothy Roberts explains that responsible reproductive decision-making includes preventative care, eliminating genetic risk, and a refusal to “burden the nation” with expensive, unproductive offspring. She argues that charging pregnant people alone for reducing or eliminating disability (or for reproducing while poor, or both) allows the State to deny responsibility for social inequality. Robert describes the logic of “responsible mothering” as eugenic because it “locates [social problems] in reproduction rather than social structure and therefore seeks to solve them by eliminating disfavored people instead of social inequities” (796). This argument effectively cautions folks already experiencing social inequities such as poverty and lack of health care against reproducing. People of color disproportionally experience both (“Poverty Rates”; National Academies of Sciences). In short, the eugenic drive to eliminate disability through selective abortion affects poor communities and communities of color in specific ways: not only because many folks in these communities lack access to health care and are denied opportunities to make informed decisions about reproduction, but also because as poor people and people of color, their children are already considered by the white supremacist State to be unwanted, unlovable, lacking in value, and punishable. Born disabled and unwanted by the State, these children may indeed also demand a story; but, unlike Henry’s, it seems theirs will not be heard.

Stories, and narrative discourse

In this dissertation, I have analyzed narratives about children with disabilities within a political-economic context. I have examined the stories (of overcoming, of tragedy) alongside narrative discourse: memoir as “truth-telling,” the uses of futurity and sentimentality, the appeal to “common sense.” My argument is that the stories in special needs memoirs draw uniformly on neoliberal rationality to make case that (some) disabled children deserve full inclusion in society. I argue that narratives of inclusion perpetuate heteronormativity and ableism and moreover exclude people of color from a world that reimagines disability as natural human variation. When the public is engaged in actively reimagining who gets to be in the world, and the representation of that someone is a white boy with autism who is also gifted, the boundaries for inclusion are much too tightly drawn.

Because of the narratives and the genre, this dissertation is about white children and their families. Here we might remember Chris Bell, who, in 2006, asked if disability studies might better be called “white disability studies” due to the failure of scholars to substantively engage with intersections of race and disability (“A Modest Proposal”). Since Bell asked, there has been an increase in engagement, notably Nirmala Erevelles’ work, Ellen Samuel’s *Fantasies of Identification,* and work by Michelle Jarman, Andrea Minear, Theri Pickens, and Beth Ferri, but scholarship on and popular representations of disability (especially when positive) remain heavily white. Disability is not white, of course. It affects all populations, regardless of class, sex, sexuality, race, gender, nationality, etcetera (though all of these statuses may or may not exacerbate the disablement that comes with atypicality or neurodiversity). As this project shows, however, popular narratives, constrained by the rules of recognition, unimaginatively limit who will be included in humanity’s scope to white, heterosexual, gender-normative, “productive” citizens. The thing about rules, of course, is that they can break. To expand the diversity of lives recognized as valuable and loveable, we need more stories about more of us, especially those of us whose stories are currently not being heard.

Appendix

Adams, Rachel. *Raising Henry: A Memoir of Motherhood, Disability, and Discovery*. First Edition, Yale UP, 2013.

Publisher's genre: Memoir

Library of Congress (LOC) classification: RJ (Pediatrics)

LOC subheadings: 1. Adams, Rachel, 1968-. 2. Down Syndrome—Patients—United States—Biography. 3. Developmentally disabled children—United States—Biography. 4. Parents of developmentally disabled children—United States—Biography. 5. Mothers and sons—United States—Biography.

Barnett, Kristine. *The Spark: A Mother's Story of Nurturing, Genius, and Autism*. First Edition, Random House, 2013.

Publisher's genre: Memoir

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Barnett, Jacob, 1998—Mental health. 2. Autistic children—Rehabilitation. 3. Mothers of autistic children—Case studies. 4. Autism in children—Case studies.

Beck, Martha. *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic*. Reprint edition, Harmony, 2011.

Publisher's genre: Autobiography/ Personal Memoirs

LOC classification: RG (Gynecology and Obstetrics)

LOC subheadings: 1. Beck, Martha Nibley, 1962-. 2. Pregnancy—Complications—Patients—Biography. 3. Fetus—Abnormalities—Patients—Biography. 4. Genetic disorders in pregnancy—Patients—Biography. 5. Parents of children with disabilities—Biography. 6. Parents of children with disabilities—Religious life. 7. Down syndrome—Patients—Family relationships.

Becker, Amy Julia. *Good and Perfect Gift, A: Faith, Expectations, and a Little Girl Named Penny*. Bethany House Publishers, 2011.

Publisher's genre: Christian Life/Memoir

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Becker, Penelope Truesdell, 2005-. 2. Becker, Amy Julia—Family. 3. Down syndrome—Patients—Biography. 4. Children with mental disabilities—United States—Biography. 5. Parents of children with disabilities—Biography.

Bernstein, Jane. *Loving Rachel: A Family's Journey from Grief*. U of Illinois P, 2007.

Publisher's genre: Memoir/Parenting

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Bernstein, Rachel. 2. Children with disabilities—United States—Biography. 3. Parents of children with disabilities—United States—Biography

——. *Rachel in the World: A Memoir*. First Edition, U of Illinois P, 2010.

Publisher's genre: Memoir/Parenting

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Bernstein, Jane, 1949-. 2. Glynn, Rachel. 3. Parents of children with disabilities—United States—Biography. 4. Parents of children with disabilities—Psychology. 5. Youth with disabilities—United States—Biography

Bérubé, Michael. *Life As We Know It: A Father, a Family, and an Exceptional Child*. Vintage, 1998.

Publisher's genre: Parenting/Family

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Bérubé, Michael, 1961-. 2. Parents of handicapped children—United States—Biography. 3. Mentally handicapped children—United States—Biography. 4. Down syndrome—United States—Case studies. 5. Parent and child—United states—Case studies

Brown, Helene. *Yesterday's Child*. First Edition, M Evans & Co, 1976.

Publisher's genre: N/A

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Mother and child. 2. Brown, Helene. 3. Handicapped children—United States

Brown, Ian. *The Boy in the Moon: A Father's Journey to Understand His Extraordinary Son*. St. Martin's Press, 2011.

Publisher's genre: N/A

LOC classification: RB (Pathology)

LOC subheadings: 1. Brown, Walker, 1996-. 2. Brown, Ian, 1954-. 3. Brown, Walker, 1996-. 4. Brown, Ian, 1954-. 5. Genetic disorders in children—Patients—Canada—Biography. 6. Genetic disorders in children—Patients—Family relationships—Canada. 7. Parents of children with disabilities—Canada—Biography. 8. Genetic disorders. 9. Fathers and sons. 10. Handicapped children—Canada—Biography. 11. Parents of

handicapped children—Canada—Biography. 12. Father-son relationship. 13. Genetic disorders.

Buck, Pearl S., and James A. Michener. *The Child Who Never Grew*. Reprint edition, Woodbine House, 1992.

Publisher's genre: Parenting/ Health

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Buck, Pearl S. (Pearl Sydenstricker), 1892-1973. 2. Parents of children with disabilities—United States—Biography. 3. Children with mental disabilities—Family relationships—United States. 4. Mothers and daughters—United States.

Cohen, Kerry. *Seeing Ezra: A Mother's Story of Autism, Unconditional Love, and the Meaning of Normal*. Seal Press, 2011.

Publisher's genre: Memoir/Parenting

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Cohen, Ezra—Mental health. 2. Cohen, Kerry. 3. Autistic children—United States—Biography. 4. Parents of autistic children—United States—Biography. 5. Autistic children—Family relationships—United States. 6. Autistic children—Rehabilitation—United States

Collins, Paul. *Not Even Wrong: A Father's Journey into the Lost History of Autism*. Bloomsbury USA, 2005.

Publisher's genre: Memoir/Psychology

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Autism in children. 2. Autism in children—Patients—Rehabilitation. 3. Caregivers

Daugherty, Paul. *An Uncomplicated Life: A Father's Memoir of His Exceptional Daughter*. William Morrow, 2015.
Publisher's genre: Memoir
LOC classification: RJ (Pediatrics)
LOC subheadings: 1. Daugherty, Jillian, 1989-. 2. Down syndrome—Patients—United States—Biography.

Davenport, Randi. *The Boy Who Loved Tornadoes*. First Edition, Algonquin Books, 2010.
Publisher's genre:
LOC classification: RJ (Pediatrics)
LOC subheadings: 1. Autism in children—Treatment. 2. Autistic children—Care. 3. Parents of autistic children.

Estreich, George. *The Shape of the Eye: A Memoir*. Reprint, Tarcher, 2013.
Publisher's genre: N/A
LOC classification: RJ (Pediatrics)
LOC subheadings: 1. Estreich, Laura Regina. 2. Estreich, George. 3. Estreich, George—Family. 4. Down syndrome—Patients—Biography. 5. Down syndrome—Patients—Family relationships. 6. Children with disabilities—Biography. 7. Parents of children with disabilities—Biography. 8. Authors, American—Biography. 9. Stay at home fathers—Biography.

Fields-Meyer, Tom. *Following Ezra: What One Father Learned About Gumby, Otters, Autism, and Love From His Extraordinary Son*. Original, NAL Trade, 2011.

Publisher's genre: Special Needs/ Memoir

LOC classification: RC (Internal Medicine)

LOC subheadings: 1. Fields-Meyer, Thomas. 2. Fields-Meyer, Ezra—Mental health. 3. Autistic people—United States—Biography. 4. Autistic youth—Biography. 5. Parents of autistic children.

Forman, Vicki. *This Lovely Life*. Original, Mariner Books, 2009.

Publisher's genre: Memoir

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Forman, Vicki. 2. Premature infants—United States—Biography. 3. Premature infants—Care—Case studies. 4. Premature infants—Development—Case studies. 5. Children with disabilities—United States—Biography. 6. Children with disabilities—United States—Case studies. 7. Mothers of children with disabilities—United States—Biography.

Fournier, Ron. *Love That Boy: What Two Presidents, Eight Road Trips, and My Son Taught Me About a Parent's Expectations*. First Edition, Harmony, 2016.

Publisher's genre: Family and Relationships/ Parenting

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Fournier, Ron, 1963- 2. Fournier, Tyler—Mental health. 3. Asperger's syndrome in children—Patients—Biography. 4. Asperger's syndrome in children—Patients—Family relationships. 5. Fathers and sons—Biography. 6. Parents of autistic children.

Gallup, Stephen. *What About the Boy? A Father's Pledge to His Disabled Son*. First Edition, Lestrygonian Books, 2011.

Publisher's genre: Memoir/Nonfiction

LOC classification: N/A

LOC subheadings: N/A

Groneberg, Jennifer Graf. *Road Map to Holland: How I Found My Way Through My Son's First Two Years With Down Syndrome*. First Edition, NAL Trade, 2008.

Publisher's genre: Parenting/ Special Needs

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Groneberg, Jennifer Graf. 2. Groneberg, Avery. 3. Mothers of children with disabilities—United States—Biography. 4. Down syndrome—Patients—United States—Biography. 5. Down syndrome—Patients—United States—Family relationships.

Hampton, Kelle. *Bloom: Finding Beauty in the Unexpected—A Memoir*. 3.4.2012 edition, William Morrow, 2012.

Publisher's genre: Memoir

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Parents of children with disabilities. 2. Down syndrome. 3. Mothers and daughters. 4. Children with disabilities—Family relationships.

Harry, PhD, Beth. *Melanie, Bird with a Broken Wing: A Mother's Story*. First Edition, Brookes Publishing, 2010.

Publisher’s genre: Memoir/ Children with disabilities

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Harry, Melanie—Health. 2. Cerebral palsied children—United States—Biography. 3. Cerebral palsied children—Family relationships

Kephart, Beth. *A Slant of Sun: One Child’s Courage*. First Edition, W. W. Norton & Company, 1998.

Publisher’s genre: Parenting/Memoir

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Developmentally disabled children—Biography. 2. Kephart, Beth—Family relationships. 3. Parents of exceptional children

Leone, Marianne. *Jesse. A Mother’s Story*. Reprint edition, Simon & Schuster, 2010.

Publisher’s genre: Memoir

LOC classification: CT (Biography)

LOC subheadings: 1. Leone, Marianne. 2. Leone, Jesse, 1987-2005. 3. Mothers and sons—United States—Biography. 4. Cerebral palsied children—United States—Biography. 5. Cerebral palsied children—Family relationships

Marchenko, Gillian. *Sun Shine Down: A Memoir*. T S Poetry Press, 2013.

Publisher’s genre: Nonfiction/Memoir

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Parents of developmentally disabled children—Biography. 2. Down syndrome—Patients—Biography.

Murray, J. B., and Emily Murray. *And Say What He Is: The Life of a Special Child*. The MIT Press, 1979.

Publisher's genre: N/A

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Children with mental disabilities—Biography.

Rapp, Emily. *The Still Point of the Turning World*. Penguin Books, 2014.

Publisher's genre:

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Rapp, Emily—Biography. 2. Tay-sachs disease—Patients—Biography. 3. Terminally ill children—Family relationships—Biography

Rummel-Hudson, Robert. *Schuyler's Monster: A Father's Journey with His Wordless Daughter*. Reprint, St. Martin's Griffin, 2009.

Publisher's genre: N/A

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Hudson, Schuyler Noelle—Mental health. 2. Developmentally disabled children—United States—Biography. 3. Brain—Abnormalities—Patients—United States—Biography. 4. Language disorders in children— Patients—United States—Biography. 5. Fathers—United States—Biography

Schank, Hana. *The Edge of Normal*.

Publisher's genre: N/A

LOC classification: N/A

LOC subheadings: N/A

Slate, Gayle. *Dana's Legacy: From Heartbreak to Healing* - *Strengthening Families of Children with Disabilities*. Morgan James Publishing, 2009.

Publisher's genre: Biography & Autobiography/ Special Groups/ Special Needs

LOC classification: N/A

LOC subheadings: N/A

Soper, Kathryn Lynard. *The Year My Son and I Were Born: A Story of Down Syndrome, Motherhood, and Self-Discovery*. First, GPP Life, 2010.

Publisher's genre: N/A

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Parents of children with disabilities. 2. Children with disabilities—Family relationships. 3. Mother and child. 4. Down syndrome—Patients—Family relationships.

Suskind, Ron. *Life, Animated: A Story of Sidekicks, Heroes, and Autism*. First Edition, Kingswell, 2014.

Publisher's genre: N/A

LOC classification: RJ (Pediatrics)

LOC subheadings: 1. Suskind, Owen. 2. Suskind, Ron—Family. 3. Disney, Walt, 1901-1966—Characters. 4. Autistic children—United States—Biography. 5. Parents of autistic children—United States—Biography. 6. Autistic children—Family relationships—United States. 7. Autistic children—United States—Language. 8. Interpersonal communication—United States. 9. Animated films—Psychological aspects.

Thomson, Donna. *The Four Walls of My Freedom: Lessons I've Learned from a Life of Caregiving*. House of Anansi Press, 2014.

Publisher's genre: N/A

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Thomson, Donna, 1955-. 2. Thomson, Donna, 1955- —Family. 3. Mothers of children with disabilities—Canada—Biography. 4. Cerebral palsy—Family relationships—Canada. 5. Cerebral palsy—Canada—Biography.

Walker, Carolyn. *Every Least Sparrow*. Garn Press, 2017.

Publisher's genre: N/A

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Parents of children with disabilities—Biography. 2. Children with disabilities—Biography. 3. Mothers and daughters—Biography. 4. Syndromes in children—Popular works. 5. Developmental disabilities

Zimmerman, Patricia. *He Just Needs To Be Loved*. First Edition, CreateSpace Independent Publishing Platform, 2014.

Publisher's genre: N/A

LOC classification: N/A

LOC subheadings: N/A

Zimmermann, Susan. *Keeping Katherine: A Mother's Journey to Acceptance*. Three Rivers Press, 2004.

Publisher's genre: Parenting/ Special Needs

LOC classification: HQ (The family, Marriage, Women)

LOC subheadings: 1. Parents of children with disabilities—United States—Biography. 2. Rett syndrome—Patients—United States. 3. Children with mental disabilities—United States.

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