



The  
**Disabled Child**  
Memoirs of a Normal Future

**Amanda Apgar**

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## THE DISABLED CHILD

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*THE DISABLED CHILD*  
Memoirs of a Normal Future

Amanda Apgar

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Textual description of cover art

The image on the front cover is a collage by Alison Owen (“untitled,” 2000). A light pink fabric covers the bottom half of the collage, like a landscape. If it is a landscape, the sky is white. Two shapes “stand” on the pink landscape. They are constructed out of camel-colored thread and look like ladders, though the sides are not straight and the rungs are unevenly spaced. One ladder figure is taller than the other. The shorter ladder has three rungs near the base and one rung at its top, but no others. Behind the lower rungs of the shorter ladder are two bright pink pieces of sequins stacked one on top of the other. The entire piece is held in place against a piece of white vellum by strips of scotch tape. The overlap between pieces of tape creates an uneven surface. The zigzagged edges of the tape strips recall the teeth on the tape dispenser, and some of these edges curl upward or away from the collage.

FOR KATHERINE



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## Introduction

This is a book about *The Disabled Child*. It is not a book about any particular child or any particular disability, but a book about a figure I call *The Disabled Child* that emerges from the stories parents tell about their real-life children with disabilities. This is a book about an expectation, an idea, and an ideal that is produced and reproduced in stories parents tell and that both captures and recreates a cultural sense of childhood and what it means to be a child with a disability. And so, this is a book about stories. It is about the shape of those stories, about their beginnings and how they get to their endings. It is about individual narratives; and it is about a collection of narratives called “special needs” parental memoirs and what characterizes this collection.

In this book I argue that “special needs” parental memoirs are a subgenre of disability life writing with distinct conventions. With notable exceptions, parental memoirs reiterate a dominant cultural narrative of disability as inherent in the individual and as compromising quality of life via the foreclosure of opportunities, especially in terms of future labor, sexuality, and reproduction. As these are markers of independence in United States discourses of development, the loss is thus narrated as a child’s incomplete future adulthood. Memoirs challenge this prognosis, and losses are often regained through a narrative achievement of normality in childhood, most typically through the enactment of gender and sexuality norms and/or narratives of value or contribution; in other words, through narratives of productivity and potential reproductivity. The obstacles posed by disability thus

overcome, the disabled child is rescripted into a normative life narrative and the promises of adulthood, rhetorically sidestepping the otherwise required adulthood achievements of autonomy and independence. By way of these generic conventions—through the telling of individual stories in familiar, generic ways—“special needs” parental memoirs collectively construct The Figure of The Disabled Child, the child who overcomes ableist exclusions of childhood, adulthood, and “normal” life.

This book, then, is also about parents of children with disabilities. Or, rather, it’s about parent memoirists and what they have written. I argue about why they write and for a method of reading what they write. I argue that they write because they are compelled by culture to do so, because the cultural imperative for self-betterment and an ableist investment in a disability-free future demands an explanation for the child with a disability: how did this happen? What will you do about it? I argue that they write about a privileged, and familiar, story of childhood that excludes their children with disabilities and that they write their children back into that story of childhood. They write, in other words, of ableist exclusions and of individual overcoming. How parent memoirists rewrite their disabled children into dominant cultural narratives of childhood is the subject of this book’s chapters. Some memoirists write that their disabled child is just like any other boy or girl, narrating their child’s life in terms of gender and sexuality norms; other memoirists depict their children “giving back” to their parents and the world in extraordinary ways, challenging the notion that people with disabilities do not “contribute to society.” Most memoirs in the genre draw on the discursive and material privileges of whiteness and the settler colonial logics of entitlement when advocating for their child’s inclusion. Put differently, and with notable exceptions, the genre is characterized by stories of overcoming exclusion via rescription into domains of power, the very same domains that stigmatize, debilitate, and exclude people with disabilities from full inclusion in all aspects of life. Parent memoirists argue, then, for their child’s seat at the table their child does not fit. They seldom suggest destroying the table itself.

## ON THE BOUNDARIES OF A GENRE

“Special needs” parental memoirs are a subgenre of disability life writing that take the lived experience of parenting a disabled child 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 nondisabled or neurotypical peers (Linton 1998, 15–16). Despite these sentiments, “special needs” remains a popular euphemism for describing disability, and childhood disability, in particular. In this book, I examine only those memoirs written by parents about raising their children. I excluded memoirs written by siblings, teachers, and friends of disabled children, as well as memoirs coauthored by parents and their children, with exceptions for those memoirs with only minor contributions (a chapter or less) made by children. I exclude these not to decenter the voices of people with disabilities, but because parents and their narratives make significant contributions to shaping public perceptions of disability and as such require explicit examination as a standalone subgenre.

It is difficult to know exactly how many “special needs” parental memoirs there are, since a good number are published by very small and/or hybrid presses (sometimes called “vanity” or author-pay presses) or are self-published. WorldCat yields only about a hundred results under the Library of Congress subject heading “Parents of Children with Disabilities—United States—Biography,” but half of these are autobiographies about growing up disabled or with a disabled sibling, rather than memoirs of raising a disabled child. “Parents of Children with Autism” and “Parents of Developmentally Delayed Children” (both also U.S. biographies) return fifty unique titles. There are many, many narratives of raising a child with disabilities organized under the Library of Congress Subject Heading (LCSH) “Biography.” Sometimes these are sub-organized under “Family and Relationships—Children with Disabilities” and grouped with parenting, psychology, or educational texts. Many of the memoirs are cataloged under RJ, the Library of Congress heading for “Pediatrics” (under the general heading, “Medicine”). Others are cataloged under HQ for “The Family, Marriage, and Women.” Searching the deepest corners of WorldCat, cross-searching the LCSH “Parenting” with “Children with Disabilities” (and several variations on this) and “Biography,” and reading through thousands of Amazon.com listings under Memoirs > Specific Groups > People with Disabilities (formerly “Special Needs Memoirs”), I have found approximately three hundred English-language memoirs about raising a child with disabilities. This is not an exhaustive list, as memoirs continue to be published and unpredictable cataloging continues to surprise me. The collection features a variety of atypical bodily,

sensory, cognitive, psychiatric, and neurological statuses. Memoirs about children with autism comprise a whole third of the genre; many others are about children with Down syndrome, multiple disabilities, and cerebral palsy. Other disabilities represented include Rubenstein-Taybi syndrome, schizophrenia, radical attachment disorder (RAD), fetal alcohol syndrome (FAS), Tay-Sachs disease, Rett syndrome, pervasive developmental disorder (PDD), optic nerve hypoplasia, albinism, and rare neurological and genetic conditions. The analysis in this book is based on more than sixty parental memoirs, and the close readings in the following chapters focus on twenty-eight memoirs and cite a dozen others. With one exception, these stories are based in the United States.

I write about publications that are almost unknown and others that have enjoyed some popularity, which I largely determined according to WorldCat library holdings, Amazon.com sales rankings, and press about the book. The data on any particular title's popularity is difficult to find. Nielsen BookScan ratings provides the most comprehensive sales data to the publishing industry, but still capture between only sixty to seventy-five percent of all sales. Moreover, this data is not publicly available nor provides a comprehensive picture of "popularity." A book's popularity can sometimes be inferred by examining bestsellers lists published by *Publisher's Weekly* and the *New York Times*. Very few parent memoirs make bestsellers lists. Among the parent-authors, several have written novels or other nonfiction works, including other memoirs, prior to writing about their children. At least five parent-authors are academics. These are among the more visible memoirs. At least ten memoirs are serial, with sequels often written after a child has reached adulthood. All three-hundred memoirs I have found were published between 1950 and 2021, and fewer than thirty were published before 2000. More than two hundred (two thirds of the entire collection) have been published since 2010 alone. The small number of memoirs published prior to 2000 relative to what has been published since corresponds with what G. Thomas Couser has called the "memoir boom" of the twenty-first century (2012, 6).

The range of publication years is useful for contextualizing my analysis in terms of the rise of neoliberal political rationality since the early 1980s. As explained below, neoliberalism names not only government nonintervention into market operations, but the hegemonic logic by which U.S. citizens understand themselves in relation to the state and one another as individuals and consumers. I argue in this book that the narrative of overcoming

so ubiquitous in the genre fulfills a neoliberal imperative for individuals to manage and contain disability's threat to the productive and reproductive future. Most of the child-subjects of these sources were born after 1980. Earlier memoirs about raising children in the 1940s, 1950s, 1960s, and 1970s—of which there are fourteen in number—provide perspective on how narratives of childhood and disability have been inflected by neoliberal rationality and a shift in parenting ideals since the 1980s. Indeed, I argue that it is the very writing of the memoir, in addition to its narrative arc, that engages in a neoliberal project of self-improvement, which makes some sense of the memoir boom in relation to politico-historical conditions.

Finally, very few memoirs are about a raising a child of color. This is the subject of chapter two in this book. Of “special needs memoirs” broadly, which include autobiography in addition to biographies by siblings, teachers, and others, published narratives are almost entirely about the experiences of white families and white people. This limited representation is mirrored in films, television, and other media about children with disabilities. Moreover, parents who write special needs memoirs are almost entirely middle- or upper-class and highly educated. 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, I interrogate the ways the published narratives both emerge from and reinforce limits around just exactly which disabled childhoods can be reimagined as good and valuable.

## COMMON SENSE

Most parent memoirists recognize discrimination against people with disabilities, even the ways they themselves feared and hated disability. These attitudes are downstream of medicalized models of disability that frame bodily difference as 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. Often, what parents describe as “grief” over their child's diagnosis is to a significant degree fear of the hardships that will likely befall their child as they navigate an ableist world. In this way, parents gesture to a more political way



to think about disability as a social experience, rather than a dysfunctional bodymind. Yet, most often, parental narratives are about establishing their disabled child's inherent right to belong to that same ableist social world. Drawing on commonsense narratives about gender and childhood, they write their children into the realms of "normality," rather than contesting the entanglement of normativity and privilege that position disabled children outside these same realms. In other words, parental fear is informed by an awareness of the devaluation of disabled bodyminds, but memoir children emerge as exceptional and exceptions to the commonsense narrative about life lived with disability.

Take Nella's story, for example. Nella, a white child born to white parents, was diagnosed with Down syndrome shortly after her birth. Upon her diagnosis, Nella's mother, Kelle Hampton writes in her memoir *Bloom* (2012) that she was overcome with grief and guilt. She had promised her older daughter a little sister but feared that Nella's diagnosis robbed Lainey of this sibling bond and would burden her with a future of caretaking. She had promised herself a perfect family, and she wept with self-pity for the type of family she felt they had become (87). Her distress was so severe and the disappointment so intense, Hampton struggled to bond with newborn Nella and wondered if she even loved her or could accept her (7, 11). Quickly, however, Hampton begins reconstructing the narrative. She reimagines Nella: no longer a disappointment, Nella was a gift that Hampton was specifically chosen to receive. 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). She explains 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 because of the ways it would enable her to transform into a new, better version of herself (65).

Kelle Hampton's memoir captures the entwined discourses that catalyze my analyses in this book: the narrative of overcoming; the entanglement of heterosexuality and able-bodied development; the "threat" of dependency; and, perhaps most saliently, the neoliberalization of inclusion. In *The Disabled Child*, I engage with neoliberalism as the governing rationality, or way of making sense, in the contemporary United States. As economic policy, neoliberalism refers to a rejection of state interventionist policies: the state's role in neoliberal economics is to ensure the free market and entrepreneur-

ial freedoms (Harvey 2005, 20–21). In practice, neoliberal policy has drastically reduced and eliminated the social safety net in the name of state nonintervention. As Wendy Brown, David Harvey, and others have argued, neoliberalism exceeds the politico-economic realm, to “disseminat[e] market values [of state non-intervention, investment, profitability, and utility] to all institutions and social actions” (Brown 2003, n.p.). Said differently, neoliberal ways of thinking have permeated all areas of life to become the primary framework by which Americans make our experiences meaningful and comprehensible to one another (Brown 2003; Hall and O’Shea 2013, 8). It has become “common sense,” or the “popular philosophy” shared by everyone. Neoliberalism constructs subjects as individually responsible for self-management and actualizing self-interests (Brown 2003) and codes all relationships in terms of commodity exchange. All citizens are “equal” as market actors; and freedom is achieved through strategic choice making to improve one’s life (Hall and O’Shea 2013, 11). Neoliberal ways of thinking thus (re)produce the notion that independence and autonomy—the capacity to make personal choices—are essential qualities of a citizen; to be an equal participant in society, to be one of the masses, one must be capable of independent, autonomous action. In this way, neoliberal rationality defines the terms of citizenship along the developmental axis. Commonsense developmentalism shifts from dependent to independent/autonomous (discussed in detail below); 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.

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” (2013, 3). 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 (2–3, 7). Disability, in contrast to this model of diverse, purchasable subjectivity, is understood as not choosable (7), and “fixed” (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 (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 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. Prospective parents can more easily decide if a child with disabilities will be born, and 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.) For example, cochlear implants, which allow d/Deaf people to “hear,”<sup>1</sup> create a number of choices: parents of d/Deaf infants must choose whether or not to implant their child (the cost of implants is covered by some insurance), which will largely determine if they will or will not learn sign language (through private lessons or at a Deaf school) and if they will send the child to a Deaf school (non-public and funded for d/Deaf children) or a hearing school (public or private). For non-implanted d/Deaf children and d/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, the meaning of deafness, and what it means to be “normal.”

Importantly, neoliberalism and normalcy 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. 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” (Lee 2008, 26). Under a neoliberal political order and the privatization of health and welfare, there are no structural assurances of inclusion; in this absence, there is “no future” (Kafer 2013, 28, drawing on Edelman) for bodies that are irreconcilable to—at the very least—the narratives of progress. Bodies that are sick, disabled, or deformed; bodies that are imagined as market non-actors; and individuals that fail to achieve independence and autonomy are marginalized by existing cultural

narratives of the life course. To reimagine disability outside these limiting representations requires reimagining the future itself.

To challenge dominant cultural narratives about disability, parent memoirists make a new kind of narrative sense out of their experiences and their children's lives. To make sense to one another, we must share common ground: a concept, a language, a narrative template. The story of childhood or the narrative of overcoming disability are prominent among "special needs" parental memoirs as shared cultural stories. And it is through this familiar idea, through the expectation about how the story unfolds, that the difference of a unique experience is articulated. The story goes, "this is what I thought would happen," because the narrator's expectations based on stories heard before. Hampton thought she would have a "normal" (2012, 7) child. She thought Nella and Lainey would grow up together, fight over curling irons, and later, commiserate about their husbands (37). Readers of "special needs" parental memoirs readily recognize parents' expectation for a nondisabled child, for a child that does the things all children allegedly do, like walk and talk and grow up to become independent, productive and reproductive adults. In that recognition, the commonsense story of childhood has been retold and confirmed; it is a time of gender normative, able-bodied, and neurotypical development preceding adulthood autonomy. Disability figures not in it.

The story of childhood as a developmental period preceding adulthood is neither universal nor ahistorical. In the Global North, children are often understood as "blank slates," a figuration not repeated in places where new lives are reincarnated souls or where children are born with knowledge of between-life realms (Gupta 2002; Gottlieb 2004). The notion of children as blank slates was shaped in part by enlightenment thinkers John Locke and Jean-Jacques Rousseau, who in the seventeenth and eighteenth centuries (respectively) variously wrote that children were like white paper upon which rules of society could be inscribed (Dailey 2009, 145). Claudia Castañeda argues that in the contemporary moment we have abandoned the notion of children as blank slates and instead imagine children as adults in the making—as potentiality, rather than actuality. By this, Castañeda implies that child is never complete in itself; it is not fully formed, but perpetually open to reformation through ongoing development. This essentialist transformative quality of childhood is also regulatory, so that if a child fails to realize its potential, they remain a "flawed child and an incomplete adult" (Castañeda 2002, 4).

Either iteration of the developing child (as blank slate or adult-in-the-making) influences a concept of childhood innocence, or childhood as a time of innocence (Ariès 1965, 106–27; Bruhm and Hurley 2004, xxxiv). Innocence in childhood refers to the absence of knowledge or experience of adult matters, namely labor and reproduction. This is why children are understood as asexual or presexual beings, and why “play” is recognized by the United Nations as a fundamental right of children. Robin Bernstein argues, however, that childhood innocence is a performance of obliviousness to one’s social statuses (2011, 6), and in this way, constructed as white (8). Bernstein writes that children of color could never be “innocent,” or ignorant, of the way they are racialized as not-white; I would add that this includes the ways in which their capacities for production and reproduction are produced in and through that racialization. The construction of childhood as a forward-promising time of innocence and play renders it “conceptually white” (Gill-Peterson 2018, 2) with material consequences for the real lives of children of color.

Similarly, the figuration of children as adults in the making has been deployed in the shaping of global hierarchies along racial and ethnic lines and used to justify subjugation of racialized others and colonized peoples via the discourses of childlikeness and dependency. Castañeda notes in particular the ways in which childhood was used by scientists during the nineteenth century to engender the evolutionary stages of the genus from savagery to civilization (see also Steedman 1998, 84). The child became a “fleshy origin for hierarchies” (Castañeda 2002, 41), a bodily container for human variation across the globe and time, a concept later taken up by United States eugenicists. As children were brought under the medico-scientific gaze, their bodies “materialized” a narrative of human history that precluded the female, racialized, insane, and disabled from achieving normative adulthood (Castañeda 2002, 40).

Taking the above narratives together, developmental achievement is widely understood as the paradigmatic purpose of childhood and the defining distinction of adulthood. Developmental potential and progress is made intelligible through whiteness and ability norms. Moreover, development is calibrated in childhood (and achieved in adulthood) by highly gender differentiated markers. For example, girls are widely understood to acquire more language sooner than boys; boys’ gross motor and spatializing skills, however, develop earlier than girls’. In both cases, “normal development” is a gender achievement. Or, as Alison Kafer argues, the categories “boys” and

“girls” themselves are constructed in and through able-bodiedness and neurotypicality (2013, 57). Put differently, bodies that do not conform to expectations of normative ability cannot provide the structure for the enactment of normative gender. This discursive exclusion of disabled children from the normative gendered categories of boyhood and girlhood demonstrates that the shift from developing to mastery occurs under a gender-normative rubric of able-bodied development. This works to potentially render disabled children “genderless” in medical and public perceptions (Kafer 2013, 57) and to produce disability in the absence of normative gender (e.g., gender dysphoria of childhood). In short, there is no gender without ability; or as Tobin Siebers has argued, “in the absence of ability, gender identity has no future and risks to disappear entirely” (2008, 175).

Kelle Hampton’s narrative evinces this entanglement: Hampton was unable to imagine a child with Down syndrome filling the role of sister and daughter according to heterosexual gender norms. Hampton assumed that Nella would grow up to be a straight, cis woman. She had hoped that Nella and Lainey would walk in each other’s weddings and share the joys of motherhood (2012, 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. 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). In other words, she assumed Nella would forever inhabit the role of a childlike, neutered sibling. While this “failure” is never explicitly resolved in Hampton’s memoir, Nella is recuperated via neoliberal logics of value and exchange: as Hampton began to understand herself as lucky, “chosen” to be Nella’s mother, she also 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).

The particular moment of pivot in Hampton’s *Bloom* is instructive. Disability disrupts the commonsense, U.S. story of childhood. Perhaps the memoirist’s child does not walk or talk. Perhaps total adulthood independence is in question. Perhaps parents cannot foresee a future in which their child becomes a productive citizen or has a family of their own. In “special needs” parental memoirs, disability catalyzes a new narrative: “this is what happened, instead.” This is a mark of the genre. Disability in childhood threatens a child’s inclusion in heterosexual adulthood; and that same dis-

abled child can be recuperated into this life course (and the social world it reproduces) by becoming an independent market actor. A teacher, a bestower of privilege; in different ways memoir children challenge the narrative of dependency by “giving back.”

In these ways, parental memoirs expose how the fundamental distinction between U.S. cultural ideas of childhood and adulthood is actually between a state of dependency and independence or autonomy. 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 United States (Duane 2013, 5). Children are, of course, dependent: without care an infant will die; they depend entirely on others for their survival. But we imagine childhood as a time during which a human being increases in capacity and becomes less and less dependent on others for their survival. Adulthood, then, is a relational time in which independence, or total capacitation, has been achieved. (This relationship of course presumes there is indeed a singular, “total” capacity against which the diminished capacity of childhood could be measured, and does so despite contrary empirical evidence that capacity is variable.) The stickiness of childishness and adultishness as qualities illustrates my point further: childishness and adultishness stick to capacity, or degrees of independence, rather than aged bodies. For example, when a child is unusually polite and conversational they are often described as precocious, “old beyond their years.” On the other side of the dynamic, adults that rely on others to make substantial life decisions or benefit from supervision are conceived, by many, as “childlike.”

The child, then, occupies a relational place in the social imagination as a dependent figure. This is the subordinate position. Independence is central to American identity and ideals for a good life. Martha Fineman writes that autonomy is the ideal that “defines the individual subject” in American neoliberal society (2004, 18). Autonomy is demonstrated by independence—self-determination or self-reliance—and results in financial and material self-sufficiency (Fineman 2004, 9). As explained above, American cultural beliefs include the notion that everyone has the same opportunities for and capacity to achieve self-sufficiency (see also Fineman 2004, 34) and dependency (on the state, on others) is un-American. In this way, dependency, like autonomy, is an issue of choice: neoliberal thinking 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. 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), sustaining the myth of autonomy in the public sphere.

It is not as though we are without other models for thinking about dependency. For example, Eva Feder Kittay and Michael Bérubé, both white scholars and parents of children with disabilities, have in different ways argued that dependency is a part of the human condition and care is a form of relationality central to humanity (Kittay 2020, 33–34; Bérubé 1998, 176). These frameworks challenge the myth and privilege of the so-called autonomous political actor and oft-regarded subject of equality. As Kittay explains, “the ideal of equality itself is vested in the ideal of the moral and political integrity of each individual” (2020, 32). She and Bérubé argue, however, for a relational basis for equality and by extension, social inclusion. Bérubé writes, for example, that his son Jamie’s independence depends on his dependence on others; or, in other words, Jamie’s “individual potential” is achieved via the mutual interdependence that binds all of us to one another (1998, 176). Fineman lists infancy, illness, disability, and old age as examples of life’s “inevitable dependencies” (2004, 161–164; c.f., Bérubé 1998, 248; Kittay 2020). Kittay argues that dependency requires care, and that relations of care are the most fundamentally shared human experience and thus the basis for equality (2020, 33). Nussbaum likewise writes of the centrality of care to human life, arguing specifically for the recognition of care labor as essential to all other human capabilities (Nussbaum 2002, 135). Like Kittay, Bérubé, and Nussbaum, I recognize parenting as a form of care work and as a site of radical potential for reimagining relationships of dependence. I argue, however, that with notable exceptions, parental memoirs often recreate the myth that dependencies are “avoidable” rather than inevitable. The narratives dominating the genre often reify the distinction between dependence and independence and the cultural significance of autonomy, rather than construct visions of interdependent human flourishing. In other words, *The Disabled Child* argues that relationships of care can, and often are, narratively reconfigured according to neoliberal individualism, including in ways that revalue care only as “mutual advantage” (Nussbaum 2006, 2).

“Special needs” parental memoirs narratives thus evince the thrust of



neoliberal rationality as common sense. Parents do this by constructing narratives in which their children meet expectations for productive citizen-subjects in the United States: children are scripted into gender normativity and heterosexuality to ensure the reproduction of the private sphere; and their children make moral and spiritual contributions to society and are thus constructed as nondependent market actors. Each is scripted into a seemingly compulsory success story as “a certain kind of achiever that other people would understand” (Hendren 2020, 181). Moreover, in writing their memoirs, parents undertake a project that manifests a neoliberal world-making ethic; parent memoirists rise to the individualized demands of self-management, social improvement, and “progress” (perhaps overcompensatorily) through the narrative elimination of their disabled children’s alleged threat to an autonomous and independent world order. Hall and O’Shea explain that commonsense feels natural but is shaped by history and sustained by the broad circulation of limited discourses that “offer [us] frameworks of meaning with which to make sense of the world” (2013, 8). I would argue that neoliberal thinking *imposes* frameworks for meaning-making more than it “offers” them. At least in the case of parental memoirs, the neoliberal-aligned reconfiguration of disability is so ubiquitous, because it is so ubiquitous. There simply are so few alternative narrative frameworks.

From the unyielding repetition of this narrative emerges a figure: The Disabled Child, the child for whom impairment would foreclose opportunities for inclusion into the discourses of childhood, adulthood, and neoliberal subjectivity, but for whom by gender normativity and narratives of value contribution are scripted into normalcy. In the new narrative, impairment itself is not usually “overcome” as these are not, generally, narratives of cure. What is overcome is exclusion from the privileged time of life and cultural ideal we call childhood and the adulthood it precedes. Parent memoirists narrate their children’s stories in ways that bring into relief the able-bodied norms and expectations of child embodiment, growth, and development, and the autonomous, able-bodied adulthood on which these depend. They reclaim these narratives for their disabled children. They reinclude them. They quite literally argue that their children belong, that their children are not so unlike their able-bodied and neurotypical peers. Parental memoirs are for this reason counted among positive portrayals of disability: they are stories of overcoming exclusion. And yet, at the same time, parental memoirs rarely challenge the logics that undervalue dependent and non-normative bodies to begin with. Recuperative strategies draw on class, race,

gender, and sexuality privilege. Positive portrayals “special needs” memoirs might be, they also replicate the logics of inclusion that compelled narrative recuperation in the first place. This tension defines the genre, and reasonably so; normativity is, after all, a utopia (Berlant 2008, 5), and most of us want to belong.

## FEMINIST/QUEER/CRIP: METHODS

*The Disabled Child* analyzes how gender, sexuality, and ability operate rhetorically to achieve a narrative of overcoming disability, as well as the discursive and material privileges of whiteness that enable that narrative recognition. I conduct this analysis using what I call a feminist/queer/crip (FQC) theory of narrative. A FQC theory of narrative combines a critical disability studies perspective with feminist and queer narrative analysis to examine how ability, like gender and sexuality, is structured by narrative. My use of feminist/queer/crip comes from Alison Kafer’s influential *Feminist, Queer, Crip* (2013), wherein she articulates a genderqueer disability studies coalitional methodology. Kafer writes to examine the ways in which “compulsory able-bodiedness/able-mindedness and compulsory heterosexuality intertwine in the service of normativity” (2013, 17). I do this too, under the rubric of narrative analysis, arguing throughout this book that narratives are a site for the production of white, settler, heteroabled normativity. I align this project with feminist disability studies that theorize disability as a relation of power within systems of oppression including racism, colonialism, and economic exploitation (Schalk and Kim 2020, 32).

My analyses proceed from a fundamental understanding of memoirs as a form of writing that enlist readers into a relationship with the text. Couser has argued that memoir’s primary purposes are to make truth claims about the narrator’s self and the world (2011, 13–14). Like other nonfictional forms of auto/biography, memoirs promise to be “true.” Memoir truths are not empirical claims, but rather subjective truths based in experience. Because of memoir’s obligation to the truth, or the “real world,” these narratives draw readers into relation with the processes and events that unfold in the narrative (14). In other words, memoirists “speak their truths,” and readers respond, “I see you.” Life writings are thus discursive formations of truth telling that are sustained by intersubjective recognition and differentiation.

While all life writing discursively constructs the auto/biographical sub-

ject, memoir's distinction is that its construction of the self is typically in relation to a significant event in the narrator's life (13–14). Memoir narratives are stories that emerge from the unexpected, when something out of the ordinary has happened and which compels evaluation and resolution (Frank 2012, 26). 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 1993, 43–44; Couser 2011, 38). Writing about “illness narratives,” Arthur Frank notes that illness is culturally understood as a moment of change and that undergoing changes is broadly viewed as a valuable endeavor (1993, 39). He suggests that we might read illness narratives as a “technology of the self,” another iteration of the sociopolitical mandate for self-regulation (49). This read overlays neatly with an understanding of neoliberal imperatives for self-management and for making a project of one's life. Scholars and activists have labored to distinguish illness from disability, and I do not collapse that distinction here; I note, however, that disability narratives similarly respond to a moment of medicalized unordinariness in the narrator's life. Disability memoirs respond to a shared cultural understanding of disability as unexpected and in anticipation of the question, “What happened to you?” (Couser 2009, 16). As disability scholar, memoirist, and mother to a disabled child Rachel Adams puts it: a baby like hers “demands a story” (2013, 108).

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 2012, 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. Ally Day explains similarly that life writing is a “technology of inclusion” that both reinforces a “particular kind of deserving American subject” and delineates “what we are allowed to experience” (2021, 35) in terms of hegemonic narratives and institutions. Autobiographical truths are not necessarily 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 2010, 16).

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.

Lauren Berlant's work 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" (2008, 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. Culturally available, positive narratives of disability are limited, hence the astoundingly common "overcoming" narrative among "special needs" parental memoirs. "Overcoming" narratives refer to those wherein the disabled person overcomes obstacles impairment is presumed to pose. The disabled person's achievements are sometimes objectively impressive, like becoming a Paralympian or getting into Harvard Law School; other times they are as mundane as making friends or having sex. Often, overcoming narratives hinge on the assumption that disability is tragic, and the disabled person overcomes their own internalized ableism and self-loathing. In parental memoirs, the overcoming narrative not only depends on the child's accomplishments or self-actualization, but also how these accomplishments relieve parents of the disappointment of having a disabled child.

The disappointment parents feel comes downstream of a medicalized understanding of impairment as a defect or deficiency that will compromise quality-of-life potential for the disabled individual and those around them. Impairment, conceived as a failure to be normal, signals reduced possibilities; it compels "normalizing" treatment and/or interventions, including cure, to restore those lost possibilities. In the case that normalization will never be achieved, the medicalized understanding of impairment might also require its elimination through genetic selection, sterilization, and selective abortion. This is not to suggest that therapeutic interventions such as speech therapy and cochlear ear implants are equivalent to selective abortion, but rather that "cure is an ideology" (Clare 2017, 69), and that these interventions exist along a spectrum and reproduce the logic of cure: impairment can and should be corrected. The site of correction is the disabled individual, rather than the limited concept of what counts as a human bodymind. In other words, a purely medicalized understanding of impairment identifies the bodyminds that do not fit neatly into the existing social and physical world and responds not by changing the world, but by attempting to change the body. Overcoming happens, then, either when individual impairment is cured or significantly reduced (for example, with a cochlear ear implant) and

thus becomes negligible in the existing social world; or, when the disabled person accomplishes ordinary or extraordinary achievements within the existing social world, despite being disabled. In neither case does the world become more accessible to diverse human bodyminds. This is perhaps why the overcoming narrative is the abled audience's most preferred storyline (Couser 2011, 44). With overcoming narratives, abled readers or film viewers need not examine structural obstacles to inclusion that overdetermine negative perceptions of life-with-disability. Instead, overcoming narratives reinforce the message that disability is undesirable, but that sometimes there are workarounds.

Parental memoirs about raising a child with disability reproduce the overcoming narrative in distinct ways. First, many parents identify a diminished or eliminated opportunity for their child to have an "ordinary" childhood and "normal life" as one of the primary obstacles posed by impairment. Disability, they write, "marks" their children, and others must be taught to see disabled children as children (Estreich 2011, 52–53). Relatedly, parents often write that impairment robs them of typical parenting experiences; for example, Rodney Peete (2010), a Black father, writes that he had expected to recreate his relationship with his father, centered around sports and masculinity, with his autistic son R. J., but that R.J.'s autism made him uncoordinated and quick to lose interest in playing ball. Finally, many parents name their own prejudices against people with disabilities as obstacles posed by their child's impairment; a number of parent memoirists wonder if they will ever love their child. Each of these obstacles is shaped by the parent's expectations for their child and their perceptions about disability, rather than the child's lived experiences of exclusion or internalized ableism. In a small number of memoirs, the disabled child experiences a kind of cure: for example, in Sophia Gant's *One of Those* (1957), her white son Peter proves "able to learn" despite a doctor's prognosis; or more currently, in Ron Suskind's *Life Animated* (2014), his white, non-speaking autistic son Owen learns to communicate with words. In the majority of memoirs, however, overcoming occurs when parents experience a perception shift. Disabled children surprise their parents by behaving much like nondisabled children; they play, make friends, love their siblings, go to school, thus securing their place in "ordinary" childhood. This restores, for many parents, the promise of typical parenting experiences. In other memoirs, parents fall wildly in love with their disabled child and overcome their previous prejudice. Almost uniformly, parents explain that the process of parenting and loving a disabled

child—thought to be unlovable—has made them a better person. In this way, parental memoirs are stories of *parents* overcoming disability to a spectacular, inspirational narrative end.

The overcoming narrative thus works in a great number of parental memoirs to eliminate the parent's problem with disability. Like other “supercrip” narratives, overcoming narratives in parental memoirs often foreground parents' grief/fear to catalyze the narrative reconfiguration and happy ending. 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 social inclusion for their children and themselves as parents. In parental memoirs, happily ever after is an individualized experience of a child fitting in (at least discursively) and a parent feeling better. Its constant reiteration produces a cultural concept (Schalk 2016, 76) of both disabled children and their parents as exceptional and exceptions to an existing, ableist cultural order. Parents have no narrative recourse to explicitly challenge the idea that “a future with disability is a future no one wants” (Kafer 2013, 3); they can, and do, however, insist on their disabled children's inherent value.

At the collective, perhaps generic, level, parental memoirs demonstrate a shared historical sense 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” (2011, 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” (10). It is the expected outcome of life in the United States; 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—the birth of a disabled child brings into relief the structural contingencies that threaten achieving a “good, normal” life. Narratives of childhood disability thus engage in complex discursive maneuvers that both resist normalization and can be regulated to existing paradigms, particularly of gendered and neoliberal subjectivity.

Again, bearing in mind the efforts of disability scholars and activists to demedicalize disability by disassociating it with illness, Ann Jurecic's *Illness*

as *Narrative* (2012) 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 insists that illness narratives have been constructed by medical, social, and other discourses and to trust a narrative “to provide access to the experience of another person is a naïve understanding of how texts function” (2012, 3). Others argue that “life writing [including autobiography and memoir] is . . . an extension of Enlightenment rationality that places the individual at the center of thought” (11). 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. But Jurecic argues that between these two models—radically suspicious disembodied criticism (paranoid reading), or didactic humanism that sees narrative as redemptive—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 too socially conditioned to truly articulate a subjective experience; 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).

Drawing on Eve Kosofsky Sedgwick’s notion of reparative reading, Jurecic forwards a practice of reading life writing that privileges a place of refusing to resolve tensions such as those that mark “special needs” parental memoirs. 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 2012, 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 2012, 124). It is reading empathically, as a practice.

I read as a feminist disability studies scholar. An empathic reading of parental memoirs must be bracketed by well-founded skepticism of parents’ roles in advancing disabled children’s wellbeing. Alison Carey, Pamela Block, and Richard Scotch’s recently published *Allies and Obstacles: Disability Activism and Parents of Children of Disabilities* (2020) shows that parents are a diverse group of fierce advocates against and willing accomplices in normality’s regime. This can also be argued about parent authors. There are of course the problems of generic conventions described above and

throughout this book, and there is also the problem of authorial voice. I am skeptical of the cultural power given to parent narratives to authorize experiences of childhood disability. Examining memoirs about raising children with autism, Bruce Mills (2010) notes that parental stories are stories about a parent's understanding of their child and not their children's biographies. Couser explains, parental memoirs "tend to be self-authorized, in that the biographers are likely to presume rather than to request the right to write their children's lives—especially in the case of an impaired child" (Couser 1998, 422). Parental memoirs thus risk invading their children's privacy (Couser 2005, 20). And, especially in the cases of children who experience communication impairments, parents sometimes toe the line between advocacy, on the one hand, and the assertion that they *are* their children's voices. Parents balk at criticism, arguing they write—indeed, live—with their children's best interests at heart. Amy Shuman points out, however, that "the act of narrating does not necessarily change the conditions of marginalization that underlie access to speaking for oneself or that assign some events to public and others to hidden status. On the contrary, giving voice to the voiceless can just as often reproduce the power relations underlying a group's or a speaker's status" (Shuman 2015, 41).

I read also, however, as a member of disability life writing's "intimate public" (Berlant 2008, viii) and approach "special needs" parental memoirs as a consumer of U.S. cultural stories about disability, gender, and the life course. Reading these memoirs empathically means I recognize the expectation of what parents thought would happen. I am deeply compelled by the problem of this genre, by the unresolved (and unresolvable) tension between writing inclusion via exclusionary narratives. It was not so very long ago that parents were advised to institutionalize their disabled children and to forget about them. Today, disabled children continue to attend segregated schools (especially when they are disabled children of color). Opportunities to develop sexual awareness and experience sexuality are withheld from many people with disabilities at interpersonal and structural levels; not only is the capacity for consent bound to culturally determined notions of "competence," but sex education is not universally available (Gill 2015), assisted sex and partnered surrogacy are not legally protected practices in the United States, and people with disabilities encounter a number of obstacles to obtaining contraception, including provider bias (Horner-Johnson et al. 2021). Only eighteen percent of the adult disabled population is employed, and people with disabilities in the United States experience poverty at twice the rate of nondisabled people. In short, inclusion, let alone opportunities to



live flourishing lives, remains very much out of reach for very many people with disabilities. Parent memoirists challenge this. They demand inclusion; they literally rewrite the narrative of “normal life” to include their children. Their children become sexual adults and contributing members to society. Their children are invited into heteronormativity and the economy, sites to which they have historically been denied access. They get to be normal. Parents show that normalcy is indeed very much a utopia. I see this too, even as I recognize the historical and present danger of “normal.”

## CHAPTER OUTLINES

The Figure of the Disabled Child emerges in this book as a cultural object that brings into relief the exclusions against which it is shaped: normalcy, individual autonomy, development, mastery, privilege. And yet, because The Figure is a mere figuration, a discourse, it is undone by the actual lives of children with disabilities. Living disabled children do not always behave the ways children are expected to behave: they may develop slowly or not at all; they may take their first steps on crutches or always crawl or be nonambulatory. They may not speak. They may never become less dependent on others for their survival than they were during infancy. Children with disabilities are of course children, but their lives during their childhood years bring into relief the ways in which U.S. cultural ideals about what childhood is are based on ability norms. Most children with disabilities also do, of course, grow up, and many adults with and without disabilities depend on others for their care and flourishing, or have not mastered speech, or have unsteady gaits, or socialize in ways considered underdeveloped. In short, the actual lives of disabled children and adults expose the constructedness of The Disabled Child, the child who overcomes, because children and adults with disabilities do not do childhood and adulthood as we know them. The Disabled Child, then, creates an inroad to destabilize the normative divisions between childhood and adulthood upon which the paradigmatic characteristics of neoliberal rationality—autonomy and independence—depend. *The Disabled Child* establishes narratives of raising disabled children as a potential site for radically anti-neoliberal discourse, however often used by parent memoirists to achieve normative ends. Radical possibilities are examined in each chapter of the book.

The book makes three primary contributions to the narrative study of disability life writing and to medical humanities more broadly. First, I con-

struct a narrative theory for developmental discourse, arguing not only for a more capacious understanding of human development, but also to bring narrative inquiry to bear on medical-developmental discourses. Second, the book responds to longstanding but historically underengaged critiques of disability studies' failure to imagine a non-white disabled subject by addressing the overwhelming whiteness of positive portrayals of disability in childhood, contextualized by the United States's historical racialization of both childhood and able-bodiedness as white. Finally, *The Disabled Child* resists disability and narrative studies discourses that include parent memoirs as disability life writing, arguing instead for a distinct theoretical framework for analyzing the genre, contextualized by the changing meanings of and expectations for parenthood and childhood, rather than disability, in the United States. The project grapples directly with questions of authorial entitlement, supporting both the centrality of "disabled voices" in constructing public disabled subjects, and underscoring the necessity of engaging with parents' complex roles in disability justice advocacy and as disability meaning-makers.

In my first chapter, I deconstruct the "narrative of progress" fundamental to both childhood development and neoliberal rationality. I examine public health rhetoric on child development over the course of the twentieth century to argue that the concept of age-specific developmental windows is a relatively recent, and not at all universal, phenomenon. I articulate the feminist/queer/crip narratology I then use to analyze the developmental rhetoric in popular child-reading texts, including *Dr. Spock's Baby and Child Care*, and medical standards including American Academy of Pediatrics' developmental guidelines and the Centers for Disease Control's milestones charts. I read these alongside *Hole in the Heart: Bringing Up Beth*, the only graphic "special needs" parental memoir published in the United States. In *Hole in the Heart* (2016), author and parent Henny Beaumont repeats drawings throughout the memoir while changing the conditions in which these drawings are understood. In doing so, her memoir takes on a time-traveling quality, even as the narrative remains nonfictional. Reading "special needs" graphic narrative through its multiple temporalities (visual and verbal) in conversation with the medical-cultural discourses that produce developmental delay enables an analysis that refuses the narrative boundaries of the existing template, creating possibilities for expectation-elasticity and other non-normative developmental temporalities.

In chapter 2, I argue that the "overcoming narrative" so ubiquitous in the genre is enabled by the material and discursive privileges of white-

ness and reproduces settler colonial logics of entitlement to belonging. I examine the whiteness of positive portrayals of disability in memoirs and media broadly and offer these depictions in contrast the material realities of many disabled people and children of color in the United States, including lower health outcomes and the “special education to prison” pipeline. This chapter argues that the narrative of overcoming is made intelligible through white racial privilege. I support my argument with a close read of *The Broken Cord* (Dorris 1990), one of only two memoirs about Native children and one in which exclusion is not overcome. Interwoven throughout the chapter are short vignettes on memoirs about children of color. These memoirs are exceptionally rare in the genre, and like most others, replicate generic conventions while advocating for inclusion. They are included in this chapter in response to an ongoing invisibilization of positive portrayals of disability among children of color. This chapter concludes with an examination of *Moose: A Very Special Person*, a 1978 memoir about a Black boy with Down syndrome, and which forwards a radical picture of interdependent, community-based living.

Chapters 3 and 4 are two parts of a conversation demonstrating the ways in which parent memoirists resituate their children in narratives of progress. In chapter 3, I examine those memoirs in which a child’s disability serves as a catalyst for their parents’, community’s, and perhaps, the world’s, improvement. In these memoirs, children are extraordinary: they are gifts, teachers, and gurus. Parent-memoirists take head-on the logics that construct disability as a “burden,” a way of being that requires investments of time and money and promises little return. Like Kelle Hampton, many parents argue that parenting, even merely knowing, their children yields returns beyond measure and advocate for a more expansive understanding of “productive citizenry.” In doing so, parent memoirists inadvertently reinforce the very neoliberal rationality that constructs disability as burdensome in the first place.

In my fourth chapter, I demonstrate the ways in which heteronormativity operates as a narrative device to mitigate the assumed negative effects of disability and to emplot disabled children in dominant discourses of childhood and adulthood. Using several memoirs, I argue that disability in childhood is queered in relation to future adult reproductive heterosexuality and through proto-heterosexual and cisgender scripts. In addition, this chapter examines the production of normative motherhood in many memoirs, and how mother-authors draw on and reproduce gendered and neoliberally-

aligned expectations for mothering behavior. Mothers do this, I argue, because of the way disability in childhood positions them as outside the realm of ordinary motherhood. In these two ways—heterosexualizing their children and claiming normative motherhood—parent memoirists disavow all things queer, and by extension, the queerness of disability. This chapter establishes, however, that cisgender heterosexuality for disabled children may indeed be a liberatory narrative framework, even as queerness is repudiated. This sets up the radically disruptive read of *Schuyler's Monster* (2008) discussed in chapter 5.

Chapter 5 reads three memoirs that resist the neoliberal/developmentalist narrative of progress via either narrative non-linearity or non-futurity. In *Schuyler's Monster*, *The Boy Who Loved Tornadoes* (2010), and *The Still Point of the Turning World* (2014), there is “no future,” because the child experiences an alternate temporality, has a fatal condition, or is written into a sexually and ability-fluid adulthood. This chapter articulates The Figure of the Disabled Child as a discursive disruption to neoliberal narratives of progress. To do so, I take crip and queer theories’ respective “no futures” (Kafer 2013; Edelman 2004) and examine them when attached to the disabled child. I show that the disabled child’s threat of nonproductivity and nonreproductivity embodies a failure of “progress.” At the same time, however, the real lives of disabled children expose the very precarity of these idealized logics. I argue that “outside of time,” rather than anti-futurity, is precisely where new narrative possibilities for writing and theorizing disabled experiences emerge.

In my conclusion, I address the criticism from disability advocacy subgroups that “special needs” parental memoirs enact an erasure or decentering of the disabled child’s “voice.” I take this up in two ways: first, as a question of narrative entitlement, to which I argue for a distinction between disability life writing and life writing that contributes to disability meaning-making; and second, as a misplaced critique against the figure of the non-disabled parent-author rather than the more accurate criticism of the so-called autonomous subject. The problem with parental memoirs, I show, is the non-autonomy attributed to children, disabled or not, and the ways in which this attribution reifies the distinction between abled and disabled in the U.S. cultural imagination.

# 1

## *Towards a Narrative Theory of Childhood Development*

### *“IT’S TIME TO CHANGE THE WAY WE VIEW A CHILD’S GROWTH”*

In 2005, the Centers for Disease Control (CDC) launched a new campaign: *Learn the Signs. Act Early* (Department of Health and Human Services 2005, 135). The campaign’s purpose was twofold: to educate care providers (including parents, teachers, physicians, nurses, and other caregivers) on behaviors indicative of autism or other developmental disabilities; and to “convince” (135) care providers to seek therapeutic interventions that would correct these behaviors as soon as possible. The launch followed the publication of the CDC’s first population-based study of autism rates in a major metropolitan area—Atlanta, in 2003—and coincided with the development of their protocol for studying “risk factors” for autism that would be used in research facilities nationwide. To aid care providers in identifying “the signs,” the CDC created “developmental milestone checklists”: a series of charts and pamphlets that designated the windows of time in which a child was expected to master a social, communication, motor, or cognitive task (“CDC—Learn the Signs. Act Early.”). The “signs,” then, of autism and other developmental disabilities, emerged as developmental moments before or after the prescribed window. The therapeutic interventions care providers were and are encouraged to seek function primarily to realign an individual child’s development with the new, standardized timeline.

The *Learn the Signs* campaign advises, “It’s time to change the way we view a child’s growth.” The CDC, and other agencies under the United States Public Health Service, had been surveilling children’s growth and development since the early twentieth century, when the concept of organic developmentalism swept through sciences and medicines (see Steedman 1998). The agency has deliberately tracked developmental disabilities since 1984. Until the *Learn the Signs* campaign, however, public health-generated questionnaires, checklists, and general recommendations tended to avoid normativizing childhood development to a strict timeline. Before the first Child Behavioral Health questionnaire supplemented the National Institutes of Health survey in 1981 (“The National Institutes of Health Interview Survey Design 1973–84 and Procedures 1975–83” 1985, 53), for example, parents (usually mothers) were interviewed about their children’s development relative to other children the parents knew, or their general conceptions of when children mastered this or that motor, social, or communication skill (32). Indeed, in the vast body of Public Health Reports produced over the course of the twentieth century, public health officials generally avoid the concept of developmental windows; on the contrary, much public health discourse underscores developmental variability—both in skill set and timeline—among children. These reports, moreover, warn against making conclusions about developmental outcomes based on growth and achievement in childhood. For example, in 1919, officials wrote that due to variability in intellectual capacity influenced by internal and external factors, developmental outcomes cannot be foretold (“Public Health Reports” 1919a, 733–35). In other words, earlier twentieth century discourses agree that children *develop*, that children are “adults in the making” (Castañeda 2002), even as the temporal markers for developmental achievement in childhood are imprecise. The new 1981 Child Behavioral Health questionnaire introduced a number of motor, behavior, and communication achievements loosely chronicled to age by means of question-set thresholds; for example, the survey advised that questions about advanced coordination need not be asked of four-month-old infants, who would not be expected to have achieved any of the skills in that set of questions (“Current Estimates From the National Health Interview Survey: United States, 1981” 1982, 82). As a questionnaire, rather than directive, the survey did not discipline parents’ expectations, but merely collected the data to be later used to these ends. By 2005, the “way we view a child’s growth” as individually and temporally diverse had fallen out of time. As the *Learn the Signs. Act Early* campaign suggests, the adop-

tion of a normative timeline for childhood development became not only a necessary tool to diagnose developmental disability, but to catalyze interventions, as soon as possible, to mitigate impairment. It is *time* that must change how we view a child's growth.

As a tool of identification and that which compels intervention, if not the total elimination of disability, the *Learn the Signs* campaign is a twenty-first century iteration of longstanding anxieties about the nation's health and future, manifest in public health discourse by the specter of disability. The *Learn the Signs* campaign is significant not because it "created" a developmental timeline, though it influenced widespread acceptance of temporally specific developmental milestones in ways previously published "schedules" had not (e.g., Gesell 1940). Its broad dissemination and uptake by American childcare providers exemplify the transfer of health management from the state to the individual downstream of two decades of the neoliberalization of U.S. health and welfare policies. The *Learn the Signs* checklists and milestones charts are tools parents and other childcare providers are expected to use for the explicit purpose of reducing impairment in the future; they are templates to ensure both a child's normative development and the fulfillment of the "narrative of progress" embedded in this expectation. *Learn the Signs. Act Early*, then, can be understood as a modern-day program of eugenics enacted not at the level of the state, but in the American household.

The *Learn the Signs* campaign brings into relief the ways in which medical "truths"—discourses of child development, for example—are both social (socially and historically contextual) and political (used to ideological ends). In what follows, I trace the "narrative of progress" fundamental to child development timelines in the United States to excavate this temporal anxiety in early and contemporary medical-cultural discourses of childhood. I draw on the United States Public Health Service reports, Dr. Benjamin Spock's internationally bestselling *The Common Sense Book of Baby and Child Care* and the Centers for Disease Control's developmental milestones charts as representative texts of broadly circulated, "commonsense" child development guidelines. I use the narrative of progress intrinsic to discourses of childhood in the Global North to establish the argument central to this book, which is that parental memoirs of raising a child with disabilities, like the *Learn the Signs* campaign, are tools for a neoliberal, individualized management of disability and impairment through narrative rehabilitation. As discussed in the introduction, neoliberalism names not only economic

deregulation and market privatization, but the wholesale dissemination of such values of state noninterference to all social actions and relationships. In other words, neoliberal subjects are responsible for—or free from government “intrusion” into—their self-management and compelled to ensure their own success. Neoliberal rationality shares with eugenics the logics of “betterment” through strategic choice-making. They are thus, both, ideologically oriented towards futurity. Parental memoirs demonstrate one of the ways in which narrative temporality enables the narrative of progress, even in the absence of typical developmental achievement. In this chapter, I forward a feminist/queer/crip (FQC) narrative framework for interpreting narrative temporality to (re)conceptualize contemporary normative medical-cultural developmental timelines as narratives. In a general sense, narratives tell about change over time. An FQC theory of narrative deconstructs the parental memoir genre’s normative investments in heterosexual, white, and able-bodied futurity, literalized through developmental discourses of ability and heterosexuality. As narrative, rather than normative, however, childhood development can be reconfigured in temporally diverse ways. Instead of premised on developing towards a disability-free adulthood, childhood could be understood as a time when new humans become themselves, whatever that might look like. Childhood could thus become a site for disability justice: for imagining and building more accessible futures in which all bodies and minds might flourish.

To forward my argument, I offer a close read of graphic memoir *Hole in the Heart* (Beaumont 2016) alongside pediatric developmentalist narratives. Graphic memoirs offer already multiple temporalities: narrative blossoms visually and verbally across the page in drawings and text. *Hole in the Heart* offers what I describe below as a “floppy” developmental temporality, one that folds back onto its already multiple narrative self to create a backwards-forwards, unstable picture of growth and change. In reading *Hole in the Heart* with developmentalist texts, I investigate the relationship between disability and narrative time in a way that draws into relief the cultural construction—and, thus, the false essentialism—of developmental disability. Throughout this chapter, disability figures in multiple ways. In public and popular health literature, disability is identifiable as an individual deviation from “normal” in bodily shape or function, neurology, sense capacity, psychiatry, or cognition. In my analysis, I approach disability from a political/relational framework that interrogates the very ideological systems that produce and reinforce concepts of normality and deviance to begin with



(Kafer 2013, 6). A political/relational model of disability undergirds my FQC theory of narrative in that I seek explicitly to examine heteroableist assumptions embedded in narratives, and also in the way that FQC allows narrative itself to be ideologically multidextrous, rather than obligated to a normative resolution.

### THE DEVELOPING CHILD

In the United States Public Health Service's earliest publications, the surgeon general-authored Weekly Sanitation Reports (1878–1895), entries related children's health are limited to data on infectious diseases. As the scope of public health expanded during the early part of the twentieth century, public health records indicate the state's interest in identifying developmentally atypical children and frame childhood health and development in relation to both the child's future self and the future "health" of the nation. In 1909, for example, President Roosevelt convened the first White House Conference on the Care of Dependent Children. Addressing the attendees, Roosevelt states, "There can be no more important subject from the standpoint of the Nation than that with which you are to deal, because when you take care of the children you are taking care of the Nation of tomorrow" ("The Story of the White House Conferences on Children and Youth" 1967, 4). The recommendations made at the White House Conference and in Public Health Reports in the early part of the twentieth century were, no doubt, influenced by paradigm-shifting developments in medical knowledge including, perhaps most significantly, eugenics. The eugenics movement took hold of the American medical establishment in the late nineteenth century and lasted through the Second World War. Eugenic discourse, like discourse on the developing child, was chiefly concerned with the "future" of the nation, particularly in terms of improving the overall fitness of the population through the selective sterilization of populations deemed "unfit" (Snyder and Mitchell 2006, 31). However, where eugenics targets reproduction and the elimination of undesirable traits from the national gene pool, public health discourse on childhood focused on corrective and intervention strategies to prevent disability in adulthood. For example, in August 1913, U.S. Public Health Service Surgeon J. W. Schereschewsky argues in the Public Health Report that, in prescribing compulsory education for the nation's youth, the state should as "a necessary corollary . . . supervise the physical

condition and environment of its children during school life as to insure their reaching maturity with their ultimate efficiency in no way impaired by easily removable or preventable causes” (“Public Health Reports” 1913a, 1793). Schereschewsky goes on to recommend teachers and school physicians be well-trained in identifying “deficiencies” among schoolchildren, primarily physical “defects,” impaired hearing or vision, and arrested mental or moral development (1913a, 1802).

While eugenic rhetoric fell out of favor following World War II, the betterment of the nation via the development of the child-as-future-citizen became only more concrete. At the Midcentury Conference on the Child in 1950, five thousand delegates gathered to address the questions: “How can we develop in children the mental, emotional, and spiritual qualities essential to individual happiness and responsible citizenship, and what physical, economic, and social conditions are deemed necessary to this development?” (“Public Health Reports” 1950, 1526). The first National Health Survey of 1968 cautions,

Today, chronic illness and disability—among both adults and children—constitute our greatest public health challenge. Chronic illness and disability lower the earning power, living standards, and the general well-being of individuals and families. They reduce the Nation’s potential output of goods and services and, in advanced stages, burden individuals, families and communities with high costs of care and assistance. The basic public health principle to be applied is the same: prevention. (“Health Interview Survey Interviewer’s Manual” 1986, A-1–2)

Here, state rhetoric explicitly ties the eugenicist thrust of normalcy to both futurity and the economy.

Despite a commonsense understanding of developmental completion in adulthood and the medical-cultural investment in reducing or eliminating impairment, twentieth-century child development advice lacks the normative constraints of the later-issued developmental milestone checklists. Instead, child development emerges as temporally variable. When, for example, arrested mental development among children is noted (“Public Health Reports” 1913a, 1792), health officials explain that it does not necessarily indicate disability (described with the catchall term “feeble-mindedness”), but rather that children develop at different rates depending on biological and environmental influences. In 1919, for example, officials write

that heredity alone does not explain “retardation,” but that “environmental also plays a part in its production,” though this was not well understood (“Public Health Reports” 1919a, 735–36). In 1913 officials similarly write “the influence of environment and the ways it reacts adversely upon the mechanisms of mental adjustment require intensive study before useful data can be collected” (“Public Health Reports” 1913b, 2031). Public health officials note that, indeed, developmental variation exists among any age group (“Public Health Reports” 1919a, 734). The Joint Committee on Children’s Development writes in 1950, “A general healthy personality is not established once and for all at any age period but can be strengthened or weakened at any stage in life” (“The Story of the White House Conferences on Children and Youth” 1967, 18).

Similarly, in the first edition of his bestselling book, Dr. Spock warns, “If I write that most babies have dry diapers around 15 months of age, you mustn’t jump to the conclusion that your child of 18 months is abnormal because he’s always wet” (Spock 1946, 2). *Dr. Spock’s Baby and Child Care*, now in its tenth edition, chronicles child development by chapter-specific age (e.g., “The First Year”; “Age Three to Five Years”) with subsections titled “Physical Development” and “Challenging Behaviors.” In this manner, developmental expectations are listed for the first twelve months and then each year of a child’s life to age eighteen. Despite the aforementioned caveat against jumping to conclusions, Dr. Spock’s language is normative, naming what children *will* do rather than what they might. From the chapters on babies aged four through twelve months, for example, Spock writes: “A baby learns to control his body. He starts with his head, and gradually works down to his hands, trunk, and legs. . . . All on his own, he follows objects with his eyes, usually by about one month, if not before, and begins to reach for things” (Spock and Needleman 2012, 115); about preschoolers, “Boys and girls now become fascinated with all aspects of babies” (183); and about school age children, this (stunningly amusing) declaration: “At this age children have the desire to put their belongings in order” (199). Though Spock’s tenth edition was published seventy-two years after the first in 1946, the language is remarkably consistent, and consistently normative. In 1946, for example, Spock writes that “The One-Year-Old” is

Feeling his oats. . . . He’s a demon explorer. He pokes into every nook and cranny . . . climbs onto anything he can reach. . . . A tired-out mother calls this “getting into everything.” . . . A baby *has* to find out about the

size and shape and movableness of everything in his world and test out his own skill before he can advance to the next stage. . . . The fact that he “gets into everything” is a sign that he’s bright in mind and spirit. (1946, 203–4, emphasis in original.)

In the tenth edition (Spock and Needleman 2018), Spock writes “Your Toddler[s]: Twelve to Twenty-Four Months” are

Feeling their oats. . . . Toddlers are determined explores. They poke into every nook and cranny . . . climb onto anything they can reach. . . . In short, they are into everything. . . . He has to find out about the size and shape and movableness of everything in his world and test out his own skill before he can advance to the next stage. His endless exploration is a sign that he’s bright in mind and spirit. (Spock and Needleman 2018, 115–17)

While the gendered language has been adjusted, slightly (discussed below), both passages convey the same message: at twelve months of age children *are* curious explorers. They move their bodies to learn about things. Doing so proves they are able-minded and intellectually typical. In addition, they must move their bodies and prove their able-mindedness before “advancing” to the next stage. They must be able-bodied to continue to develop; and they must continue to develop towards able-bodiedness and able-mindedness. Spock not only fashions a eugenicist entanglement of able-bodiedness with able-mindedness, but he draws the boundaries around the category of “child” in terms of able-bodied and able-minded achievement and promise. Young humans who do not move, poke, or climb, do not explore, and are not “advancing to the next stage” are, it seems, something entirely other than “children.”

Gender works in Spock to underscore independence and developmental achievement through the masculine figure. In 1946, Spock only uses “he” to refer to the baby, explaining that “she” is necessarily reserved for the mother; he begs forgiveness and understanding from parents of female babies (2). After being taken to task by Gloria Steinem at the National Women’s Political Caucus in 1971 (Hagan 1973), Spock first revised his *Baby and Child Care* in the 1976 edition, shifting to a gender-neutral and, in this case plural, “they,” and alternating between “she” and “he” elsewhere. In the tenth edition, Needleman explains that he tries to use “she” and “he” at random (xxvi).

Despite the claimed egalitarian use of pronouns, however, developmental achievement emerges as masculine-coded in the narrative. In the passage from the tenth edition above, for example, “he” has to explore and “test his skill” before “he advances” (Spock and Needleman 2018, 117); on the same page, “she will *gradually* become more independent” (emphasis added). In the following section, Needleman addresses the risks during this period of exploration; here, “she” is described as unreasonable and hard to control; she gets dirty, which is allowed, but she also eats handfuls of sand and finds ways to hurt herself (118). While not exactly formulaic, the gendering is notable: when “he” is afraid of things, he needs the opportunity to explore, the “little scientist” that he is (122); when she is afraid, she needs comfort and to be given gradual opportunities to build her courage (123). A similarly gendered narrative can be found in the CDC’s milestones chart, wherein the more developmentally “advanced” children (those that run and hop and talk) are represented in typical boy’s clothes and with short haircuts, while the younger, less developed children, are depicted in pastels and don bows and barrettes, suggesting femininity. In the packet “Milestones Moments” (n.d.) “he” calms himself at two months of age and parents are advised to help “her” calm herself (4). It is also worth noting that on one Milestones chart (figure one), the youngest, and therefore most undeveloped child is a brown-skinned baby, and the oldest, most developmentally advanced child is a white boy. The chart depicts, in this way, not only a gender hierarchy, but the entire Western colonialist and eugenicist narrative of progress (Castañeda 2002, 13).

The CDC’s milestone chart exemplifies the disciplinary character of developmental timeline and the end goal of able-bodied achievement suggested in Spock and manifest in the figure of the white, able-bodied man. For starters, one of the *Learn the Signs*’ campaign’s motifs is a colorful game-board: a series of connected rectangles along a path similar to those found on *Candyland* or *The Game of Life*. Like the board games, the object is to advance along the path to win the game. In *The Game of Life*, the goal is to become a “Millionaire Tycoon” (Life [1977vers.] pdf); in the game of development, the child’s goal is to complete their fifth year without incidence of developmental delay. Like Spock, the CDC milestones charts use normative language: at two years, a child “says sentences with 2 to 4 words,” and at 4 years, “hops and stands on one foot for up to 2 seconds.” In the packet “Milestones Moments,” each age-marked section (e.g., two months; eighteen months; three years) checklists the social/emotional, language/com-



Figure 01. Centers for Disease Control, “Learn the Signs. Act Early.” (CDC 2021)

munication, cognitive, and movement/physical development expectations, along with suggestions for how to “help” the child develop (read: meet the milestones). Towards the end of each section is a checklist of signs of developmental delay, all of which are the direct inverse of the milestones listed just above. Parents are to check one set of boxes or another. This creates a fundamental binary between expected development and developmental delay, and opportunities, first bimonthly, then yearly, for children to lose the game.

When commonsense guidelines note that childhood development happens along varying timelines, they do so in a way that reinforces a binary distinction between normal and abnormal development. The CDC’s milestones charts explains, for example, “Developmental milestones are things *most* children can do by a certain age” (emphasis added, Centers for Disease Control n.d). Spock writes “*most* babies learn to walk” (Spock and Needleman 2012 121) and “Young children often show uneven progress in their

development” (Spock and Needleman 2012, 943). Rather than gesturing to a capacious sense of “child development,” however, within the broader context of winners and losers, milestone-meeters and developmental delay, these phrases evince normativizing timelines and expected outcomes. For example, the quotation from Spock continues, “and many children with developmental delay eventually catch up, often without the help from therapists and other professionals” (Spock and Needleman 2012, 943). “Milestones Moments” goes on to list achievements for babies and children under the prescriptive subtitles, “What babies do at this age,” and “What children do at this age.” The group “most children,” in these examples, reinforces the boundaries of childhood development by constructing a category of children who are not part of “most.” Not only are the boundaries of normative childhood development established, atypical developmental progress is simultaneously pathologized; the CDC instructs parents to “act early” and “tell your child’s doctor or nurse” if a child exhibits any “signs of possible developmental delay.” The CDC similarly warns that missed milestones are a medical problem. Similarly, according to Spock, “developmental delay,” is something that requires the help of therapists and other professionals to address and ostensibly eliminate, via “catching up” (Spock and Needleman 2012, 943).

In the tenth edition of *Baby and Child Care* Spock and Needleman reproduce a commonly held understanding of the meaning of developmental delay, wherein the label suggests the child is “behind schedule,” however might eventually be developing alongside their peers. Spock writes, “the label [developmental delay] doesn’t say anything about why the delay exists or what it means in the future” (2018, 843). As Gail Landsman has noted, upon hearing their child is “developmentally delayed,” many parents perceive the label as an indication that “the permanency of the delay has not been established” (Landsman 2009, 107). A distinction then, is made, between developmental delay as a nonpermanent status and “disability” as a permanent status. This distinction is compelled by and in fact reinforces the idea that “disability” is an undesirable state: as one doctor in Landsman’s study explained, developmental delay “means your child is [intellectually disabled] but I don’t have the courage to tell you” (107). Yet, Spock also describes children as “with developmental delays” (2011, 943) in much the same way a one might be a “child with” a more “permanent” disability like cerebral palsy. Moreover, outside the pediatrician’s office, “developmental delay” is operationalized exactly like a diagnosis of disability, which is to qualify the



child for state- and government-funded disability services. The purposes of these services, however, are to mitigate the effects of impairment or, in other words, eliminate the “delay.” Developmental delay, then, seems to be both something a delayed child “has” and something a child “does.”

The debate about whether or not “developmental delay” is a “disability” relies on a false understanding of disability itself as “permanent.” Besides the fact that many impairments are actually temporary, the so-called permanency of disability really refers to structural ableism. Disability is imagined as a permanent condition of an individual body and symbolizes a threat to collective “progress” towards better, more perfect bodies and lives. The lived experiences of people with disabilities have taught, however, that disability is a social, relational, and political experience of denied access on the basis of bodily, sensory, neurological, and/or psychiatric difference. This means disability is situational even if bodily difference is not; consider Deaf sign language users who are not “disabled” in signing-only spaces. Whether a child *has* developmental delays or *is* developing along a delayed timeline is not the point; the child is disabled when access is denied and inclusion withheld. Moreover, developmental delay itself, whether used euphemistically in place of “disability” or not, is always nonpermanent: if impairment persists, the developmental delay diagnosis either morphs into “developmental disability” or another diagnosis (including, sometimes, autism), as the child ages out of “development.” Development ceases to be delayed, regardless of developmental achievement, once the developmental period—the developmental window, and later, childhood—is over.

The meaning of developmental delay is imprecise and shifting because, like all diagnoses of impairment, it is constructed in relation to a norm: an expectation, an idealization, a disciplinary tool used to justify segregation and subjugation. It is based upon and reinforces entangled cultural ideas: that all children grow and develop (some do not); that the childhood developmental timeline is universal and precise (it is not); and that child development is completed in independent adulthood (many adults are dependent, and all are interdependent). “Developmental delay” works to ensure that children are “adults in the making” (Castañeda 2002) through the disciplinary timeline; it also structures the “narrative of progress” that defines childhood (and with it, the imagined future of the nation) as it perpetuates the false essentialism of developmental achievement. The timeline and its endpoints are, in these ways, part of a complex web of medical-cultural ideas that perpetuates a distinction between childhood and adulthood on



the basis of developmental achievement, usually called independence. Children are *becoming* independent; adults *are* independent. In this way, children are deficient, incomplete, in relation to what they will become. We do not consider children to be impaired humans, however, because of the promise of developmental achievement. The distinction between children and adults, in turn, sustains the rhetoric that pathologizes atypical childhood development (e.g., if she reads too early, she is hyperlexic; if she reads too late, she has a learning disability). It also works to infantilize disabled adults through equating “child-like” dependency with underdeveloped or “unmastered” skills (Brown 2012, n.p.). Characteristics of adulthood, then, depend on the construction of characteristics of childhood as those which they do not share past a certain age; the developmental timeline preserves the binary while disciplining the subjects according to the norms. In a sort of self-fulfilling prophecy, then, “developmental delay” reproduces the very timeline from which it derives.

### BRINGING UP BETH

I want to argue for developmental possibility through temporal fluidity; for temporal multiplicity as a potential narrative template for disability justice. To do so, I forward a feminist/queer/crip (FQC) theory of narrative to analyze the graphic memoir *Hole in the Heart: Bringing Up Beth*, by Henny Beaumont, and bring narrative’s temporal possibility to bear on contemporary childhood development timelines. My analysis draws on feminist and queer theories of narrative broadly and narrative temporality, specifically. To say that questions of temporality are instrumental to narrative analysis, narratology, and theories of narrative is an understatement. Paul Ricoeur argues, for example, that narrative is what makes time “human” (cited in Phelan 2016, 240); by this Ricoeur and others mean that narrating existence and experience is what renders the abstract concept of time meaningful. H. Paul Abbott writes similarly that narrative is the “principal way our species organizes its understanding of time” (Abbott 2008, 3); this, Abbott argues, is perhaps the primary function of narrative itself. In what follows, I forego a strictly formalist-structuralist narratological analysis (Lanser 1986, 342) in favor of feminist interpretation that accounts for both specificity and difference among authors, readers, and social-political contexts in which narratives are composed and read. As Robyn Warhol and

Susan S. Lanser (2015) argue, feminist criticism of narrative has attended to that which classical narratology has historically overlooked via false universalisms and generalizations. Feminist and queer theories of narrative have unearthed both normativities in narratology (as a discipline) as well as the norms (of gender, sexuality, and race, for example) embedded in narratives. These are thus political projects of exposing the “dominant stories keeping the binaries in place” (Warhol and Lanser 2015, 8). Turning again to Ricouer and Abbott’s lessons about narrative as “human time,” a feminist theory of narrative reminds us that historically the boundaries of the “human” have been contested and drawn along gendered, racialized, and various other embodied lines. “Human” has never meant “all humans”; nor, too, do the conditions of our lives position us in any way to share an understanding of time. Queer theory has of course drawn attention to the ways in which time is a key producer of normalcy, specifically heteronormativity (Halberstam 2005, 152–53). Halberstam writes, “notions of normal . . . may be upheld by a middle-class logic of reproductive temporality” characterized in part by the emergence of the mature adult (4). Judith Roof has argued that narrative’s fundamental function is to “reproduce” (systems, concepts, ideologies, culture, experience [1996, xv–xvii]), suggesting a heteronormative function. When analyzed according to structuralist narratology, narrative itself reinforces heteronormative logic; or, as Roof explains, “structuralist theories of narrative assume a heterosexual ideology . . . evidence [of which] can be found in those places where theorists finally attempt to account for just what brings narrative together—for what transforms narrative from a series of dissociated events into a cogent form” (41). A queer theory of narrative, then, compels us to consider both a reading of narrative as a kind of heteronormative closure according to binary resolution, and the ways in which narrative temporalities operate in relation to heteronormative time.

Throughout this book, I use a feminist/queer/crip theory of narrative to analyze parent memoirs and demonstrate the genre’s conventional investments in heterosexual, white, and able-bodied futurity. A feminist/queer/crip (FQC) theory of narrative brings a crip politics of futurity and a critical disability studies perspective to feminist and queer narrative theories. My use of “feminist, queer, crip” comes from Alison Kafer’s influential *Feminist, Queer, Crip* (2013). In her introduction, Kafer writes that the contemporary preoccupation with cure, if not prevention, of impairment implies that disability does not figure in commonsense imaginings of a “better future” (2); indeed, Kafer argues that the “figure of the disabled person, especially the

disabled fetus or child, becomes the symbol of this undesired future” (2–3). Disability haunts the present with a sense of delayed or thwarted progress; it is “out of time” (28), if not atavistic; a mark of the past. A crip politics of futurity imagines futures differently, imagines disabled people living within the better—this time figured as the more accessible, more openly interdependent—future. A crip politics of futurity insists that disabled people are valuable. This has ramifications for how disability is viewed in the present. Bringing a crip politics of futurity and a critical disability studies perspective to feminist and queer theories of narratives engenders a more expansive, and more intersectional narrative analysis in two primary ways: first, building off the insight that “narrative represents, structures, and constitutes gender and sexuality” (Warhol and Lanser 2015, 3), an FQC theory of narrative examines the ways in which dis/ability, too, is structured by narrative, and moreover how narrative representation of gender and sexuality are produced through and thus reenforce narratives of normative ability. Second, feminist and queer theorists of narrative posit that narrative analysis is enriched (if not meliorated) by intersectional understandings of time and place (Lanser 2015, 29); an FQC theory of narrative understands normative temporality as already shaped by heteronormative *and* able-bodied expectations, in the same way that place is structured to fit some, but not all, bodies.

In what follows, I use an FQC theory of narrative to examine *Hole in the Heart: Bringing Up Beth*, one of the only English-language graphic memoirs about raising a child with a disability. Author Henny Beaumont is a political cartoonist, illustrator, graphic novelist, and the mother to three children. Her youngest, Beth Beaumont, has Down syndrome, which, in addition to its genetic marker, is commonly symptomized by “developmental delay,” or the failure to meet developmental milestones by the expected age. *Hole in the Heart* was named one of the top ten books about motherhood of all time by “Mumsnet,” an influential U.K. parenting website. *Hole in the Heart* was published in the United States in 2016. It was originally published in the United Kingdom; this sets *Hole in the Heart* apart from the rest of my archive, which focuses on North American and primarily U.S.-based publications. I include it here, however, not only because of the generative analysis graphic narrative invites, but also because the context in which Beth Beaumont was born and raised, and in which the memoir was written, shares with the United States the same characteristic neoliberal economic and social rationality (Harvey 2005, 9), as well as a similar rise to dominance of “developmental timelines” (“NHS KIDS About Us” 2017; Rivett 2019, n.p.).

While not representing the genre in its entirety, *Hole in the Heart* is useful in depicting both disability and narrative's relationships to temporality, and thus helps shape an analytical framework for examining other memoirs, many of which are similarly in conversation with developmentalism. In *Hole in the Heart*, Beaumont engages temporal fluidity that exposes the narrative construction of heteroable time. This is accomplished by the ways in which significant, and ableist, images are repurposed in the narrative in such a way as to undo their past, ableist meanings, thereby embedding into the narrative a crip futurity. Perhaps more than these specific incidents, as a graphic narrative, the memoir's very form destabilizes normative time. Hillary Chute writes that we might define graphic narrative "as a hybrid word-and-image form in which two narrative tracks, one verbal and one visual, register temporality spatially" (Chute 2008, 452). If narrative is the tool by which time is organized and made "human," graphic narrative's form is one that allows for complex, sometimes multiple and sometimes nonlinear temporalities at once (454). Regardless of any individual narrative's temporality, narratives unfold in the reader's present. With the dual tracks of graphic narrative, however, narrative sequence and the spatial organization of drawings on the page do not necessarily unfold for the reader simultaneously. In this way, at least two temporalities are potentially at work (perhaps three or more, if we account for the multiple unfoldings the reader resutures into narrative moments). Moreover, the space of the page, and the use of panels, gutters (the space between panels), illustrative perspective and depth, and visual signals of speed and movement create not only moments of time *in narrative time* but also invite readers to experience haste, stillness, pause, precipitation, and other temporal states in the absence of any verbal narrative signal. Verbal-only narratives are not strictly linear, of course, and regularly destabilize normative temporal expectations. In verbal narratives, these happen within the singular narrative diegesis through analepses, prolepses, and other anachronies. In graphic narratives, however, the dual narrative tracks have the potential to create at least dual temporalities even in the absence of any kind of narrative nonlinearity. By doing so, graphic narratives bring into relief the processes of constructing time—making time human, to use Ricouer's language—and, specifically, the ways in which any ordering of time is malleable, potentially multiple, mobile, and unreliable.

Like most other "special needs" parent memoirs, *Hole in the Heart* reproduces the narrative of progress via the generic tragedy-to-acceptance template. In this story line, disability's onset is often grieved or constructed as

loss before renarrated as a gift, blessing, or other benefit to parents, the community, and the world (see Piepmeier 2012). Whereas most other memoirs, however, move linearly to a verbal point of reflection along the lines of “I realize now” (e.g., Ott-Dahl and Ott-Dahl 2016, 220), several of Beaumont’s actual drawings reappear in the memoir, enacting not evolution from the past to present but a rewriting through the repurposing of imagery. Beaumont’s narrative concludes with an acceptance that is produced in and through an initial rejection. Beaumont prepares readers for this repurposed narrative, and the temporal entanglements through which it is produced, through sustained engagement with narratives of time, growth, and progress beginning with her first description of daughter Beth as not able to learn or do things “as fast” as other children (2016, 45).

In one series of panels, for example, Beaumont is walking with her oldest daughter along a path that recedes into the distance. Her daughter wonders to herself if she too has Down syndrome and has not yet been told. When she finally asks, her mother exclaims, “no, of course not,” and “let’s hurry up so we aren’t late for school” (66). In the penultimate panel of the series, mother and daughter reach the end of the path. The figures are small, indicating just how far they have traveled. Mother kisses her daughter on the top of her head, and, in the last panel, the background imagery disappears. Not only does this series indicate that the sister’s life is progressing along a path at the expected speed (hurry, so we aren’t late), but also that their journey is marked by love and affection. Elsewhere, Beaumont rollerblades while pushing the baby stroller, in which the baby Beth has been replaced with a bag of potatoes (83). She writes, “If I go fast enough . . . no one will notice.” Going fast is unremarkable; slow stands out. There is no tender care in this hurrying sequence, only Beaumont’s tears and a baby with Down syndrome completely dehumanized as “vegetable” in her “slowness.” In these two examples we see the relationship between childhood development and time, and specifically the idea that normative development is not “slow,” in contrast to the disabled child’s “developmental delay.”

Towards the middle of the book, Beaumont’s future self comes to visit (101–6) in a moment that Hillary Chute calls “intersubjective relation” enabled by temporal collapse (Chute 2015, 206). The Beaumont of the narrative moment (2001), whom readers have come to understand as the authorial Beaumont, stands in darkness. Future Beaumont enters from a sliver of light on the right side of the page and gives 2001 Beaumont a

gift that promptly disappears, unopened. She then asks to hold the baby. As 2001 Beaumont's side of the page gradually illuminates, the two selves confess infanticidal ideation to one another, both past, "I used to hope," and present, "I feel like" (2016, 103–4). In the following panel, which fills the entire page, 2001 Beaumont offers her future self a beverage, presumably a cup of tea, as future Beaumont explains that her feelings about her daughter have changed (figure two). The two Beaumonts stand across from each other. Their faces, shoulders, and what they each hold—a baby in one set of arms, two cups of tea in the other's hands—are outlined darkly and clearly, while the lower halves of their bodies disappear into the gray wash of the background. The largeness of the panel indicates it is an important moment, one which a reader must slow down and consider. This slowing down is underscored by the offered mug: not only is it centered on the page, but it is also the frontmost object, positioned in front of and partially obscuring the bubble that contains 2001 Beaumont's question: "So what changed?" The entire image seems to surround this mug which, regardless of what sort of beverage it holds, must be rather still. The stillness of the mug brings into relief the total temporal chaos of the panel: the past inflected in the future, the future influencing the past; the constantly shifting nowness of time.

In these pages, author Henny Beaumont creates a fictional scene in which her practically present self—the 2015 Beaumont—visits her past self, the 2001 Beaumont. 2015 Beaumont says, "I've often wished I'd been able to visit you" (101) indicating that Beaumont's future self did *not* visit her past self until she was drawn doing so on the page. Her past self says, "Thanks so much for coming," suggesting that in 2001 Beaumont welcomed, perhaps expected, the visit. In retroactively wishing, Beaumont suggests that she knew, in 2001, that her future self would offer the comfort that things with Beth would become more "manageable" (106). This is indicated by 2015 Beaumont's gift, and the light she shines on the dark present. However, 2001 Beaumont tells readers and her future self that she does *not* in the moment know the future-manageability to be true. In fact, she denies the possibility, saying, "If I could love her it would be OK" (102), but, "I can't love her" (103). In these ways, 2001 Beaumont suggests that she is unwilling to accept any such reassurances. At the conclusion of this section, 2015 Beaumont tells her past self "It gets better. . . . You get used to it" (106), to which 2001 Beaumont responds that she does not want to accept her daughter's diagnosis: "I'm not sure if I want to get used to it . . . if I accept that, there can be no improve-



Figure 02. Henny Beaumont, *Hole in the Heart: Bringing Up Beth*, 2016, 105.



ment and she'll never get better" (106). She underscores the permanent non-futurity associated with intellectual (and other) disabilities.

In this series of panels, Beaumont entangles multiple temporalities. The fictionality of the scene allows Beaumont to capture aspects of her parenting journey lost through "true" chronology; fictionality then, in this case, allows both for the bending of time and anchors the narrative conclusion yet to come, in which things do indeed "get better" for Beaumont. Moreover, readers are made aware of the remembering undertaken in constructing a memoir through the visual depiction of the future self meeting up with the past self to compare notes, as it were. We also understand 2015 Beaumont in relation to Beaumont the actual author, closer *in time* to 2015 Beaumont, perhaps, and yet removed enough to illustrate her on the page. There are three Beaumonts: Beaumont, the author of the true present; and her two avatars: the 2001 Beaumont (who we have heretofore come to know as Beaumont's present self); and the 2015/future Beaumont who acts in this section as a stand-in for the actual/true Beaumont. In the fictional meeting between the 2001 and 2015 Beaumonts the normative progression of time seems unchanged despite the time travel/visitation; there remains the past, present, and future all in relation to each other and marked by a progression, in this case, a "getting used to" (106). And yet, in telling 2001 Beaumont "you get used to it," it is unclear if future Beaumont is saying "you will get used to it" one day in the future, or "you got used to it" at some point before now to herself. This temporal multiplicity is further underscored by the way the two Beaumonts stand across from each other as mirrors in the panel (106). The normative progression of time from then to now is brought into question; what we have instead of linear progress is multiplicity, temporal infusions. Meanwhile, readers know that it is actually the authorial Beaumont who is meeting her past selves in the construction of her memoir, and that the *now* she constructs in the text is actually the past, both remembered and fictionalized.

Beaumont repeats this folding of then-into-now in several other places in the memoir. In the set of panels before the visitation scene, Beaumont is jogging with a friend and listing all the activities she believes Beth will never be able to do including run, swim, and ride a bike. In one panel, Beaumont stands, head hanging and hair in her face, arms at her sides, and says, "We'll never be able to have a walking holiday as a family" (97). Her friend comforts her, extending an arm and offering, "I think she might surprise you" (99). Later, the same drawing of Beaumont appears following an exchange with



Beth's school principal (174). It is not merely a similar drawing, but the same illustration and a similar conversational context. In the second appearance, instead of hanging her head in despair over the things she imagines Beth unable to do, Beaumont despairs over the school's failure to include Beth in "sports day" with the other children (170–73). In repurposing her same illustrated self across time, Beaumont collapses the past, future, and present into a singular embodied moment. Her friend's comforting words speak to the unknowability of the future. At the same time, Beaumont's fears about what Beth will not be able to do are realized in the future scene: Beth *is not able* to do these things, but it is because she is excluded from participating, not because she is incapable. Indeed, at this point in her young life Beth is an avid swimmer, cyclist, and hiker.

At the memoir's conclusion, Beth asks for her birth story, the "floppy head" story (267). In these final panels, Beaumont completes the narrative of progress by rewriting the verbal narrative that accompanied fraught illustrations from Beth's infancy in the memoir's earlier passages. In Beth's original birth story, Beaumont asks her husband, "Who does she look like?" (14). In the panel, the husband (who, like Beaumont's other children, is never named), eyes downcast and slightly smiling while holding baby Beth, thinks to himself, *They all look the same to me*. A few pages later, nurses gather around Beth's cradle, drawn in by a large white question mark, over which are written the phrases "I can't tell," "I don't know," "I'm not sure," and "Best not to worry" (29). At the end of the memoir, these drawings reappear: this time, the two parents face one another to hold Beth in a single panel; Beaumont asks, "Who does she look like?" while her husband thinks *she's beautiful* (277). The nurses gather again, drawn in not by a question mark but by the phrases "Isn't she beautiful, she's perfect, you must be so proud" arcing over their bowed heads (275).

As the memoir initially unfolds, Beth's older sisters fight over who gets to hold the baby. One sister, eyes twinkling, holds an infant Beth upright, nuzzling her nose in Beth's fuzzy hair, while the other complains it's her turn (90). Over their bickering, literally, in dark panel squeezed tightly above the illustration of all three children, Beaumont tells her husband "They will never be able to love her" (90). Then, exasperated by their whining, Beaumont says, "Enough, I'm going to hold her" and takes Beth from her sisters, seemingly oblivious to the girls' affection for Beth (92). Later, Beth asks her mother about when her sisters fought over her. Here, the drawing of Beth's twinkling-eyed sister reappears (279). In her lap, Beth has repurposed an



Figure 03. Henny Beaumont, *Hole in the Heart: Bringing Up Beth*, 2016, 21.

earlier drawing in which newborn Beth is examined and diagnosed with poor muscle tone, or hypotonia, often described in child-care books as “floppiness.” In the first drawing (figure three), Beth lays on an examination table as a physician pulls her arms, causing her back to arch and her head to hang (21). When the drawing reappears (figure four), Beth’s twinkling-eyed sister is supporting the same examination-table Beth’s head with her hand, telling her mother, “I need to hold her. I love her floppiness” (279). Beaumont tells Beth about how she intervened to end the girls’ quarreling. In this second iteration, however, Beaumont tells her daughters, “No, you can’t hold her because. . . . She’s my baby and I want to hold her. I love her” (282–83). She is not only aware of the sisters’ affection, but shares in it and indeed, has a larger claim on it. Like the panels described in the paragraph above, the disappointment and rejection Beaumont felt during Beth’s infancy have been replaced with acceptance and admiration.

In these examples, Beaumont does not erase the past. She repurposes the visual narrative by which it was previously constructed. By recycling the illustrations and modifying the context in which they appear, Beau-



Figure 04. Henny Beaumont, *Hole in the Heart: Bringing Up Beth*, 2016, 279.

mont implies *some truths have not changed* even as the ways in which we understand them have changed. This is particularly evident in the final two pages where Beaumont juxtaposes an illustration in which she is cuddling fourteen-year-old-Beth (figure five) with a photograph that is similar to, but not the same as, the illustration (figure six). In both the drawing and the photograph Beth laughs with her eyes closed. In the drawing Beaumont is whispering into Beth's ear, "She's my baby and I want to hold her." In the photo, however, Beaumont smiles directly at the camera.

The juxtaposition creates multiple temporal truths and multiply temporal truths, one constructed on the page and the other a "snapshot" in so-called real time. The photograph behaves as documentary evidence alongside the illustration, as more "truthful" because captured on film rather than reconstructed through illustration. Beaumont's eye contact with the reader reminds us of our relationship to her as the audience. Memoirs make autobiographical truth claims (Couser 2011, 13–14), which are not necessarily verifiable facts, but rather shared understandings of life produced through intersubjective exchanges between narrators and readers (Smith and Watson 2010, 16). The photo says, "this is true," and readers agree. The agreement based on the documentary evidence of the photo brings into relief the "truthiness" of the preceding drawing. In other words, Beaumont has invited her readers to become suspicious.

In constructing and concluding her memoir this way, Beaumont allows, maybe compels, readers to hold her accountable to the negative feelings she had about her disabled baby while simultaneously asking her audience to give her second chance, another look, as it were (just turn the page!). Beaumont might perform this sort of narrative repurposing as a means to "correct" her narrative, leaving the earlier illustrations/moments in a gesture of transparency. Because the illustrations do not change, while the conclusions to which they point *do* change, Beaumont may be alluding to the permanence of her daughter's diagnosis and her own failure of imagination as a means perhaps to scold or forewarn readers. Or she may be trying here to deal head-on with the ethical dimensions of her work, including not only the questionable inclusion of infanticidal fantasy, but reiterating the tragedy-to-acceptance narrative in the first place. It is difficult to know, exactly, Beaumont's motives. She further complicates her intentions in a series of panels in which Beth, looking for her mother, is told by her sister that Beaumont is "working on her 'oh my life is so inconvenienced because I had a disabled child' book" (2016, 259). The comment is tongue-in-cheek



Figure 05. Henny Beaumont, *Hole in the Heart: Bringing Up Beth*, 2016, 283.



Figure o6. Henny Beaumont, *Hole in the Heart: Bringing Up Beth*, 2016, n.p.



and self-effacing, demonstrating the ways in which Beaumont herself recognizes the problematic narratives *Hole in the Heart* espouses. However, when Beth asks her sisters for clarification, they dismiss her and laugh. Beth is not given the chance to understand, and readers are, willing or not, in on the joke. So, on the one hand Beaumont seems to draw attention to the ways in which she has moved on to accept her daughter's diagnosis and even to disavow the genre and its problematic conventions. In the same stroke, however, she indicates that she perceives Beth to be unable (or undeserving?) of the opportunity to participate in a process her other children, and readers, are presumed to understand. Beaumont draws Beth excluded.

Beaumont's narrative intentions are unclear, but neither is it necessary to know them to understand what the repurposing accomplishes for the memoir and for developmental disability discourse more broadly. Simply put, the narrative repurposing disrupts the linear progression of time in the context of a diagnosis that is constructed in and through a normative developmental timeline. Temporality becomes multiple and developmental delay loses its meaning. Developmental moments characterized by "slowness" are recharacterized by love, inclusion, and disability justice, even if the recharacterization in *Hole in the Heart* is inconsistent. The temporal floppiness of Beaumont's memoir shows that time can be constructed, deconstructed, and multiple, and is only one of many possible frameworks for understanding life experiences. Her work brings into relief how temporally linked expectations can be obstacles to life flourishing; but that, really, normativity is a narrative, and narratives can be rewritten.

## CRIP TIME

*Hole in the Heart's* floppy temporality is an example of "crip time," or one of disability's temporal orientations. Alison Kafer writes that crip time describes how inflexible expectations for punctuality can be explicitly ableist, as not all bodies can accomplish the same tasks at the same rate; it also challenges normative time by embracing a refusal to keep to the schedule (2013, 26–27). Ellen Samuels explains that crip time is time travel; she writes, "Disability and illness have the power to extract us from linear, progressive time with its normative life stages and cast us into a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings" (Samuels 2017, n.p.). In other words, crip time is a way

to describe pace, as in “we are on crip time” and hence things will happen in temporally unexpected ways; and we can “crip” time: we can bring a politics that embraces what is elsewhere disparagingly called irregularity, slowness, or prematurity to our understanding of time. Both framings bring into relief the way time is normative and falsely perceived as “natural.” Disability and illness can be “strange temporalities” (Halberstam, cited in Kafer 2013, 35) not only because of variable pace in movement, speech, thought process, et cetera, but in the way normative temporality can be made strange; how it can become unfamiliar once uncovered as a narrative.

Beaumont’s floppy temporality crips time through time travel and temporal multiplicity, undoing the linear, progressive narrative of developmental progress, and refusing to be punctual. Sara Hendren writes that crip time “suggests the clock may be every bit as much the culprit in a mismatch between a life like [a developmentally disabled child’s] and the world” as their diagnosis (2020, 182). Beaumont’s floppy narrative temporality destabilizes the hegemonic representation of life stages produced in and through the normative script of child-becoming-adult because it fundamentally challenges the meaning of “developmental delay.” Developmental delay is a diagnostic regime that purports to locate disability in bodies in time; really, it diagnoses a cultural fear—the specter of future disability. If, however, disability is a social and political experience, then “developmental delay” characterizes not atypical movement, communication, cognition, and sociality in childhood but the limitations imposed by ableism. Beaumont’s narrative shows this: what she fears will be the markers of embodied developmental delay—Beth’s inability to walk, run, and swim—becomes, in the narrative, structural ableism: Beth’s school refusing to include her in “sports day” (2016, 165); and Beth’s swim teacher refusing to teach her (205). The developmental delays are the delays in social progress; they are unmet expectations based on ablebodiedness, exclusion, and failures of imagination.

Because the temporality of childhood is fundamentally ontological, destabilizing that temporality likewise destabilizes ontology.<sup>1</sup> “Developmental progress” is not, in fact, the defining characteristic of childhood; it is a discourse in the Global North, a framework by which events and experiences are interpreted. It is a scaffolding that erects the Child as a figuration for cultural and political values: the child-becoming-adult is the “better” future. Developmentalism reinforces the distinction from which it derives, and both childhood/development/dependence and adulthood/mastery/independence are exposed as social fictions produced in and through the



other. As discourses and social fictions, they can be imagined otherwise. The story of childhood does not necessarily need to be a narrative of progress that culminates in independent adulthood. Indeed, in many places in the world childhood is a time of loss and forgetting, of losing what a soul once had (see Gupta 2002; Gottlieb 2004). Challenging this narrative means undoing the discourses on which it depends, including, significantly, the idea that any singular child could be “off track,” or developmentally delayed.

A narrative of childhood without “developmental delay” already appears in the existing texts. The phrase “developmental delay” does not itself even appear in Public Health Reports until 1982 (though it was used in British journals and health reports, which were read and consulted by U.S. public health officials, as early as 1936). Early U.S. reports, while expressing zero-tolerance for “feeble-mindedness” in adulthood, state, “the ultimate mental development of young children thus classified [as intellectually disabled] cannot be foretold” (“Public Health Reports” 1919a, 735). U.S. Public Health Service Surgeon Walter L. Treadway argues that

no distinct demarcation exists between the so-called higher types of feeble-mindedness on the one hand and normal mentality on the other. Nature’s method is one of gradation; shading, as it were, all her activities from one complexion to another. Moreover, the routine application of the formal psychological tests by untrained persons may readily lead to serious mistakes by classifying as feeble-minded, children whose mental development has merely been retarded [i.e., delayed]. (732)

Treadway makes a distinction here, between “feeble-mindedness,” i.e., disability, and slower mental development compared to other children. The adverb “merely” tellingly indicates that the latter is of little concern. In 1919, U.S. Public Health Service surgeon J. W. Schereschewsky writes that compulsory education must develop children’s “mentality to the point of greatest working efficiency, but also . . . secure their perfect adjustment on the intellectual level *determined by their respective innate capacities*” (“Public Health Reports” 1919b, 2031). And in 1930, President Hoover opened the Third White House Conference of the Child with the statement, “In democracy our progress is the sum of progress of the individuals—that they individually achieve to the full capacity of their abilities and character” (“The Story of the White House Conferences on Children and Youth” 1967, 8). The Committee on the Physically and Mentally Handicapped responded: “If

we want civilization to march forward it will march not only on the feet of healthy children, but beside them, shoulder to shoulder, must go those . . . children we have called ‘handicapped.’ . . . All these children are ready . . . to make their contribution to human progress; to bring what they have of intelligence, of capacity, of spiritual beauty” (10). Each of these examples either has little concept of, or points to the shortcomings of, standardized assessments of child development—“they must not be mentally regimented to a single mold or the qualities of many will be stifled” (8)—and the capacious possibility of understanding child development as a process of individual becoming, rather than becoming an able-bodied adult.

Spock compels our cultural imagination further. In 1946, Spock wrote that a growing child is “following the whole history of the human race” (145), from a single cell, to “like a fish,” to learning to walk and in doing so “celebrating that period millions of years ago when man’s ancestors got up off all fours” (145). In 2018, the story has changed: “By the time a woman misses her period . . . the embryo is a little disk with three layers. . . . At ten weeks, the fetus looks almost human, but tiny” (13). Spock’s, and later, Needleman’s story of development reflects the scientific and cultural norms of the moment, shedding over the course of the second half of the twentieth century the colonialist rhetoric that would position the child of English-speaking parents as the pinnacle of the human race. In both stories, the child grows and develops, though the teleology changes and so too does the meaningfulness of that growth and development. Significantly, Spock writes in 1946 that “every baby’s pattern of development is different” (21); and later, “Development is bumpy. . . . Children need an environment that allows for the next developmental achievement but doesn’t push them into it” (Spock and Needleman 2012, 99); and most recently, “don’t focus too much on the timing. Being fast or slow doesn’t matter in the long run” (Spock and Needleman 2018, 77). Perhaps most tellingly, in my first edition copy of *The Common Sense Book of Baby and Child Care*, purchased used on eBay, the back pages have been filled by the parent of a child born in 1957. On the page for chronicling developmental milestones indexed by the child’s age, the biographer has disregarded the columns altogether, and instead noted in neat, blue ink when the child had measles and chicken pox, the severity of symptoms, and the number of days absent from school.

These passages from Spock emphasize developmental progress according to individual capacity rather than a standardized, normative timeline. They moreover suggest that communal (national, maybe) progress can and

will be achieved through the capacitation of each person according to the body and world within which they live. While this does not challenge the “narrative of progress” per se, it does indicate a different meaning of progress, one in which progress is measured not by the elimination of disability, but rather by accessibility and inclusion. How then, might a more capacious concept of development be brought to bear on the CDC’s Milestones Chart? To begin with, the Milestones chart’s primary purpose could shift from identifying developmental deviance to identifying developmental variability. Instead of prescribing “At two months, your baby will . . .” the Milestones charts could ask at two months, “What new things did your baby discover about themselves or their world?” or, “How does your baby move their body and communicate their needs?” Instead of advising care providers to “help” their children stay “on time,” the Milestones Moments packets could advise care providers to “pay attention to the ways your child communicates”; and “encourage your child to explore their body and their world to their fullest capacity.” The “signs” of the *Learn the Signs* campaign could be understood as the signs of ableism at work: learn to identify ableist exclusions and stigma and act early to become an educated ally and advocate. *Learn the Signs. Act Early.*

Perhaps this is what Spock had intended all along when he advised readers, early in *Baby and Child Care*, to “love and enjoy their child for who [they are], what [they] look like, and what [they] do” (1946, 22). I propose to change the narrative as Spock changed the pronouns. In no way does a more temporally diverse narrative of childhood imply development should be discouraged; nor does it imply that development—growth and change—is a fiction. Instead, this narrative compels an examination of our investment in “progress” and the shape of that imagined, better future. Childhood as floppy temporality is no longer juxtaposed to adulthood; this frees the concept of adulthood from able-bodied and autonomous norms and releases children from bearing the responsibility to manifest a disability-free social and political future. No longer becoming-adult, disabled children, and all children, might become themselves. This narrative is a template for disability justice, one in which the better future is more accessible, more inclusive, and more imaginative.

## 2 *Settler Colonialism, Anti-Blackness, and the Narrative of Overcoming*

In 2012, a white lesbian named Andréa Ott-Dahl agreed to be a traditional surrogate for a lesbian friend and her partner. Sperm was donated by an interracial gay couple (white and Black), friends of the intended parents, Liz and Erica. When prenatal testing detected Down syndrome, Liz and Erica decided to terminate. Andréa and her soon-to-be-wife Keston, also white, volunteered to release Liz and Erica from the surrogacy contract, continue the pregnancy, and become the baby's parents. The donors expressed a desire to coparent with Andréa and Keston. Discussions of finances and visitation schedules quickly escalated to angry threats to sue for custody and child support. The arguments resulted in bitter animosity between Andréa and Rod, the Black donor. Shortly before the birth, Andréa prays the child will not be biologically related to Rod. Keston promises the baby has not yet, and will not now, "let them down" (Ott-Dahl and Ott-Dahl 2016, 208). The reassurance implies that the baby has met all her parents' expectations. In this passage, Keston directly eliminates any and all previous fears she had about raising a disabled child, the exploration of which comprises the bulk of her memoir, *Saving Delaney; From Surrogacy to Family*. The only threat that exists and which could potentially diminish the familial, if not biological, "link" between parents and child is that the baby might be Black. The white donor, Shawn, is irrelevant and his biological material poses no threat to the family's bond. When the doctors describe the infant's "fair hair" in the

delivery room, the new parents interpret this to mean the baby is white, and smile at one another with relief (216). They name her Delaney.

*Saving Delaney* is one of hundreds of “special needs” parental memoirs published in the United States since the 1950s, and one of only two published by lesbian parents. The genre is overwhelmingly comprised by narratives written by white parents about white children. “Special needs” parental memoirs create new ways to imagine disability as a valuable, meaningful, and positive form of human variation. The children of these narratives, children who years ago might have been institutionalized, are described in their parents’ books as valuable members of the community. Parent narratives are almost uniformly recuperative: they challenge the exclusions of daily life, the ableism they and their children encounter, the eugenicist logic that would eliminate disability, totally. They write their children into childhood and into life. They write themselves into the parenthood they desired and expected. The narratives do this, however, in problematic ways that do little to challenge ableist logics, as discussed throughout this book.

As explained in the introduction to this book, the true number of published “special needs” parental memoirs is hard to know. The collection is variably catalogued under Library of Congress headings as disparate as “Parents of Children with Disabilities”; “Mothers and Daughters—United States”; and “Down Syndrome—United States—Case Studies,” making an exhaustive list tricky to build. Many memoirs are self-published and not held in WorldCat libraries. To build my archive, I searched subject headings through WorldCat and through the Amazon.com Biography & Memoir subcategory “People with Disabilities.” I often followed Amazon recommendations: “Customers who bought this book also viewed . . .” and eventually combed through every listing in the subcategory. I crosschecked my bibliography with lists generated by users on GoodReads.com and disability advocacy websites. I stopped compiling titles yesterday, after noticing a new memoir slated for publication early next year. Altogether, I have found just over three hundred unique memoirs about raising a child with disabilities, all of which were published in the United States between 1950 and 2021. Twenty-five of them are about children of color.



Miracle was born in 2013. While in utero, Miracle’s neural tube failed to close, and she became anencephalic. Doctors advised Miracle’s mother Markisha

Galloway, a woman of color, that babies with severe cephalic disorders do not often survive gestation, and if they do, they typically die soon after birth. Galloway chose to continue her pregnancy and made plans to donate Miracle's organs upon Miracle's death. When she was five months pregnant, Galloway's doctors told her that Miracle was a girl. Galloway's daughter Tanaeah was ecstatic to get a little sister. Miracle lived over two years. She was adored by her mother and sister and the extended family of relatives and medical staff who cared for her. She passed away in her mother's arms in early January 2016. Toward the end of her life, Miracle lived in a care facility where she could receive twenty-four-hour supervision. Her care staff, especially Kristen and Nicole, loved having a baby on their rotations. In her short memoir, *Raising Miracle* (2018), Galloway writes that the extended network of care created with the staff at Sunshine Children's Home enabled her to be the hardworking and attentive mother she wanted to be to her two daughters, both girls of color. The narrative's sustaining conflict is the ongoing abandonment of Galloway, Miracle, and Tanaeah by Miracle's father, Christian. And while Christian's absent-presence in the memoir is significant, at each moment he failed to show up for Galloway, she finds herself held, cared-for, and supported by her family, church, and community. Indeed, Galloway's memoir is, overall, a story of support webs and interdependence, entanglements woven by the brief life of a well-loved child.



"Special needs" parental memoirs are a subset of disability life-writing that, though representing diverse experiences and disabilities, are generally, but not entirely, written by abled, white, middle- and upper-class heterosexual parents. As noted in the introduction, the popularity of "special needs" parental memoirs, especially in the last twenty years, is part of a broader trend in publishing towards auto/biography and specifically an increase in life-writing about illness, trauma, health, and disability. Parental memoirs typically abide by a formulaic narrative that begins with the disabled child's diagnosis and the parents' grief or sense of loss (see Piepmeyer 2012). Later, the negative feelings are overcome. In parental memoirs, the overcoming narrative not only depends on the child's accomplishments or self-actualization, but also how these accomplishments relieve parents of the disappointment of having a disabled child. Overcoming happens, then, either when individual impairment is cured or significantly reduced

and thus becomes a smaller obstacle to integrating into the existing social world, or when the disabled person accomplishes ordinary or extraordinary achievements within the existing social world, *despite* being disabled. With overcoming narratives, readers need not examine structural obstacles to inclusion that overdetermine negative perceptions of life-with-disability.

Parental memoirs about raising a child with disability reproduce the overcoming narrative in distinct ways. In the majority of memoirs, overcoming occurs when parents experience a perception shift. In this way, parental memoirs are stories of *parents* overcoming their negative feelings about disability. Overcoming narratives are a variety of “super crip” stories that depend on the perception of disability as tragic and undesirable to catalyze a story of happily ever after. In parental memoirs, happily ever after is an individualized experience of a child fitting in and parent feeling better. The ubiquity of the overcoming narrative in parental memoirs is not surprising given the ableist cultural preference for the narrative (Couser 2012, 44). It is significant, however, in that its constant reiteration it produces a familiar cultural concept of both disabled children and their parents as *exceptional*: “God only gives special kids to special parents.” They produce, and reproduce, a story of loving and accepting disability *despite* disability.



In a handful of memoirs, disabled children are more or less “cured” by the narrative’s end. This is the case in *Not My Boy! A Father, A Son, and One Family’s Journey with Autism* (2010). R. J., the titular son, is diagnosed with autism at age three, after almost total speech regression, increased emotional dysregulation, and loss of motivation for and apparent understanding of reciprocal play. His parents, former NFL quarterback Rodney Peete and successful actor Holly Robinson fault routine childhood vaccinations for causing R. J.’s autism (25). Holly Robinson exhausts available treatment options, enrolling R. J. in both ABA (applied behavioral analysis) therapy as well as the alternative, “Floortime.” R. J. receives speech therapy, occupational therapy, tutoring, and enrolls in a private developmental preschool for children on the spectrum. He is put on a gluten- and casein-free diet, and receives chelation therapy under the supervision of Jay Gordon, a Los Angeles-based physician well known for his vaccine hesitancy. Over time, R. J. became highly verbal, athletic, social, and a skilled musician (Peete and Morton 2010, 4; Mazziota 2018).

Peete initially responds to R. J.'s diagnosis with "denial" and avoidance. He had convinced himself that what R. J. needed to "get out of his strange world" (42) was the kind of combination father-coach Peete's own dad had been for him. Peete's father, an assistant football coach at University of Arizona, taught Peete to value and pursue athletic prowess and normative masculinity. Peete writes, however, of young R. J.'s refusal to engage in any type of reciprocal athletic-based play like catch or kicking a soccer ball. Peete experienced this as a missed opportunity for a typical father-son relationship with his boy. Over time, Peete develops new ways to engage with R. J. that work with his neurology, rather than against it, for example, by clarifying exactly how many times the ball would be kicked between them and providing R. J. with visual and verbal structure for his day and activities. R. J. thrives in his supported environment, and as R. J.'s interests and skills diversify, his father enjoys a kind of restoration to the type of fatherhood role he had envisioned playing in his children's lives. This is most apparent in the memoir's form: Part One, "R. J.'s Story," details the above; Part Two, "Advice," is a series of chapters directed at other fathers of children with autism. Each chapter begins with an anecdote from Peete's life before offering a series of points under the subheading "Tips for Success." The memoir concludes with an appendix, "The Welcome to Autism Handbook," in which Peete offers another set of advice, observations, and resources. In these pages, Peete fully inhabits the role of father-coach, writing from a position of firm and unquestionable authority.



On the one hand, parental memoirs of overcoming seek to claim a place for their families at the proverbial table; on the other, the very arc of their narratives depend on a cultural understanding that they are the exceptions to the rule. The extreme overrepresentation of white children in the genre, and in positive portrayals of disability more broadly, has significant implications for disabled children and their families and the limits of inclusion. "Special needs" parental memoirs generally seek to challenge negative stereotypes of disability that perpetuate their children's exclusion from the social world. It is necessary, then, to examine how whiteness works not only in individual narratives, but at the generic level, to construct the figure of the exceptionally disabled white child.

In this chapter, I examine the ways in which whiteness engenders not



merely visibility for disabled children and their parents, but recognition, and by extension, acceptance—a literal and material “you are one of ours.” As Cheryl Harris argues, whiteness is conceptually grounded by the “right to exclude” (1993, 1714). The material inclusion engendered by whiteness makes sense of the overcoming narrative in parental memoirs: there is a social world, childhood, a life course, that disabled children overcome *to*; a destination to which they arrive after prevailing over the narrative hurdle in their parent’s memoir. The narrative of overcoming is, essentially, about claiming one’s place in the world, literally surmounting obstacles to gain access to the things to which one believes themselves to be entitled. It is none other than the mythic American bootstraps narrative, itself a version of manifest destiny. In this narrative, America is mythologized as a land of possibility. This story, however, is premised on the violence of settler colonialism and the false premise of settler entitlement. Under settler logic, Indigenous people and their claim to the land must always be erased; they exist only in the past and as such must always be disappearing in the present. The same logic insists on white settlers’ ongoing entitlement to land. Historically, and with implications for the present, land could only be truly “possessed”/owned by the (white) settler state (1722). The claim made in overcoming narratives is one of entitlement to a relation of domination premised on the legacy of whiteness *as* property, or the ways in which the rights in property in the United States are produced in and through race.

I argue that the ubiquitous “overcoming” narrative is itself a manifestation of settler colonialism. For whom, in American history and life, has hard work, has overcoming, led to flourishing? The overcoming narrative itself is premised on the notion that ableist-based exclusion is a bit of a surprise; things were not supposed to be this way for the white settler. Overcoming the obstacles is a form of recuperation, restoration, and return, all of which imply an original claim to possession; in this case, what is possessed is the right to belonging itself, the privilege of having a place and of taking space in society. In the context of the United States, this narrative is distinctly settler colonial and reproduces the false legitimacy of white belonging *because* of whiteness. Ableism and settler colonialism often appear together on lists of oppressive social structures; their intersections, however, are relatively underexamined in critical disability and feminist disability studies (in comparison to race and or gender and settler colonialism, for example). Susan Burch argues that settler colonialism and ableism overlap distinctly

in denying subjugated populations self-determination, a commonality manifest explicitly in the mass incarceration of Natives in Indian Asylums (2021, 4–5). As Jess L. Cowing notes, however, “the vast majority of feminist disability studies projects have failed to address narratives of Native/Indigenous sovereignty beyond reductive rhetorical gestures to ‘decolonization’” (2020, 11). Though the overcoming narrative, along with other figurations of the “supercrip” have been extensively examined and deconstructed in feminist disability studies, below I argue that the narrative is distinctly settler colonial. The overcoming narrative in disability life writing and representation is merely another version of American meritocracy, a myth premised always-already on a white settler’s sense of entitlement to determine who does and does not belong and the legal and social mechanisms of privilege and exclusion.

In what follows, I establish that the overwhelming whiteness of the “special needs” parental memoir genre is enabled by the material and discursive privileges of white settler colonialism and, in particular, a white supremacist sense of entitlement to belonging. This conclusion proceeds from a disability justice framework that understands that “able-bodied supremacy has been formed in relation to intersecting systems of domination and exploitation. The histories of white supremacy and ableism are inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination” (Berne 2015, n.p.). I examine the whiteness of positive portrayals of disability in memoirs (and media more broadly) and offer these depictions in contrast the material realities of many disabled adults and children of color in the United States, including lower health outcomes and the “special education to prison” pipeline. I support my argument with a close read of the popular memoir *The Broken Cord* (Dorris 1990), an exception to the genre in both the absence of an overcoming narrative and that the child is Indigenous. Woven throughout the chapter are summaries of independent and small press published memoirs written by families of color about their disabled children. Most of these memoirs are held by few libraries and have received little, if any, critical attention. Among these memoirs, the overcoming narrative and the genre’s characteristic appeals to normativity are sometimes reproduced, and sometimes challenged. They are thus indicative of how whiteness operates as a relationship of power rather than something that emanates from “white” bodies. They are included here in direct refusal of the genre’s conventional invisibilization of stories about families of color.



Darryl E. Lawson's self-published memoir is called *My Nia, My Purpose* (2018). On the cover is a photograph of a young Black child. She wears a yellow T-shirt and a denim jacket, and her huge smile shows spaces between her still-baby teeth. Lawson's memoir is about coming to recognize the significant role parenting a child with autism and cognitive disability plays in his life. He struggles to let go of the goals he had before he became a single father to a disabled child, especially finding a lover and having his own car. However, the memoir does not pivot on a single moment of breakthrough or discovery. Instead, Lawson tells a (sometimes) chronological story of frustration and resolve, of steps forward and steps back. His narrative foregrounds the language of "being chosen" to parent Nia (e.g., 55), of making his life about her; at the same time, however, much of the memoir details the people and systems that enable opportunities for both Nia and Lawson to thrive. Lawson depends on his mother, neighbors, the New York public school system and state respite services to balance Nia's care. These sometimes fail; buses come early or late, employers have little tolerance for Lawson's need for flexibility; neighbors are, at times, unavailable. But, more often than not, Lawson and Nia are buoyed by neighbors, extended family, and especially Lawson's tight-knit group of friends from childhood. This group of Black men appear throughout the memoir as confidantes and counselors, and guests at Nia's birthday parties. The memoir concludes somewhat abruptly and rather anticlimactically: it is another school day, Nia's bus has come and gone early, and Lawson might be late to work. Lawson had recently, finally, bought himself a car, and finds that for the first time he has an additional option for independently getting Nia and himself through their day. He concludes by writing, "I had come [far] in my job of raising Nia . . . she was My [sic] Nia and my purpose for living, and my reason to be a better man" (196). In this statement, Lawson reproduces a narrative of parental self-improvement in relation to a disabled child, even as the memoir overall resists framing Nia herself as a catalyst for others' growth and development.



I am writing this chapter in May 2021. Amazon's best-selling book lists are based on sales and updated hourly. Today, May 2, at 11:30 a.m., there are six

“special needs” parental memoirs on Amazon’s list of the one-hundred best-selling memoirs about “People with Disabilities” (Amazon’s subcategory of “Specific Groups” under Bibliography/Memoir). These six are:

- *Loving Tiara* (self-published under Twig Decor Press 2019), by Tiffani Goff, a white mother writing about a white child with a rare genetic disorder (Kindle edition, ranked #37). Goff is an active blogger and runs an interior design business. She worked as a home keeper and raised her three children for sixteen years. *Loving Tiara* received little critical attention, but Tiffani Goff’s story and her memoir were featured in the *Los Angeles Times* (March 2020). Twig Decor Press shares its name with Goff’s design company, Twig Decor. *Loving Tiara* is the press’s only title.
- *I Have Been Buried Under Years of Dust* (William Morrow 2021), by Valerie Gilpeer with her autistic daughter, Emily Gordin, both white women (hardcover, ranked #51). Gilpeer is a civil attorney who represents families of children with disabilities seeking education accommodations. *I Have Been Buried Under Years of Dust* was reviewed by National Public Radio, *Kirkus*, *Library Journal*, the *Washington Post*, Temple Grandin, *LA Review of Books*, and a number of autistic advocacy organizations.
- *Half a Brain, Confessions of a Special Needs Mom* (self-published under Mile 18 Press 2020), by Jenni Basch, a white woman whose daughter experienced a brain injury in utero and grew to be multiply disabled (Kindle edition, ranked #52, and ranked #1 under Amazon’s educational texts subcategory “Developmental and Intellectual Disabilities”). Basch is an educator and therapist. She offers an online newsletter for teachers and parents of children with disabilities that discusses therapies and special education. An Internet search for Mile 18 Press yields no results.
- *Raising a Rare Girl* (Penguin 2020), by white mother Heather Kim Lanier about her white daughter, Fiona, who has Wolf-Hirschhorn syndrome (hardcover, ranked #68). Lanier is a writer and professor of writing. Her essays have appeared in the *Atlantic* and *Salon* (among others), and her poetry is award-winning. *Raising a Rare Girl* was reviewed favorably by the *New York Times Book Review*, *Slate*, *Booklist*, *Publishers Weekly*, and *Kirkus*. Malcolm Gladwell nominated *Raising a Rare Girl* for the *Next Big Idea Club*’s list of must-read titles for summer 2020.
- *This Boy We Made* (Catapult 2022), by Taylor Harris, a Black mother to a Black child named Tophs, who has a genetic “variant of unknown significance” (hardcover, prerelease ranked #84). Harris is a writer. Her

work has appeared in the *Huffington Post*, the *Washington Post*, *McSweeney's*, National Public Radio, and *Babble*. At the time of this writing, *This Boy We Made* is prerelease and has not received critical reviews.

- *The Warner Boys: Our Family's Story of Autism and Hope* (Little A 2018), by Ana and Curt Warner, Black parents to three Black boys, two of whom have autism (Kindle edition, ranked #86). Curt Warner is a former professional football player with the Seattle Seahawks and the Los Angeles Rams, and College Football Hall of Famer. Warner founded the Curt Warner Autism Foundation. *The Warner Boys* was reviewed by *Publishers Weekly* and *Kirkus* and the Warners were profiled by a number of small media outlets, including the *Seattle Times* and *The Art of Autism*.

To summarize, the first four memoirs are written by white parents, two of them are self-published ebooks; the other two are published by major presses and written by a disability advocate and professional writer, respectively, and have received positive critical attention from major news outlets. The remaining two memoirs were written by Black parents, the first of whom is a professional writer who published with an independent press, the second of whom is a famous athlete who published with an Amazon imprint.



Shemeka Cherry Jackson's self-published memoir, *Specially Wrapped Gifts* (2019), shares its title with her Tennessee-based nonprofit organization that supports families of children with disabilities. She started the organization after her daughter Candace was born with Down syndrome and a congenital heart defect. Jackson, a woman of color and devout Christian, describes her organization as a "ministry," meaning that her work is motivated by her faith and she hopes it will demonstrate God's love for families of children with disabilities. In her memoir, Jackson writes that she is blessed to have been chosen by God to care for her daughter Candace, a child made in the image of God.



In 2012, Roxane Gay systematically researched the racial background of every writer whose book was reviewed by the *New York Times* and found that nearly ninety percent of the books were written by white authors (Gay

2012, n.p.). In winter of 2020, Richard Jean So and *New York Times* staff writer Gus Wezerek published an article in which they noted that during the summer 2020 protests against the murder of George Floyd, fiction and nonfiction written by authors of color climbed to nearly fifty percent of the *New York Times* bestsellers lists, before descending to the twentieth percentile by the end of the year (So and Wezerek 2020). So's book, *Redlining Culture* (2020), while focusing on fiction, finds that between 1950 and 2000, white authors wrote ninety-seven percent of novels published by Random House, a publisher "committed" to Black literature (29). Using So's method, So and Wezerek found that among English-language fiction published by major popular presses (Simon & Schuster, Penguin Random House, Doubleday, Harper Collins, and Macmillan) between 1950 and 2018, white authors wrote eighty-nine percent. Many argue that the absence of published work by writers of color is due in part to the whiteness of publishing. Cécile Cottenet (2014) writes that in the United States the intermediaries (editors, publishers, agents, and reviewers) between texts and markets have historically been predominantly white. In the current moment, this remains true: Lee & Low Books's 2019 industry-wide diversity survey found that seventy-six percent of publishing personnel are white. This number jumps to seventy-eight percent and eighty-five percent at the executive and editorial levels, respectively (Lee & Low Books 2020). 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" (Gay 2012, n.p.). To her point, Lee & Low Books' survey finds that eighty percent of literary agents and reviewers are white (Lee & Low Books 2020).

As noted above, "special needs" parental memoirs are similarly overrepresented by white families, especially those memoirs that receive critical attention. In 2020, Judith Newman, white author of *To Siri With Love* (2017), a memoir about raising her autistic son Gus, reviewed a newly published memoir, *We Walk: Life with Severe Autism* (2020), by white author Amy Lutz, for the *New York Times Book Review* (Newman 2020). Newman's *New York Times Book Review* joins only five others reviewed in the last twenty years; these include Newman's own memoir, Ron Suskind's *Life, Animated* (2014), Emily Rapp's *The Still Point of the Turning World* (2014), Michael Bérubé's *Life as We Know It* (1998), and Heather Lanier's *Raising a Rare Girl* (2020). Each of these memoirs is about a white child, and five of the six are about boys. Suskind's *Life, Animated* went on to inspire a documentary film released in 2016.

Three other films were also based on memoirs about white children: *Miracle Run* (2004), *Beautiful Boy* (2018), and *Extraordinary Measures* (2010). *The Broken Cord*, by Michael Dorris, about his adopted Native son, Adam, who had fetal alcohol syndrome, was produced as a television drama in 1992 (discussed below). The visibility of disabled white children, and especially boys, is mirrored in fictional film and television, too. For example, today's popular disability-centered television shows on major platforms include: *Speechless*, a series about a non-speaking, white, teenage boy with cerebral palsy (American Broadcasting Channel/ABC); *Atypical*, a series about an autistic, white teenage boy (Netflix); *The Healing Powers of Dude*, a series about a white boy with anxiety, who is supported by his best friend, an East Asian girl who uses a wheelchair (Netflix); *Switched at Birth*, a series about a white, Deaf teenage girl (ABC Family Channel); *Everything's Going to be Okay*, a series about a white adult with anxiety and his two white teenage sisters, one of whom has autism (Hulu); and *Raising Dion*, a series about a Black boy with "superpowers" that sometimes resemble autism, and whose best friend is a light-skinned, brown haired girl named Esperanza, who uses a wheelchair (Netflix). Popular films in which disability is positively portrayed produce a similar demographic (e.g., *Wonder*, *Simon Birch*, and *The Secret Garden* all feature white boys). Taken together, it appears that the popular, positive story about disability in video media and memoir is usually one about a white child, often a boy.

Couser writes that one of the defining characteristics of the memoir boom is authorship by otherwise unknown people—nobodies (2012, 5)—who experience atypical embodiment. Calling these "some body" memoirs, Couser explains that popular topics include disability, illness, accidents, drug addictions, and other sorts of physical or emotional trauma, whereas prior to the twenty-first century, popular memoirs were largely written by popular people: famed politicians, celebrities, and other cultural figures. The parental memoir genre is majority "nobody." While a handful of memoirs are written by prominent journalists and another bunch by well-known academics, for the most part, parental memoirs are written by un- or little-known writers and/or are written by parents for whom writing is a personal or leisurely pursuit. Five memoirs were written by famous athletes. Of the twenty-five memoirs about disabled children of color, a hugely disproportional total of three are written by well-known persons, each a professional athlete; there are only an additional two penned by athlete parents among the hundreds of memoirs about white children. Taken together, these data



suggest that a white “nobody” has access to conversation space about overcoming disability that even a well-known somebody of color does not.

John K. Young makes two points when writing, “the predominantly white publishing industry reflects and often reinforces the racial divide that has always defined American society, representing ‘blackness’ as a one-dimensional cultural experience” (2006, 4). Young’s argument is not only about whose stories get told and circulated, but of how that circulation reproduces cultural fictions and material worlds. Young’s critique is not new. In 1950 Zora Neale Hurston wrote that booksellers are interested in selling stories that reproduce a desired social reality, which (then and now) includes white dominance and stereotypes of Blackness (cited in Raynaud 2014, 123). In other words, fictional and nonfictional narratives alike reflect and influence the material world both through the buying and selling of narrative and the discursive reiterations of power contained therein. In the case of “special needs” parental memoirs, the invisibility of families of color must be examined against the stories these memoirs tell, the social reality they construct. In the vast majority of parental memoirs, disability’s negative effects are overcome (albeit problematically), and the disabled child is folded into an accepting family and community. The critical reception of some memoirs and their circulation provide narrative templates for families to make sense of their own experiences, in much the same way as Emily Perl Kingsley’s “Welcome to Holland” (which is indeed reprinted in countless memoirs), or the phrase “God only gives special kids to special families.” Parents of children with disabilities are able to imagine themselves and their children in a narrative of overcoming and inclusion. The invisibility and absence of families of color in the genre says nothing about the circulation of the overcoming narrative; rather, it suggests that the material and discursive privileges of whiteness enable a kind of positive visibility for white disabled children and their families that may be withheld from children of color.

Diana R. Paulin writes that visibility does not necessarily guarantee recognition (Paulin 2017, n.p.). Though she is writing specifically about diagnostic labeling, her insight is instructive. Indeed, the process of recognition depends first on a shared framework for making sense of what is seen, and the display of vulnerability is often withheld from people of color in white supremacist cultures. Moya Bailey and Izetta Autumn Mobley write that a white supremacist cultural context demands Black bodies “transcend” all suffering, or at the very least, conceal signs of weakness (2019, 21). They



write of a reluctance among Black people to identify as disabled, when “they are required to be phantasmically abled in white supremacist society” (22). Most parent memoirists do not “identify” their children *as* disabled but rather *with* disability; to identify their children as disabled would be anathema to most memoirists’ narrative purpose in challenging impairment’s relevance to their identities as parents and children *first*. However, Bailey and Mobley imply here that identifying as disabled means making visible injury, trauma, difficulty, and potential weakness, something most memoirists do, in fact, do, in order to catalyze the narrative of overcoming. In this way, it is the process of making one’s (or one’s child’s) disability “problem” visible that engenders the positive reframing. It is at the same time, a cultural context in which white bodies are afforded the narrative complexity that bodies of color are not. The question of absence and invisibility, then, is as much one of publishing bias as a white supremacist generic convention: white bodies are safe to display vulnerability, and white overcoming is not only believable, but also engineered.



D’Jonte “Tae” Malik was born when his mother was fifteen years old. Tammy Floyd-Westmoreland, an African American teenager living in her parents’ house in Cincinnati, did not intend to become pregnant. She was a varsity cheerleader and on the honor roll. She scheduled an abortion only to find out her pregnancy had progressed too far for her local clinic to perform it. Without other options, Floyd-Westmoreland successfully hid her pregnancy from her parents for several months; when they found out, they initiated their daughter’s prenatal medical care. Floyd-Westmoreland’s pregnancy continued without complications, and her baby was born November 8, 1995, after nine hours of active labor. She had learned from television that babies cry immediately upon birth, but Tae made no sound (2018, Kindle location 192). Tae was diagnosed with cerebral palsy and epilepsy. Doctors told Floyd-Westmoreland that Tae would be totally dependent, non-verbal, and non-ambulatory. When she heard this, Floyd-Westmoreland fled the medical conference room to her son’s NICU isolette, held him, and told him how much she loved him.

During his infancy, Tae’s grandmothers and aunts shared in his care. Tae was his mother’s friends’ “honorary baby.” This extended network of aunties (Kindle location 1322) took turns with baby Tae’s overnight care and watching him while the others went out and partied like the teenagers they were.

They brought Tae with them whenever they could. Floyd-Westmoreland writes because of these friends, she and Tae were never excluded (Kindle location 288). She began to understand her *self*, her own identity, as Tae's mother, as someone whose purpose on earth was to care for Tae. When Tae was eight years old, he moved into a care facility. Though his mother writes that the decision was incredibly difficult, Tae required more care and supervision than she was able to provide on her own. Floyd-Westmoreland went to nursing school with the ultimate goal of resuming Tae's care. She did, for several years, until Tae was simply too big and returned to a care facility.

Tae passed away at fifteen. The care facility called his mother in the middle of the night and said Tae was having trouble breathing; minutes later, he passed. Floyd-Westmoreland writes that in that moment she lost part of herself (Kindle location 856) and that she felt that Tae's death had extinguished her purpose on earth (Kindle location 920). It was not until two years after Tae's death that Floyd-Westmoreland began to understand her purpose in life anew. She explains that, though Tae is gone, she must continue to live her life for him. She writes that through loving and losing Tae, God has given her a testimony, a story that speaks to God's goodness and wisdom; her role is to share Tae's story, "to be his voice" (Kindle location 1126), to spread awareness about cerebral palsy and to be an advocate and support for other families. In doing this work, and thereby from the lessons learned from parenting her son, Floyd-Westmoreland writes that she has become a better woman and mother (Kindle location 1135).



The invisibility and absence of families of color among parental memoirs is contrasted by the hypervisibility and overpopulation of people of color, especially Black children and adults, in disability and/or disabling settings. It is disabled children of color, or children of color marked as disabled, who are in fact hypervisible, however under an unforgiving, surveilling gaze. For example, children of color, especially boys, are overrepresented in special education classrooms (Ferri and Connor 2005, 93–95). Teachers and school evaluators label children of color with intellectual disability (ID) or emotional disturbance (ED) with greater frequency than they do white students who exhibit the same behaviors. White students, in contrast, are more likely to be identified as having a learning disability (LD) or Attention Deficit Hyperactivity Disorder (ADHD). Children of color are nearly seventy percent less likely to receive an ADHD diagnosis than are white children (Mor-

gan et al. 2013, 85). While all four labels indicate that a child needs accommodations in the classroom to ensure their full participation, ID and ED are more likely than LD or ADHD to result in a segregated education setting for all or part of the school day. Moreover, the eligibility categories “intellectual disability” and “emotional disturbance” stigmatize children as unteachable and dangerous, respectively. Children of color are *so* overrepresented in special education that Ferri and Connor argue we must view special ed as a form of educational resegregation post-*Brown v. Board of Education* (2005, 96). Subini Annamma explains that multiply marginalized students located at the intersection of race and disability—like children of color in special education—are made more susceptible to incarceration by the same processes of surveillance that overidentify “disability” among them (Annamma 2017, 12). To wit, 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 (2011, 178). Nirmala Erevelles (2014) similarly writes that the segregation of children of color in special education mirrors their overrepresentation in prison. The total number of students in special education has also increased over the last decade. Black students make up sixteen percent of students served by the Individuals with Disabilities Education Act (IDEA), and Native students make up seventeen and a half percent (“Digest of Education Statistics” 2018). To compare; Black children comprise fourteen percent of all American children, and Native children comprise only one percent (“Child Population by Race | KIDS COUNT Data Center” n.d.).

Special education data do not indicate that children of color are more like to “have” disabilities. Rather, the overrepresentation of adults and children of color among people with disabilities is part of a United States tradition of pathologizing bodies of color. As Douglas Baynton has noted, whites justified the enslavement of Africans on the false notion of white intellectual superiority (Baynton 2001, 37). After emancipation, eugenicists relied on pseudoscientific “sciences of the surfaces” (Snyder and Mitchell 2005, 38) like phrenology, which claimed to identify a person’s moral and intellectual capacity based on the size and shape of their head, to popularize an intelligence hierarchy that fell along racial lines. Michelle Jarman has noted that the racialization of disability was so encompassing that whites believed *all* Black folks were cognitively disabled (Jarman 2012, 92). A long view of this history is instructive: disability is exposed as nonbiological, interpreted

as biology only through racist medicines and sciences. Moreover, disability can be seen as an individual quality or group designation constructed in and through other social statuses (like race and gender). In both ways, U.S. histories of “diagnosing” people of color (and women, and migrants, see Baynton) with disability has been a political project for securing white supremacist, settler, and patriarchal dominance.

Post-emancipation, white disabled people were institutionalized in asylums for the “feeble-minded,” while disabled people of color were incarcerated in prisons or altogether abandoned by the state (Ben-Moshe, Chapman, and Carey 2014, 8). Following deinstitutionalization in the 1960s and 1970s, the number of folks incarcerated in psychiatric hospitals and state institutions dwindled (Ben-Moshe 2020, 3), while the imprisoned population has increased six hundred percent (The Sentencing Project 2016, 1). Data also show that nearly half of all prison inmates have mental illness (cited in Ben-Moshe, Chapman, and Carey 2014, 11), as many as twenty percent of prisoners have a cognitive or developmental disability like autism (“Prison Is Even Worse When You Have a Disability Like Autism” 2020), and that people of color are significantly more likely to be incarcerated than their white peers (The Sentencing Project 2016, 5). In other words, post-emancipation, disability discrimination and racialization have worked in tandem to produce variable lived experiences for the diagnosed.

Alongside these shifts in both the purpose of carceral spaces and the place of people with disabilities among their communities rises the “special needs” parental memoir. The earliest “special needs” parental memoirs appeared in the 1950s. As Alison C. Carey, Pamela Block, and Richard K. Scotch note, parent advocacy for children with disabilities grew in the 1950s and 1960s. Parent activism contributed to the expansion of services people with disabilities and has raised public awareness about disability (Carey, Block, and Scotch 2020, 24); both outcomes play a role in increased social acceptance and integration of people with disabilities. While Carey, Block, and Scotch focus on parent advocacy organizations, the rise in parental memoirs, and especially the genre’s common (albeit not universal) resistance to institutionalization and other forms of social segregation can be tied to the parental activism movement. In large part, both comprise two axes of a larger, broader movement towards equitable inclusion of people with disabilities.

It is within the context of this larger effort that memoirs about children of color are absent. Like the parental memoir genre, many parent activist

movements were dominated by white, middle-class parents advocating for white children, even in diverse cities (43). I want to suggest that these are examples of more than a centering of whiteness, or a hypervisibility of white families among an otherwise diverse population. As noted above, it is disabled children of color, or children of color marked as disabled, who are hypervisible. The visibility of whiteness is propelled—or perhaps compelled—by uninterrogated white entitlement to belonging. For parent activists and memoirists alike, faced with the threats of exclusion engendered by a hostile, ableist world, whiteness offers a powerful inroad to social acceptance. The material privileges of whiteness—as property owning, as space-taking—creates in memoirs the narrative logic. It is at once the basis for recuperation and the recuperative end: the destination. To claim one's place, to insist on not only visibility, but recognition and acceptance, and to do so in the absence of interrogating the structural obstacles that render that inclusion provisional, is to reproduce an investment in maintaining those structures. In the United States, white supremacy is (re)produced first and foremost through entitlement claims on land, bodies, and space. It is a structure of belonging premised on a shared sense of entitlement, itself premised on active and ongoing violence against Indigenous peoples.



*The Broken Cord*, by Michael Dorris (Lakota), contradicts the characteristics of the “special needs” parental memoir genre almost, but crucially, and painfully, not totally. It was written in 1989, making it one of fewer than thirty published before the twenty-first century. The memoir is about raising a Native child, the only one of its kind, and Adam (Dorris’ child) was adopted, another relatively rare relational characteristic in the genre. Adam is one of two children in the genre that has fetal alcohol syndrome (FAS). Most memoirs are written by mothers. Not only a father, Michael Dorris was unmarried when he adopted his first child, Adam. Moreover, while according to WorldCat, forty percent of “special needs” parental memoirs are held in ten or fewer library collections worldwide, and twenty-five percent are held in none at all, *The Broken Cord* is held in 1,787 library collections, surpassing the next most-held memoir, *Running with Walker*, by more than three hundred copies. A made-for-television film based on the memoir was broadcast in 1992. Michael Dorris was a Dartmouth appointed anthropologist, and one a dozen among minority academic-parent memoirs. Like other memoirs by

academics, *The Broken Cord* is part memoir, part intellectual project, and the subject of downstream academic study. Michael Bérubé's memoir *Life as We Know It* (1998), for example, is as much about raising Bérubé's son Jamie as it is a study of normality, a foundational inquiry in academic disability studies. *Life as We Know It* is widely read and often drawn into critical conversations about disability and social life (see, for example, Nussbaum 2002, Rapp and Ginsberg 2011, Couser 2003). Dorris' memoir weaves raising Adam with Dorris' research about alcohol consumption among pregnant Native peoples in North America. *The Broken Cord* has been studied at length in disability life writing (see Couser 1998), but also in Indigenous studies (e.g., Cook-Lynn 1989), adoption studies (Shackelton 2017), and studies of addiction (DeVries and Waller 2004). And while it is nearly impossible to determine any single's texts popularity in terms of sales or library loans, at the time of this writing, *The Broken Cord* is among the top one percent of books sold on Amazon.com.

Taking the above features together, *The Broken Cord* is unique among the genre as a widely read, critically received, all together highly visible story about a non-white disabled child. The memoir's narrative arc, however, is a far cry from the standard story of overcoming. *Kirkus* writes that the memoir is devastating, alarming, and wrenchingly told (1989). The *New York Times* described the film adaption as "anguishing" (1989). Couser argues that Dorris's objectification of Adam as a "kind" among an ethnicized group of boys with FAS, combined with Dorris's insistence on Adam's incapacity for improvement, smacks of eugenics (1998, 435). Adam does gain some independence and by the memoir's end is employed and living in a group home for adults with disabilities. Dorris does not write of these as successes for Adam, but instead as signals of everything Adam cannot do; in other words, unlike other memoirs in which a child's increased self-sufficiency proves disability's irrelevance to the child's life opportunities, for Dorris, Adam's adult life is described as a failure of independence. Couser argues that Dorris concludes the memoir in this way because his project is, ultimately, one of preventing future births of children with FAS. It is clear that Dorris loves his son, but he writes repeatedly that Adam is a victim, someone who did not ask to be born and who should have been born differently (262), implying throughout the memoir that perhaps Adam, and children like him, should not be born at all. Dorris and his wife, Louise Erdich, who wrote an introduction to *The Broken Cord*, describe Adam as imprisoned in his own life (xviii) and living each day in "the act of drowning" (264). Adam's parents' despair

and rage is palpable, and over the course of the memoir Dorris and Erdich come reluctantly, albeit definitively, to advocate for incarcerating pregnant Native peoples for the duration of their pregnancies to prevent them from consuming alcohol. He does not altogether elide a structural critique, writing that, although “victims are victims of victims in an endless linkage that has been smithed by history, racism, economics, by bad luck” (193), ultimately, the pregnant person had made a choice and in doing so had denied Adam, and others like him, their rightful life. This position, which Dorris writes is both unavoidable and truly at odds with his “liberal” values (167), becomes the memoir’s conclusion and ultimate message.

*The Broken Cord*, then, with its narrative that descends deeper into heartache and despair, is juxtaposed sharply with the vast majority of narratives that comprise the “special needs” parental memoir genre. There is no overcoming for Adam or Dorris, and impairment’s effects are not only negative, according to his father they literally rob Adam of full personhood, imagination, and capacity to be human (Dorris 1990, 168). I suggest that *The Broken Cord*’s narrative end should be read alongside the text’s broad circulation and the racialization of Adam. Despite its tragic narrative and the irredeemability of disability, *The Broken Cord* abides with utmost fidelity to generic conventions: this is a genre in which a narrative of overcoming and its recognition among a reading audience is engendered by the material and discursive privileges of whiteness. *The Broken Cord* is a disabled Native boy’s failed redemption, not because his disability will not be overcome, but because the overcoming narrative, itself, is a white, settler story.

The narrative of overcoming in parental memoirs is not unlike an “It Gets Better” storyline for children with disabilities. The “It Gets Better” campaign, launched in 2010, instructed gay youth to persevere, to triumph over adversity, as anti-gay bullying and suicides among gay youth briefly held the media’s attention and thus appeared to be on the rise. As Jasbir Puar has pointed out, the “It Gets Better” campaign is a narrative of progress, a “coming of age success story” (Puar 2017, 7) that “parallels” disability’s “inspiration porn”—the idea crystallized by Stella Young and which names a cultural obsession with the disabled person who achieves amazing (or banal) things and thereby inspires abled people to strive similarly for greatness (7); “if *she* can do it, certainly so can I.” “It Gets Better” is about individual overcoming, rather than social responsibility. Puar argues however, that far from universal betterment for gay youth, the “It Gets Better” campaign draws into relief the ways



in which some, but not all bodies, have structural—material, discursive, and affective—access to improvement, while others do not. Puar cites the material ways in which “it” is more likely to get better for white, male, liberal subjects (10) to articulate her usage of debility as both the status and result of ongoing “structural inequality and suffering” (1) experienced by subjects for whom it does not, in fact, get better. She then explains that debilitation is the counter mechanism to capacitation, or the social and political processes of privilege: safety, access, recognition. Puar argues that while debilitation causes disability, privileged disabled subjects have access to recapacitating mechanisms. For white male gays, recapacitation looks like homonormativity: marriage, children, property ownership, dog joint-adoption. For people with disabilities, recapacitation does not necessarily imply cure, but rather recuperation into the social and political institutions disability is presumed to foreclose: marriage, employment, independence. For both privileged gay and disabled subjects, recapacitation refers to the structural availability to be visible as an overcoming subject. As Mia Mingus explains, to be recapacitated means to have a seat at the table (cited in Puar 2017, 15).

Puar argues that ultimately the “It Gets Better” campaign, and by extension, bootstraps and other narratives of progress, “reproduce neoliberalism’s heightened demands for bodily capacity” (1), or individualized responsibility for health, wellbeing, and upward mobility. I agree and argue further that these are discourses not only of how white privilege capacitates, but of white privilege specifically understood through settler colonial logics as the entitlement to belonging. In Puar’s analysis, to become visible as disabled means to invite state recognition, a visibility codified in the Americans with Disabilities Act. In this rendering, “disability,” as identity, cannot adequately identify individuals who are injured, made sick, and debilitated by state violence, including racism and settler colonialism. Nor does the empowered-identity model of disability reasonably appertain to the experiences of those for whom impairment has preceded increased medical and juridical surveillance over their lives, a population by and large comprised by disabled women and children of color (see Annamma 2017, 14; Ervelles and Minear 2010). Debilitation excludes; it expels, it propels subjects away from inclusion and recognition. Indeed, Puar likens debilitation to Lauren Berlant’s concept of “slow death,” the deliberate deterioration of a population (2007, 754; also Puar, 1). Debilitation characterizes settler colonization. I can think of no more apt narrative inversion of overcoming.





*Moose: The Story of a Very Special Person* (1978) is extraordinary among parental memoirs for several reasons. It is one of twenty parental memoirs and one of only three written about children of color published prior to the twenty-first century memoir boom (the others are *A Special Kind of Normal*, 1983 [1979] by Carolyn Betts, a Black mother writing about her Black son, and *The Broken Cord* by Michael Dorris). WorldCat locates *Moose* in one-hundred-fifty-four libraries worldwide. Chester Wayne Oden III, “Moose” was born in 1959 to Dr. Chester Wayne Oden Jr., then a medical student, and Pauline Pinkston, daughter of Dr. Greene Fort Pinkston, one of rural Tennessee’s first Black physicians. Moose was diagnosed with Down syndrome upon birth. While holding Moose, the diagnosing pediatrician, Dr. Hampster, recommended institutionalization, predicting Moose would neither walk, talk, or become a social being (1978, 6). Upon Hampster’s recommendation, Moose promptly defecated all over the good doctor’s lab coat and trousers. Moose’s father responded with an internal “right on” (10).

So begins Oden Jr.’s memoir, cowritten with a friend and collaborator, Scott MacDonald, about a Black, intellectually disabled child growing up in the 1960s and 1970s in Minnesota. While *Moose*’s narrative conclusion is paradigmatic for the genre—the memoir concludes with Moose’s stable employment and impending heterosexual marriage (these topics are explored in chapters 3 and 4 of *The Disabled Child*)—the journey there is anything but generic. Following Moose’s diagnosis, for example, his father notes briefly that Moose’s life experiences will be shaped by race *and* disability, writing, “we [Oden Jr. and Polly] both knew our son had enough trouble, being black [*sic*]. But this. Talk about being handicapped. This made being black seem easy” (9). This brief passage also comprises the entirety of the Odens’ expressed concern, misgivings, or hesitation regarding having an intellectually disabled child. While Oden Jr. writes that Moose’s birth was a shock (23), from birth Moose is fully integrated into his familial and social world, and not a single line in the story is shaped by the grief or tragedy typical for the genre. Indeed, Moose radically disrupts the parental memoir’s generic conventions, in that it is not a narrative of overcoming exclusion but memorializes Moose’s unapologetic membership in an interdependent community.

Moose was the Oden’s fourth child, and in the years after Moose’s birth, the Odens would produce another seven boys. Later, upon receiving an

inheritance following Oden Sr.'s death, Oden Jr. and Polly purchased a large house and farm, and with the space fostered an additional seven boys. Like all the children, Moose was responsible for farm and household chores, for his own personal hygiene, and for obeying household rules that ensured everyone's safety and wellbeing. All the children participated in sports, reading, and group outings. The Odens regularly opened their doors to neighborhood children and offered rides to Oden Jr.'s colleagues. They hosted parties and invited other children with disabilities into their home, for many of which the Odens' invite was the first of its kind. Moose attended school and summer camp and participated in the Oden boys' team of local lawnmowers and snow shovelers. In none of the scenarios described by Oden Jr. is Moose a source of inspiration or a morality lesson for the others. No family members become better people by mere proximity to Moose. The story Oden Jr.'s memoir tells is remarkable in that Moose's childhood is rather unremarkable; Moose himself is just another one of the Oden "pups" (92).

This blanket inclusion yields a dramatic result in the Odens' lives and for a possible shared social understanding of interdependence. One September, when Moose was in his early teens, he was instructed by neighborhood boys during a baseball game to beat up a child who was not playing fairly. The children, including the targeted child's brother, told Moose they were playing a game called "choke Jimmy" (104). Jimmy was, unfortunately, seriously injured during the incident. He recovered, but his parents pressured the school board to permanently expel Moose from public education on account of his "threat" to community children. Oden Jr. gives no indication of the racial makeup of his town, though does note that Jimmy and his family are white. Moose's parents, though shaken and without guaranteed sympathy from other parents at the school board meeting, argued that the boys who cajoled Moose shared responsibility for Jimmy's injuries with Moose. Oden Jr. writes, "[Moose] cooperated with the rest of the boys because he trusted their judgement. Moose, more than the rest of us in this room, *must* trust others" (105, emphasis in original). The other parents eventually agreed.

What is astonishing about this incident is that while Jimmy's parents initially argued that Moose was a danger to the community on account of his disability, all the other parents in attendance came to understand that the danger was the abled children's willingness to exploit Moose's trust in them. Oden Jr. implies that Moose has been taught to trust the judgement of others, and that doing so is fundamental to his survival in the world. Oden Jr. does not scapegoat Moose's disability or absolve him of responsibility;

however, he indicts the neighborhood boys, faulting them for failing to keep their end of a necessary social agreement established by Moose's disability. In agreeing to shared responsibility, the Odens' community effectively includes Moose into their fold on the *basis* of interdependence. Moose is a full community member as one who due to intellectual disability may not always make the best judgement calls. Moose's inclusion is contingent upon others providing him with access—in this case, good judgement. When those community members fail to do so, it is they who are not full participants in the social world, rather than Moose.



The overcoming narrative would leave the social world unchanged. The narrative does not seek to overturn the table at which seats are limited both in number and shape. The overcoming narrative is, fundamentally, about fitting in to the existing world; to inhabiting normativity, being recognized as one who belongs in and here. It is insufficient, however, to understand the overcoming narrative as a strictly disability story. Rather, the narrative of overcoming is engendered by the material and discursive privileges of whiteness, particularly white entitlement as manifest through settler colonial logics: the entitlement to the destination, the table itself, property, visibility, access, and safety. This is why for the Ott-Dahls, whose memoir was discussed at the beginning of the chapter, disability is constructed as easily surmountable if/when Delaney is racialized as white. This also explains why the overcoming narrative shows up in memoirs by and about families of color. Whiteness is not biological and overcoming does not manifest in white bodies, but rather, whiteness is a logic and a discourse that produces material realities.

The subgenre of disability life-writing I call “special needs” parental memoirs is comprised by a large and diverse body of texts. There are exceptions to any ruling characteristic I might apply. And each time I think I have found every last memoir another pops up in some academic bibliography or buried in a comment on Goodreads.com. Few, however, depart from the overcoming narrative described above; and only slowly do narratives about children of color appear on my lists. There are of course a number of memoirs I have not yet read and an overlapping number of memoirs (today this number is fourteen, to be precise) in which the parent and child's racial and or ethnic identity is unclear. This number, small as it is relative to the whole,

does not make any significant difference to the generalizations about the genre I have made in this chapter, specifically about the overcoming narrative and the ways in which it is engendered by the privileges of whiteness.

I have argued that overcoming often occurs when parents experience a perception shift. Writing in 1985, white author of two memoirs about raising her autistic daughter, Clara Claiborne Park argues that in the few memoirs published by that time parents typically present *themselves* as heroic, as persevering in the face of disappointment and community indifference (116). Several early memoirs in fact chronicle a parent's quest to institutionalize their children, the achievement of which serves as the narrative catalyst for happy ever after (e.g., *Label Me Jeff*, 1979; *Yesterday's Child*, 1976; and *Heart of This Family*, 2020, however about a child born in 1953). But this narrative disappears over the latter half of the twentieth century, replaced with, as I describe here, a different kind of narrative of progress in which impairment has little effect (or at least much less than initially imagined) on a child's life course and parents become better humans through caring for their children. Parental memoirs of the late twentieth and early twenty-first century reject the idea that disability burdens, and with that reject the possibility of social or state responsibility to care for disabled citizens. The rise in the number of published memoirs, as well as the genre's overall character, neatly emerges from the coincidence of deinstitutionalization in the 1960s and 1970s, and the ascendance of neoliberal rationality manifest as individual choice making to improve the outcome of one's (and one's child's) life. While earlier memoirs validated logics of incarceration and segregation for people with disabilities, later memoirs reproduce the meritocratic logics of entitlement through self-betterment. Neither fundamentally challenges the idea that there is a threshold for what counts as a meaningful life, or that not everyone belongs in it. And similarly, both are the settler's recitation—both insist that the narrator has a place in this world to claim.

If there is indeed a figuration of childhood disability that emerges from the parental memoir genre, and I argue throughout this book that there is, its consolidation depends as much on readerly recognition as it does on narrative construction. This means that readers, too, recognize the narrator's claim on belonging. The genre is, in this way, just one part of a massive constellation of narratives, figures, images, and myths that reproduce white, settler colonial logics through reiterative citation. The Disabled Child, then, figures among these texts as a symbol of what is at stake, as much as her narrative recuperation reproduces the very same precarity.

# 3

## *A Better Future*

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 2013, 195)

### *“EXTRAORDINARY” NARRATIVES AND NEOLIBERAL LOGIC*

In the introduction to *The Disabled Child*, I wrote about Kelle Hampton, a mother-memoirist whose daughter, Nella, has Down syndrome. In her memoir *Bloom* (2012), Hampton writes that she responded to Nella's diagnosis with grief and despair. Hampton's plan for her life was nothing less than perfection: a perfect husband, a perfect family, and a perfect little sister for her one-year-old daughter, Lainey. Nella's diagnosis threatened this vision, and when Lainey entered her mother's hospital room wearing her “big sister” shirt and a flower in her hair, Hampton blinked back tears (13), convinced she had failed to deliver on her promise to her family. As the story unfolds, Hampton reconstructs her vision. Instead of a loss, she begins to see parenting Nella as an opportunity. She comes to a place where she begins to see herself as “lucky,” as “privileged” (18) to have Nella, the child who would be a “constant reminder” (18) to Hampton about the *true* mean-

ing of life. Allegedly perfect exteriors would fall away and parenting her disabled daughter would give Kelle Hampton the opportunity to grow, to become more grateful and more real, to become a better person (163).

Many parent-authors of special needs memoirs describe their children as improving the parents' lives in profound ways. Parents explain that 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 do extraordinary things: they 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 memoir 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 2012, 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 2012; Saxton 2000, 148). They are narratives that ascribe value to disabled children in its perceived absence (see Parens and Asch 2000, 23). By claiming that their children bless them and elevate them, parents challenge the way atypical embodiment and neurodivergence are seen as worthless attributes, and how disabled people are understood to be under- or nonproductive members of society (see McRuer 2006, 8; Piepmeier 2013, 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 emerge 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” parental memoirs, the narratives depend on a common narrative arc (or perhaps “shape”) in

which the story's protagonist experiences a 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 them and their children, "tragedy" is not as frequently used to describe sleepless nights and colic. Parents of disabled children, however, often use this language. Tragedy, hardship, grief, pain, fear, anger, and confusion are among the more common sentiments and experiences represented in special needs parental memoirs following a disability diagnosis (Piepmeier 2012, n.p.). 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, the problematics of those narratives notwithstanding. This is striking given that narratives of "improvement" are fundamental to the way we understand childhood and how we describe childhood development. 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 does not actually restore disabled children to a typical childhood narrative of progress. On the contrary, the emphasis on the parents' betterment 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 made by disabled children, because it emphasizes the child's essential, inherent, disabled specialness that overdetermines 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 disabil-

ities. In many “special needs” parental 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 2011, 225). While this can read as an affirmation of acceptance, I want to suggest that this minimizes the humanity of disabled children. Not only does the sentiment limit the child’s complexity and personal identity, but it also positions them as “exceptions to human capability” (Thomson 2001, 341), permanently displaced from the realm of the ordinary and excluded by virtue of their essentialized specialness. Parents of able-bodied children may similarly 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 of their child’s person to a singular characteristic 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 reinforces 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. At the same time, these narratives gesture toward 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 commonsense notion that all relationships can be—and should be—understood in terms of value and exchange (Harvey 2007, 3); what we as individuals can “get” out of relationships with one another, value based on “mutual advantage” (Nussbaum 2006, 2). Parental love and care for disabled children is rationalized in memoirs 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 (2013) 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 non-economic spheres of life. Neoliberalism 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 reconceived 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, the slim potential of monetary profits too).

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. Rather, they reflect the cultural salience of 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.

Extraordinary narratives thus 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. 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 (2011, 1). Writing disability in terms of benefit, rather than cost, contains the threat and allows parents to remain optimistic that the promise of a good life is still theirs. Their optimism is cruel, 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. These parental narratives intend to be liberating, and indeed, affirming, yet they also replicate an 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 often reaffirms, rather than challenges, the very schematic that devalues disability because of its assumed foreclosure on the individual person's potential for productivity. 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 examines several memoirs to discuss how parents construct narratives of extraordinariness and challenge the assumption that raising a disabled child is a burden/is burdensome. These narratives are engendered by the material and discursive privileges of whiteness and settler colonial logics of entitlement, discussed at length in the previous chapter. And, like the narratives examined in the following chapter, 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. 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. By claiming inclusion via neoliberal narratives of value and exchange, parent memoirs elide the narrative exclusions that operate along the gender-ability axis (discussed in chapter 4).

The benefits of raising a disabled child take different forms in the memoirs under analysis in this chapter. Susan Zimmermann, white author of *Keeping Katherine* (2004), learns to love less conditionally. Paul Collins, a white father, is able to place his son—and himself through proximity—in the company of geniuses in his memoir *Not Even Wrong* (2005). Amy Julia Becker (2011) and Martha Beck (2011), both white, 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, for example *Melanie, Bird with a Broken Wing* (Harry 2010) or *Dana's Legacy* (Slate 2009). In *Jesse, A Mother's Story* (2010), Marianne Leone transforms into a "warrior mother" who battles grief, fear, and school districts, inspired and led by her "warrior boy," Jesse.

The shape of extraordinary narratives emphasizes a profound improvement in the parents' lives that results from their child's diagnosis. The children 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 it is assumed to be 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 gain 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 2004, 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 | National Institute of Neurological Disorders and Stroke" n.d.). The onset of Rett syndrome occurs after a year or two of typical infant development. It is caused by a gene mutation on the X chromosome and affects females almost exclusively.<sup>1</sup> 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 2004, 37).

In medical terms, Katherine's disability would be categorized as "profound" ("DSM-5" 2013). Her intellectual disabilities and mobility limita-

tions compromise Katherine's independence and her ability to care for herself almost totally. She is non-speaking. In Katherine's mother's terms, Kat "does nothing" but "simply is" (Zimmermann 2004, 140). Zimmermann was devastated by Katherine's disabilities. As Katherine began more and more to exhibit symptoms of Rett 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 (159). She describes Katherine throughout the memoir as a "hurt child," (and crueler, eugenicist-inspired terms, e.g., 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 (cultural markers of femininity), 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 2010, 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.<sup>2</sup> 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 (c.f. Robey, Beckley, and Kirschner 2006). As discussed in the introduction, there is no universal quality to childhood; rather, childhood is a socially constructed life stage (Ariès 1965). In the West, one of the prevailing notions about childhood is that children are “blank slates,” uncorrupted by adult desires and concerns. Because of the way intellectually disabled people are, to vary-

ing degrees, dependent on caregivers and aides, they are often described as childlike. In the instance that an intellectually disabled person is also non-speaking, like Katherine, not only might they be imagined as child-like, but in the absence of a means to express themselves, they are sometimes 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, might see in the non-speaking, disabled child, a truth about the human condition, and thereby a means by which to draw a comparison with their own humanity.

This is an active, albeit perhaps unconscious, denial of personhood and interiority. 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 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 (2004, 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, or at least yellow, or perhaps bears. Yet Zimmermann’s narrative 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, *anything*. 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. In the wake of Zimmermann's project of self-betterment lay Kat, communicating the desires of her heart, unanswered.

### *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" (2013). Auerbach writes that while autism is challenging for her family to manage, in her son Gabriel's case it has its upsides, too. 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 a hyperactive auditory input process (190–91). 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 enjoys the awe Gabriel's musical ability inspires in those around him, especially in his guitar teacher (194–95). 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. In doing so, she reminds readers of the culturally accepted low expectations held for children with disabilities: readers are supposed to be impressed.

Paul Collins uses a similar narrative to structure his memoir, *Not Even Wrong: A Father's Journey into the Lost History of Autism* (2005). The title comes from Wolfgang Pauli, a theoretical physicist who used this phrase to describe colleagues that disagreed with him (Collins 2005, 86). In Collins's read, Pauli argued that his colleagues were "not even wrong" because they were so completely off-base to start with; in other words, "only a per-

son working from the same shared set of expectations” could be wrong, or in disagreement with Pauli.<sup>3</sup> Collins writes that we should remember this moment when trying to understand autism. He explains that autistic people use different parameters than those of non-autistic people to solve problems and understand their environments. 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’s book maps this autistic world. It is a genealogy 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 archetypal Autistic Person, a figure that embodies the distinction of the autistic mind and “otherworldliness” (86) of autism, and whose mere existence benefits the lives of those in proximity. Collins uses this figure to validate his retrospective 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’s son, Morgan. As a result of his research and reflection, Collins explains that he 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. 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.<sup>4</sup> 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* (1976).<sup>5</sup> 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 1976, 105, 109) to support the discussion, and briefly engages with Bruno Bettelheim's<sup>6</sup> 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 1976, 114). Collins claims that for Stark, Peter the Wild Boy presented "an early case of autism" (Collins 2005, 57). Upon examining Stark's text, however, I find 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 1976, 114, 116). In addition, Stark does not actually 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 (109).

Though the connection is quite 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 2005, 64) and landed in Hans Asperger's Vienna clinic in the 1930s, boys Asperger described as "talented eccentrics living among us, albeit in a sphere of their own" (87–88). 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). He learns that in Bruno Bettelheim's clinic in Chicago,<sup>7</sup> autistic behaviors led Bettelheim to conclude that autists live within "a protective shell" (71). In Cambridge and the office of leading contemporary autism researcher 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 (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 (7). Collins connects the theme to two of recent history's most notable mathematicians, Sir Isaac Newton and Alan Turing (92, 214; 106–9), 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 animal science (179–80).<sup>8</sup> George Fields and Septimus Piesse were famous nineteenth century synesthetes who published works on the colors of sounds and the sound of odors, respectfully (123–28). 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 2005, 40); “Asperger’s charges were capable of feats of incredible brilliance” (67); James Pullen was called the “Genius of Earlswood Asylum” (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 2005, 180); and Turing, of course, saved the world from the Nazis during World War II (106). Morgan, the “happiest child” Collins has ever seen (175), the precocious reader (7) who associates shapes with colors (119), and has a tendency to avoid conversation (148), figures in Collins’s narrative as next in the long line of eccentric geniuses.

The problem with Collins’s narrative, however, is that excluding Temple Grandin, the children in Asperger’s and Baron-Cohen’s clinics, and Morgan himself, the men comprising Collins’s autistic lineage were not diagnosed with autism. They could not have been, since a diagnostic profile for autism was not established before the 1940s in Asperger’s and Leo Kanner’s clinics.<sup>9</sup> 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 2011, n.p.). Collins’s memoir was pub-

lished in 2005, before Peter was re-retrospectively diagnosed. Still, Peter the Wild Boy could not have been autistic. Neither could Issac 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 2003, 28–30; MacGregor and Darger 2002, 660–61) amidst shifting diagnostic criteria.

As many neurodivergent scholars and activists have noted, there is a great deal of joy and delight to be found in retrospective diagnoses of autism, in reading against the grain for neurodivergent subtext. Retrospective diagnoses of “famous and talented dead people” can be a source of encouragement to and pride for living people with autism/Autists (Russell 2021, 95). Writing about retrodiagnosed literary figures, Sonya Freeman Loftis (2015) suggests that retrospective diagnosis is enabled by shared experiences of social alienation, communication obstacles, and neurotypical expectations rather than name; in this way, a retrodiagnoses of autism are based on a similar social experience in diverse cultural settings, while the diagnostic category stays unstable (152). Writing about self-diagnosis, Alison Kafer argues for the necessity of including within disability communities those who do not have “official” diagnoses as both a way to destabilize disability and extend possibilities for disability affinities (2013, 13). In Collins's text, however, retrodiagnostics privilege a clinical understanding of diagnostic category, ascribing a sort of truth to the medical criteria that has ironically worked historically to mis-, over-, and underdiagnose historically and at present. In other words, Collins's retrospective diagnoses rely on a static, definitional autism, even as the defining characteristics of autism have shifted over time. With these shifts, prevalence too, has been adjusted. Yergeau writes of autism as definitionally dynamic, “a mode of becoming” (2018, 43). Writing on retrofictional diagnoses, Julia Miele Rodas cautions that doing so forecloses the possibility of that movement, by binding autism in “culturally finite terms” (2018, 119). Cornelia Dayton (2015) cautions against posthumous autism diagnoses, explaining that despite any constellation of symptoms resembling autism that emerges in the historical record, retrodiagnoses problematically position the historian who makes them as an “objective” researcher. At the same time, 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 (Dayton 2015).

In *Not Even Wrong*, Collins's reliance on a retrospectively diagnosed lineage supports his narrative end goal, one that does not necessarily serve to advance justice and inclusion for the neurodivergent. He assumes that unusual habits of concentration and attention to detail necessarily indicate autism. His broad-brush strokes paint many a quirky somebody who was exceptionally good at something as autistic; in doing so, anyone whose behavior might be described as idiosyncratic or strange can also 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 different colors. Collins assumes the man is autistic, and also that he is brilliant, the "Isaac Newton of light bulbs" (2005, 211–14). Both may be true, neither is certain, but the assumption is pivotal to Collins's project. If unusual social behavior *always* indicates autism, and autistic otherworldliness always conceals brilliant insight, then Morgan Collins is a very special boy, and the possibility that something is wrong with Morgan is *not even wrong*.

Collins's story is ultimately about 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), invoking the popular stereotype of the "supercrip," the high-achieving disabled person (Schalk 2016). Collins's narrative, however, fails to honestly portray autism, not only because the figures he describes may not actually have autism, but also because he focuses almost entirely on men without high support needs. As such, *Not Even Wrong* contributes to a persevering cultural obsession with the autistic-savant like Dustin Hoffman's character, Charlie, in *Rain Man* (1988), 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" (2005, 214). To a degree, Collins's suggestion represents a shift away 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 dis-

courses irrelevant in light of autism's beneficial yields. At the same time, Collins's emphasis on the "otherworldliness" (86, 91) of autism is exoticizing and dehumanizing. Moreover, unlocking "autistic potential" seems to reinforce the idea that autism is only acceptable when it has value under capitalism. 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 speaking, highly-independent autism without actually challenging exclusion or trying to make the world less hostile to autistic ways of being. Instead, autism becomes the key characteristic of some sort of club for extraordinary children, and 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 2007, 6). No studies, however, have demonstrated sex-specific genetic influence on the heritability of autism (Frietag 2007, 5). Yet, boys are diagnosed with autism at four times the rate that of girls (Rivet and Matson 2011, 958). In the 1940s, both Asperger and his U.S. contemporary Leo Kanner noted the gender disparity among their patients (958). 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" (Baron-Cohen 2003, 149). But other studies suggest sexually dimorphic autistic phenotypes (Van Wijngaarden-Cremers et al. 2014; Hiller, Young, and Weber 2016, 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 (CDC 2020),<sup>10</sup> and increased public awareness about autism and ASD. Autism Speaks, the largest autism advocacy organization in the United States, was established the same year Collins's 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 (Wake-

field et al. 1998) and had engendered a huge response from the media that reverberated for years.<sup>11</sup> *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.<sup>12</sup> 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 Speaks 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" ("6 Facts You Need to Know About Autism" n.d.). Temple Grandin is an exception to the male-dominated public of autism. It is worth noting, however, that regardless of her gender self-conception, Grandin presents as gender non-conforming.<sup>13</sup> The fact that there are only "boys" in Morgan's autism class comes as no surprise for readers, and the link to masculinity, the thread connecting autism to being male that has woven throughout Collins's story becomes, at this moment in the text, vibrantly clear. And as it does, Morgan's inheritance is secured. He is autistic, he is a boy, and his autistic forefathers were geniuses.

Collins's 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 phallogocentric family tree, within which Morgan can be found and will blossom. Collins's 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" (2005, 229). Morgan's tribe of geniuses, it seems, is Collins's too, by proximity. It is not insignificant that 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" (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). And 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, liter-

ally 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, antisocial, and unable to love—is a challenging prospect for a parent to face. Collins’s 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’s autism as nothing “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, anti-autistic exclusions.

#### *PENNY AND ADAM: FROM TRAGEDY TO INSPIRATION*

Penny is a child with Down syndrome and the subject of her mother’s memoir *A Good and Perfect Gift* (2011). 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 to see," *all* people are equally, albeit differently, broken, separated from God by sin (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 the formerly incarcerated). 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 (Lee 1968, 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 (2011, 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 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,” nondisabled 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 the New Testament: Matthew 5:48, “Be perfect, therefore, as your heavenly Father is perfect,” where elsewhere “telos” is translated as “complete” (e.g., Matt. 19:21<sup>14</sup>), and “the end” (e.g., Matt. 24:13<sup>15</sup>). 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).<sup>16</sup>

In this memoir, Penny’s specialness is inextricably bound to disability. Her specialness, however, has 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. Penny-with-Down-syndrome makes Becker a better person. 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). And 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. And 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 (2011). Like Amy Julia Becker, Martha Beck is an Ivy League-educated (Harvard), self-described perfectionist (8–9). Both women are white. Beck's 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; 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). And 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 repeating, her view that intellectual disability and any “birth defect” is a tragedy (137). She writes, cruelly, that she had always been repulsed by people with intellectual disabilities (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).

Adam’s conception ushers a host of hard-to-explain, miraculous events into his parents’ lives. Like Penny Becker, Adam is living proof of an unseen spiritual force, somewhere between an angel, deity, and clairvoyant, and is connected to “another realm” (e.g., 343) or “the other side of the veil” (3–4). 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); the puppeteers 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 by a placental abruption and decides, against her doctor’s instructions, not to go to the emergency room (163–69). 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, 109–10). 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

overlooked, 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)

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 her pre-Adam self 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. Beck narrates this radical shift as outside the realm of control. She describes Adam’s conception as the puppeteers’ plan, 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; again and again, the puppeteers, who guide and surround Adam, intervene and make her life better. She writes, “Adam sees beyond the outward ordinariness ‘to the magic . . . inside’” (197–98), 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 assumption of tragedy that accompanies the birth of a disabled child is why Rachel Adams writes that a baby with Down syndrome “demands a story” (2013, 108). 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 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 2013). 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. As Alison Piepmeier (2012) has argued, grief is overrepresented among parent memoirs, even when unhappiness is not the dominant emotion in the families’ experiences. These parents reflect the belief that they and their children have let the community, 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 is the disabled person who overcomes “their limitations,” by exceeding the expectations set for them, which are often very low. 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 (Oxygen 2016). (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 (Thomson 2001, 340) rather than of pity. And, unlike the “tragedy of disability,” inspirational disabled people embody the (eugenicist) promise of progress through the reiterative act of overcoming their limitations.

Tragedy and inspiration narratives both reinforce the medical model of disability, which locates disability in the person’s body, rather than in “the experience of social oppression” (Scully 2011, 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. 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. And while “overcoming” refers to achieving some degree of normalcy, 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 (Shuman 2011, 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 the 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 2011, 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. At the same time, extraordinary narratives can still be read as attempts to recuperate access to narratives of normalcy. 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 overdetermine 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 2011, 10; Harvey 2007, 3), all of which is engendered by the privileges of whiteness (discussed in chapter 2). As argued in the introduction, market logics overdetermine not only how we, in the United States, 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* (2014), 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” (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 draws on Amartya Sen's capabilities approach to assessing Nicholas's wellbeing within the existing neoliberal political economy. Sen's capabilities model for understanding poverty and assessing its impacts was developed in the 1980s and since used in a variety of means to measure growth and development. It 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 2004, 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 2006, 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" (quoted in Thomson 2014, 37).<sup>17</sup>

While typically used to assess wellbeing 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's disability 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 (Thomson 2014, 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 wellbeing. 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 2004, 735). Economist Sophie Mitra writes that the capabilities approach may even be useful for defining disability (2006, 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) (241). In Nicholas’s 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 (Thomson, 2014, 93). However, Nicholas’s 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 one 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 effective way to secure Nicholas’ wellbeing and

his practical opportunities to living a life of value is by shielding him within PLAN, a private organization to advocate for Nicholas and act on his behalf if and when necessary, funded by family and charitable contributions. Nicholas's 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 and *incapacitate* those who cannot be recuperated via narratives of production and potential reproduction.

# 4

## *Gender Normal Future*

Ezra Fields-Meyer was born in the mid-1990s in Los Angeles. When he was three years old, he was diagnosed with autism. He is the middle child of three brothers (Fields-Meyer 2011, 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* (2011). 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 (e.g., 142; cf. Collins 2005, 161); but unlike other parents, Fields-Meyer does not attempt to make his son more like his neurotypical peers, to unlock an "inner," ostensibly "more normal" Ezra (2011, 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 is 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 Tank Engine, 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.<sup>1</sup> 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 and overwhelmed by the noise and number of children and adults there to engage him (2011, 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 he thought was still in many ways like a "toddler" (212). Yet, Ezra surprises his father, successfully performing the rite of passage and, in a grand gesture, claiming his place in the adult community. Ezra's autism becomes neutralized through Ezra's performance of his Jewish identity—an identity that, importantly, is made intelligible through intertwined gender and developmental achievement.

In 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" (Daugherty 2015, 52, 265, 354). Daugherty, a white father, writes in his memoir of raising Jillian, *An Uncomplicated Life; A Father's Memoir of His Exceptional Daughter* (2015), that he and his wife, Kerry (also white), expected Jillian to "overcome" (239) Down syndrome and achieve an ordinary life, to belong, to have "a seat at the table" (245). Throughout the memoir Daugherty constructs a picture of ordinariness that is, above all else, cisgender and heterosexual. On the day Jillian was born, for example, Daugherty mused about her future kisses under a porch light with a young man (182), and of walking her down a church aisle one day (11). Daugherty believed that without these things Jillian's life would be a "half existence," hardly a life at all (188). To Daugherty's 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 (225–26), and later the two moved out of their parents' homes and into an apartment together

(326). Nothing, Daugherty 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 (326–32), and finally, their engagement and wedding (367, 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.

In the preceding chapter, I demonstrated how parents construct narratives of their children's extraordinariness as a way to challenge negative stereotypes about disability, particularly the idea that impairment is a social, financial, emotional, and public health burden. I argued that narratives of extraordinariness, in which parents' lives are fundamentally enriched through caring for their children, ascribe value to disabled children in its perceived absence. This is a version of the overcoming narrative, or the narrative wherein the person with a disability accomplishes that which is assumed to be impossible because of impairment. Here, I examine narratives in which parents describe their children and their lives as completely ordinary. Contrary to what parent-memoirists had expected, impairment does not prevent their children from living an ordinary life. I show that among these memoirs, "ordinary life" means, quite unambiguously, cisgender heterosexuality. Gender is a powerful organizing category and among the most meaningful devices of social recognition. Parent memoirists frequently articulate disability's threat as a perceived denial of their child's opportunities for future heterosexuality and gender enactment, and by extension, full social inclusion. As a result, the overcoming narrative in these memoirs is completed when the disabled child becomes a cisgender, heterosexual adult (real, or imagined in the narrative).

## GENDER AND CHILDHOOD DEVELOPMENT

Cultural common sense dictates that boys and girls and men and women are gender-differentiated creatures and that cisgender is ordinary; an unmarked

gender category. The debates rage over the cause of gender differences, but that gender denotes difference, and that boys and girls are “naturally” different from one another, is a stable and persistent concept both popularly and scientifically. In many medical developmental models, childhood is not overtly gender-marked: “children” are distinguished from each other by age (babies, “birth-to-five,” teenagers) 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). The American Academy of Pediatrics developmental milestones checklist (“American Academy of Pediatrics: Ages & Stages” 2017), for example, is not gender differentiated: expectations are the same for boys and for girls until puberty. Developmentally speaking, according to popular child psychologists anyway, childhood development is disentangled from toy cars and dollhouses and biological sex is irrelevant to learning to walk, talk, run, or engage in social life (Spock and Needleman 2011, 731; Hathaway, Eisenberg, and Murkoff 2003, 494).

In practice and in discourse, however, gender informs the interpretation of ability as well as what counts as normal childhood development and behavior. As Spencer Cahill showed decades ago, children themselves may acquire their gender identities in relationship to child development: she was a “baby,” but now she’s a “big girl” (1986, 302). The following examples from two popular parenting websites illustrate this further: “Boys’ gross motor skills (running, jumping, balancing) develop slightly faster, while girls’ fine motor skills (holding a pencil, writing) improve first” (“Child Development 101: The Differences Between Boys and Girls” n.d.). 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 n.d.). In these examples, developmental achievement (gross motor skills, language acquisition) is gender aligned. Developmental delay is suspected when a child fails to meet developmental milestones within the spectrum of what is typical for their sex. For example, studies have shown that girls are underdiagnosed 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 2016; Rivet and Matson 2011). Though ASD is characterized by a diversity of symptoms, atypical social behaviors and communication practices are among the primary diagnostics for ASD (“DSM-5” 2013; Sipes et al. 2011). This implies 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. Autistic girls complicate the existing diagnostic criteria for autism (and expose clinician bias towards “male” autism). Gender is implicated in assessing neurotypicality, ablebodiedness, and ablemindedness.

While boys are expected to run and jump and girls to talk and imitate, at some point both groups “catch up” with the other to comprise the category “most children” against which children with disabilities are measured. Here, too, gender influences developmental achievement. For example, at each developmental moment (e.g., two months, six months) in the Centers for Disease Control’s Milestones Checklist (2005) a set of abilities are listed under the title “What Most Babies Do at this Age”; these include, for example, “Turns head towards loud sounds.” On the opposing side of the page is an inverse list, i.e., “Doesn’t turn head towards sounds.” Beginning at one year old and at each milestone moment after caregivers are advised to seek medical attention if their child “loses skills *he* once had” (emphasis added). Skill “regression” is (mis)understood to be a common marker of autism. The repeated pronoun “*he*” associated with skill regression reinforces the false idea that autism only affects boys, producing a pathological, developmentally askew boyhood.

For disabled children the influence of biological sex or gender on development seems to be negligible; children with Down syndrome, for example, are expected to develop “slower” than their peers, regardless of gender or sex. Kafer (2013) argues that the categories “boys” and “girls” are based on ablebodiedness and ablemindedness (57). Disabled children are made strange (perhaps queer) by a gender normative rubric of development from in-progress to mastery. Kafer suggests that this exclusion has the effect of rendering disabled children “genderless,” even neutered, in medical and public perceptions (57). Here, I define gender as relationally positioned and culturally specific notions of masculinity and femininity that preserve the assumption of dimorphic sex. Feminists differentiate sex from gender by arguing that gender is a cultural discourse, a means by which to distinguish between bodies and behaviors, and a way to at once conceptualize and deconstruct relationships of power. In doing so, feminists disrupted the biology-as-destiny paradigm, or the idea that sex category determines gender (and social role). Gender is real, but enacted and embodied, rather than bodily. The Combahee River Collective (1977) and other Black and Women of Color feminists advanced understandings of gender to account for the

ways in which normative masculinity and femininity are also racialized, classed, and heterosexual (Spillers 1987; Lorde 2007).

Despite feminist efforts to reframe gender as a social discourse however, arguments for biological gender endure in medical, psychological, scientific, and much popular literature, like the parenting guides described above. Elsewhere, Simon Baron-Cohen, a clinical psychologist and one of the world's leading autism researchers, argues that men and women are fundamentally different at the biological level (2003, 10). Boys and men have what Baron-Cohen calls a "systemizing brain," which causes them to be interested in how things work (4). Girls and women have an "empathizing brain," which causes them to be interested in people and relationships (2). According to Baron-Cohen, the differences between male and female brains are due primarily to the influence of prenatal testosterone, which is argued to increase the right hemisphere's rate of growth, and thus increase a person's spatializing abilities (a feature of systematizing) relative to language abilities (103–4). But, as feminist neuroscientist Lise Eliot demonstrates in *Pink Brain, Blue Brain* (2010), 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 by Baron-Cohen are due largely to social influences that shape young people's developing brains. Eliot shows 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. In other words, while gender is a social experience, gender *becomes* biology through learning and doing, behaviors that shape the structure of the brain itself (6). Eliot's work forges a sort of middle ground in the "nature-versus-nurture" debate, or 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, stating, "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). In other words, for Eliot, our "brains" are hardwired according to gendering; and at the same time, there is no gendered brain apart from the gender that makes those circuit connections meaningful.

I revisit the nature-versus-nurture debate here because I want to suggest that the conversation itself relies on an assumption of normative ability. To



argue that gender is the effect of reiterative and citational practices necessarily implies a body that does things in predictable and typical ways: for enactments to be registered as gendered, they must be recognizable. To argue that gender is linked to biology relies on the same assumptions of embodied behaviors, all of which are culturally, historically, and regionally specific. 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 the next 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. And if gender is the effect of biologically determined dispositions and interests, one must still be able to do gender. In short, there is no gender without ability; or as Tobin Siebers has argued, “in the absence of ability, gender identity has no future and risks to disappear entirely” (2008, 175). 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 Butler’s words, “developmental failures” (1999, 24). Butler’s choice of words here is significant. As my read of the CDC milestones checklist shows, gender informs the diagnosis of “pathological” childhood development. Besides the boy who does not roughhouse with others, or the girl who lines up her dolls instead of pretending to feed them, gender incongruence in childhood (also known as gender dysphoria or GD) is a medical diagnosis found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Trans children are quite literally produced in medical knowledge through pathologizing gendered behaviors.

I also 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” (Butler 1993, xx), but bodies that push the limits of hegemonic discourse, that resist the constraints of intelligibility through the enfleshment of incoherence. Karen Nakamara once called this embodied noncompliance.<sup>2</sup> Butler’s discursive body is the one that is materialized predictably and stabilized through the reiterative enactment of gender norms. Because, according to the terms of hegemonic discourse that construct masculinity and femininity as ablebodied statuses, disabled bodies cannot achieve “normal” gender. I want to go beyond this body of discourse and the discursive body itself

to make the argument that materialization-as-citatoriality relies on the assumption of a typical, nondisabled body. The sexed body, discursively constructed, is able-normative because it is made intelligible by normative gender. The gendered body is a body that does not need to give an account for itself, but rather is accounted for through able-bodied gender recognition. This body is not the spastic body, the seizing body, the stammering body, the body missing limbs or digits, or the body that operates with diminished sensory perception.

In sum, I join others in arguing that the expression of gender differences depends on able-bodiedness and a predictability of form, shape, and function, as body shape, bodily movements, gesticulation, speaking styles, and even cognitive abilities are all gender-marked. The presence of disability may disrupt the discursive and/or material structures by which gender is made intelligible—through atypical body shape, movements, or speech, for example. Taking these ideas together, I argue that disability is imagined as an obstacle to living an ordinary life not because of impairment itself, but because of the ways in which impairment brings into relief the unnaturalness of gender, thereby risking its intelligibility. Analyzing how gender works to achieve the narrative end in parental memoirs exposes the ways in which gender is based on what I call hetero-able-bodiedness, or how binary gender is always-already premised on nondisabled enactment.

This ordinariness claimed in parental memoirs, then, is a gender-differentiated childhood, a boy or girlhood, produced in and through that which in the United States is unremarkable. This also includes whiteness and middle-class status. These social markers—gender, ability, race, and others—are discursively co-constituted, meaning the dominant cultural figuration of femininity, for example, is an idealized white and nondisabled femininity (Spillers 1987; Schalk 2018, 42–43). In general, the children of parental memoirs who overcome their disability through gender normative heterosexuality are white and middle class. This is not because only white parents narrate overcoming through the achievement of gender normativity; indeed, norms of masculinity play a significant role in *Not My Boy* (Peete 2010), *The Warner Boys* (Warner 2018), and *The Beauty of Love* (Posada 2010), all memoirs about raising disabled boys of color (notably all sons of professional athletes). Rather, most of the “ordinary” children are white because the parental memoir genre overall is mostly about white children. As discussed at length in chapter 2, the genre is characterized by a narrative of overcoming, itself engendered by white, settler colonial logics of entitle-

ment. Overcoming is based on a sense that an obstacle has unjustly been placed in one's way. The narrative resolution is social inclusion—a seat at the table—based on *unquestioned* assumptions about belonging that only white Americans enjoy. Gender is one of several narrative mechanisms used by parents to restore their child (and themselves) to the dominant social order (others are discussed throughout this book). The ways in which gender expectations are reiterated through whiteness and middle-class norms enhances the possibilities for white families to narrate their children's social recuperation. There is a similar gendering of the genre: two-thirds of the memoirs are about raising a boy or boy twins and nearly fifty include “boy” or “son” in the title, while only thirteen include “girl” or “daughter” (out of approximately one-hundred memoirs). The difference suggests that disabled boys may more convincingly personify an overcoming narrative, or that stories of boys' overcoming obstacles are more marketable, or both. (Contrast this with authors' genders, discussed below.)

Invoking gender norms to convey a sense of ordinariness is not unique to Daugherty or Fields-Meyer or even a small number of memoirs. Rather, the language of gender normativity, gender-charged descriptions, and importantly, the absence of gender ambiguity or queerness, is ubiquitous in “special needs” memoirs. White mother 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” (2010, 39), and as a teenager “still cute” with her ivory skin and the dark curls that hung over her eyes (64). White mother Amy Julia Becker describes her daughter Penny's delicate fingers (2011, 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). White mother 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?” (2004, 228). Melanie, a Black girl who has cerebral palsy, is a beautiful little bird (Harry 2010); white mother Kelle Hampton's memoir (2012) 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 white mother Marianne's “warrior boy” (Leone 2010). Jeremy, a white boy who has pervasive developmental disorder (PDD), obsesses over trains and

cars (Kephart 1998). His first friendship with another boy evolves after they find they both are interested in swords and playing with toy 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 boy and girl children.<sup>3</sup> Few parents raise their children with gender identity as an open question. Rather, it is a taken for granted assumption by most parents that gender, sexuality, and sex status will reproduce cultural ideas about 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 based on perceived gender failure. Gender normativity becomes the scaffolding for ordinariness and an anchor for the child's future; in other words, the narrative catalyst for overcoming.

Paul Daugherty grieved upon Jillian's Down syndrome diagnosis 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" (2015, 188). Bracketing for a moment the assumption that all nondisabled children are guaranteed homecoming dances, Jillian was able to do these things, and much more: 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 twenty-two-year-old woman, literalizing in one fell swoop the infantilization of femininity and of intellectual disability. 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.

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 U.S. expectations for mothering that emerge in mother-authored memoirs. And while I am interested in the ways parents explicitly engage gender norms to claim a normal childhood experience for their disabled child, 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 scripted into predetermined brother or sister roles; 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 cisgender, 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 2010, 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 2017) and, as Simi Linton argues, reinforce a sense of relative value to both descriptors (1998, 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 neurodivergent. In memoirs and educational, medical, and cultural discourse, disability and typical are mutually exclusive categories; for example, white mother Whitney Ellenby writes of her son, "Despite

his autism, there are still many ways in which Zack is typical” (2018, 227); and white girl 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 2008, 174). “Typical” packs less of an 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 “American Academy of Pediatrics: Ages & Stages” 2017). 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, medically speaking, typical and atypical development refer precisely to children that reach or do not reach developmental milestones within the normal window (see chapter 1).

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 something other than simply “children.” Parents of children with disabilities recognize the impossibility of normalcy, even when they recognize that normalcy is a moving target (Cohen 2011; Schank 2015). And so, with no chance of being “normal,” parents hope their children will be “as ordinary as possible” (Adams 2013, 85), or that their lives will resemble those of their “normal” peers. Carolyn Walker, for example, whose white 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 (2017, 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, causing 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” (Thomson 2011, 598); in other words, that they are ordinary. Kathleen Stewart describes “the ordinary” as the present moment (2007, 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 and habits (see also Das). Stewart goes on to write that the ordinary connects to *something* (12), it is tethered to a shared organizing idea; it pulls (29) and, thus, suggests that *ordinariness* is in a discourse circulation (40), a concept that is reiterative and citational, much like gender. 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 2005, 193). Anne Waldschmidt contrasts normativity with normality. Normality, she explains, is “less static, and less oriented towards stability; [it is] based on change and dynamics,” since norms themselves are data points 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. Normativity, however, 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 (statistically average) and ordinary (unremarkable) can be further illustrated by the pursuit of normality that defines some memoirists’ experiences of raising a disabled child. Stephen Gallup’s memoir (2011), for example, is a nearly-four-hundred-page account of Gallup and his wife, Judy’s (both white), attempt to “fix” his son Joseph, to cure him of the symptoms of his brain injury, NOS.<sup>4</sup> 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 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 medicine; behavior modification therapy (67); spiritual healing by a famous evangelist (338); sen-



sory integration therapy; herbal foods; acupuncture; adaptive alternative communication (339); a little-known “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” (329), meaning, “normal.”

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. (Susan Zimmermann [2004] also used patterning in an attempt to cure her daughter Katherine; this is discussed in the previous chapter.) 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. 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 on Children With Disabilities 1999, 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 normality. Gallup “could not accept this” (2011, 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). And, 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).

Nowhere in Gallup's memoir does "ordinary" figure as a possibility for their lives; indeed, their quest to normalize Joseph, the Gallups' go to extraordinary lengths, costs, and distances. The pursuit of normality, at the expense of something less remarkable, distinguishes Gallup's memoir from others under consideration in this chapter. Even for Gallup, however, normality is embodied by the figure of the "well boy," Joseph's birthright. When Gallup asks in his memoir's title *What About the Boy?*, he asks both "What shall be done to cure this boy?" and "What about the boy this 'injured child' was destined to become?" What about *that* boy? Joseph does not "recover" from his impairments. Towards the end of the memoir, when Joseph is ten years old, Gallup stops trying to cure him but holds out hope for a "scientific breakthrough" that would (373). He writes in the closing pages: "I will *never* give up on him" (373) beckoning the titular boy, the one after whom Gallup asks, "What about him?" In this way Joseph achieves neither normalcy through cure *nor* boyhood due to how these statuses are mutually constituted in his father's memoir.

### "SISTERS. SO MUCH ALIKE."

Gillian Marchenko's memoir *Sun Shine Down* (2013) 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 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 (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 (119–22).

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 surprised her (91). One night, while drunk, Marchenko stumbled into her girls’ shared room in search of Polly (82). The girls’ shared 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, less like the different child Marchenko imagined Polly would be,

Marchenko is increasingly able to see Polly as like 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* (2013), 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’s 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 (2011, 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 [boy] does,” Ami says (2011, 220). 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 (e.g., Gallup 2011; Kephart 1998; Rummel-Hudson 2008) and sometimes have more children (e.g., Cohen 2011; Zimmermann 2004; Becker 2011), 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,” meaning, what Ezra does not do (2011, 200). Ezra is, at this stage, still more “autistic” than ordinary young man, again demonstrating the way typical development and typical gender are made intelligible in and through each other.

Gender is a process of social interaction and relationship that stratifies society. It is constructed and maintained through expectations, meaning gender is a product both of learned concepts and conformity to or rebellion against them. Gender expectations are built into social structures (like family), and are reinforced through interactions with parents, peers, siblings, teachers, and persons of authority. Parents, for example, are among the most influential when it comes to instructing young children in gender norms and behaviors (Witt 1997, 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 1986, 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 2008, 5) and membership in the dominant group is what makes binary gender narratives a resource for parents of disabled children. And when typical (read: gender normative and nondisabled) 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

The constructedness 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. White father Ron Fournier’s memoir, *Love That Boy* (2016), for example, is a chapter-by-chapter exploration of how Fournier’s son Tyler’s autism led 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. And 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 1998, 37–39); or connecting with Early Intervention Services in the weeks immediately following the child’s birth (Adams 2013, 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 2015, n.p.). White mother 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.p.).

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” (2011, 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. Many parents call attention to their parental position: e.g., “A Father’s Journey” (Brown 2011; Collins 2005; Rummel-Hudson 2008); “A Father’s Memoir” (Daugherty 2015); “What One Father Learned . . .” (Fields-Meyer 2011). 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 2015, 11) and chasing off potential heterosexual suitors (Rummel-Hudson 2008, 254); and they also reflect on their own fathers and how they feel they measure up to a “dad” ideal (e.g., Fournier 2016, 101). And they write about how disability makes them feel unlike a “regular father” (Brown 2009, 7).

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” (2013, 54) after bearing a child with Down syndrome; and white mother Kerry Cohen’s entire memoir (2011) explores what it means to be a “good mother.” Marianne Leone (2010) 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). And, though Beth Kephart questions her ability to mother her son Jeremy appropriately (e.g., 1998, 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. 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 (for example in Brown 1976; Hampton 2012; Marchenko 2013; Soper 2010; and Zimmermann 2004), or because the child’s care needs consume the mother’s time and energy (for example in Barnett 2013; Kephart 1998; and Zimmermann 2004), and sometimes even become the impetus for a disability-related career change. Trinidadian mother Beth Harry (2010), for example, became a special education specialist after her daughter Melanie was born with cerebral palsy; white mother Donna Thomson, whose son Nicholas also has cerebral palsy, founded a nonprofit organization to support disabled adult children (2014); white mother Jane Bernstein became a spokesperson and advocate for people with disabilities after her daughter Rachel was diagnosed with optic nerve hypoplasia (2007); and Dana’s white mother Gayle Slate became a psychologist specializing in disability in families after Dana passed away due to complications resulting from a traumatic birth (2009). Two father memoirs are quite literally about their child’s disability becoming a life project, including white father Paul Collins’ “lost history of autism” (2005) and white father Ian Brown’s memoir, which chronicles his worldwide search for models of disabled and nondisabled interdependence and community living (2009). And while Steven Gallup’s memoir 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 2011, 346–54).

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 explored in depth by G. Thomas Couser in *Signifying Bodies*. “Nobody memoirs” are those that are written by people who have no “preexisting audiences,” unlike, for example, politicians and celebrities, who author “somebody memoirs” (Couser 2009, 1). Autobiography has historically privileged a “master narrative of the sovereign self” (Smith and Watson 2010, 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 2010, 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 2010, 4). Mother memoirs about children with disabilities capture these multiple shifts; they are written by women and almost centrally concerned with caretaking and childrearing; 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 United States, 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. And 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 (1998) argues that that in the contemporary United States, 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” (Elliott, Powell, and Brenton 2015, 351), and is characterized as child-centric, time consuming, and emotionally involving, albeit satisfying for the self-sacrificing mother (Arendell 2000, 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” (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 (2013, 15). Others argue that the contours of motherhood shifted with cultural understandings of childhood, coincident with industrialization (Ehrenreich and English 2005, 208; Hays 1998, 32–33; see also Welter 1966). During industrialization, gendered labor divisions became more fixed for white, 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. White 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 2005, 173; Bassin, Honey, and Kaplan 1996, 5).

Elliot, Powell, and Brenton (2015) 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). Elliot, Powell, and Brenton neatly situate the ideology of intensive mothering within the rise of a compulsory neoliberal social and political order in the United States. As Wendy Brown argues, neoliberalism is better understood as form of governmentality, or a mode of governance that produces subjects and organizes the social realm (2015, 47). In his work on governmentality, Foucault explored how 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, wellbeing, and future outcomes. Elliot, Powell, and Brenton show how neoliberal ideologies compel mothers of all racialized and class statuses to take individual responsibility for their children’s health outcomes and life choices, even well into adulthood.

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 wellbeing, our contemporary governing regime insists that subjects “make a project out of their lives” (Cossman 2009, 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 (cited in Cossman 2009, 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 2013,

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 takes time away from 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, and mothering practices meaningful in a social environment that excludes and denies recognition.

We can see this at work in white mother Kristine Barnett's memoir, *The Spark: A Mother's Story of Nurturing, Genius, and Autism* (2013). Barnett's son Jacob has autism and is intellectually gifted. Mother and child are white. 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 nonresponsive 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 (the space 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 was 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 of alphabet cards (3); when he wanted to spend hours doing puzzles and tangrams, Barnett provided materials and sat with him to watch him work (62). When he became inter-

ested 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 a typical childhood experience. 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 [sic] . . . 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. She notes that Saturday's activities brought the "dads" out in droves; dads, she writes, "in sweat-pants 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). Barnett’s sports project, and the narratives by which she envisions and describes it, allow her to claim for Jake 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 another memoir, *Seeing Ezra* (2011), white mother 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, 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). In other words, she wants his life to be ordinary. 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). Ezra takes antidepressants (220). She enrolls him in a private school for autistic children that costs as much as college tuition (257). Yet, 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 wrestles with the ways her embrace of Ezra’s autism renders her a “bad mother,” she conveys the pervasiveness of intensive mothering ideology in the contemporary United States 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 by failing to cure Ezra, 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” (1998, 245). She is like Gillian Marchenko, who shifts from being a “mother of a child with special needs” to a “mother of three girls” (2013, 122). She is like Vicki Forman, who “comes to be” her children’s mother over time (2009, 254). 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.

Barnett’s, Cohen’s, and Marchenko’s narratives and concepts of motherhood contrast with the picture of motherhood that emerges in white mother 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 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’s birth, but her change depends on accepting the “burden” of a disabled child (209) while also refusing to let her child define her. The

difference between Helene Brown's memoir (and others about raising children during the same period including *Label Me Jeff* [1976] and *Heart of This Family* [2020]) is in the way good mothering includes willingly involving, even seeking, the state in the care of a disabled child. The contrast brings into relief the ways in which neoliberal policies like the privatization of care and deinstitutionalization work alongside a rationality of self-sufficiency and self-management to shape parenting practices and discourse in the late twentieth and early twenty-first centuries.

The intensive mothering ideology works in "special needs" parental memoirs to align both gender and neoliberal rationality in the pursuit of an ordinary life. This is in no small part due to the ways the overcoming narrative works with intensive mothering practice. The dual purpose of intensive mothering, whether a child is disabled or not, is to fulfill a cultural demand for gendered parenting and to clear the path, as it were, for a child's upward mobility (be it cultural, economic, or ability-wise). Intensive mothering is about becoming, about making a project out of one's life and self so to reproduce the cultural mother-figure. When a child is disabled, and "ordinary childhood" is made to seem unavailable, achieving "ordinary" motherhood is an overcoming. At the same time, the very nature of intensive mothering promises the reading audience that mother is exhausting every available measure to increase the likelihood of her individual child's improvement. It is both that through gender, she abides by neoliberalism's demands, and by neoliberal rationality, she reproduces gendered parenting.

### COMPULSORY HETEROABLE-BODIEDNESS

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 2011, 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. So while claiming normative gender and embracing sexuality 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 here 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 1998, 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” (2011, 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* (2004) 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. As Rosemarie Garland Thomson argues, fitting occurs when “a generic body enters a generic world” (2011, 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 disabil-

ity experiences when we recall that disability is already (probably) queered by the failure to enact normative gender and sexuality. Stereotypes of disabled people as either asexual, nonreproductive, 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 (1980) argues, that which renders it compulsory, and, as Ahmed argues, what gives heterosexuality a quality of “everydayness” (2004, 147). The everydayness of heterosexuality, I contend, is essentially, the everydayness of nondisability in that heterosexuality is contingent on ablebodiedness. The failure to achieve ablebodiedness, then, can be understood as an inability to embody an “ordinary life” through gender failure.

These narratives evince a continued discursive and material investment in the elimination of disability that can be traced to eugenicist practices of the early twentieth century. 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. They reinforce taken-for-granted assumptions about gender and sexuality and thereby are complicit in the reiteration of compulsory heteroable-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. At the same time, however, the effect of narrative appeals to normative gender and sexuality is to reduce the significance of disability to a child’s overall identity and thereby to challenge exclusion on the basis of cisgender enactment.



# 5

## *“There is no narrative”*

### Childhood Disability, Queerness, and “No Future”

#### *JEREMY AND THE NOT-QUEER HAT*

On the cover of Beth Kephart’s memoir *A Slant of Sun* (1998) 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 on an empty suburban street, his back turned towards 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” (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 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 “muscu-

lar men in sleeveless ribbed shirts” as a mark of her failure to “raise a man’s man” (40). Fretting that people in her community think her little knowledgeable of either 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, is never again mentioned 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, “obsessions,” 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. In overcoming narratives, disability figures as a “personal defect that must be compensated for” by disabled people themselves (Thomson 2005, 1568), who are made responsible for managing and transcending disabling obstacles. 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 who are becoming his friends. In *A Slant of Sun*, the hat obsession suggests Jeremy might be queer, and in turn this possible queerness stands in for the disability he will later overcome. For 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 (Kephart 1998, 38). Jeremy may be “abnormal” in some ways, his mother wants us to know, but he is *not* queer. The not-queer hat remains a marker of Jeremy’s difference—his atypical neurology, not atypical gender or sexuality—and a symbolic and material obstacle that he must, and does, overcome. It emblemizes the denial of queerness that sets Jeremy up for a heteronormative and disability-free future. 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 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 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 a normal future, in which disability and queerness are, as Alison Kafer describes, "out of time" (2013, 66).

This chapter examines three memoirs that resist a "normal future." Through queering growth, anti-linear composition, and refusing to replicate the "overcoming" narrative, these memoirs potentially destabilize "normal" childhood temporality. They point to new possibilities for thinking about the relationships between childhood and adulthood, and by extension, dependence and autonomy. Throughout this book I have examined the ways the childhood development is constructed in relation to adulthood autonomy through racialized gender and ability norms and how disability in childhood interrupts heteroable maturation. I have shown that the "special needs" parental memoir genre can be characterized by an overcoming of disability that writes disabled children into productive and reproductive futures. I have argued that these memoirs are recuperative and radical, that they challenge ableist exclusions and meaningfully contribute positive reconfigurations of disability, even as they do so according to neoliberal, settler colonial, and heteronormative logics.

There are, of course, exceptions to my characterizations of the genre: a small number of memoirs do not replicate these exclusive social structures. In chapter two I wrote about *Moose, The Story of a Very Special Person*, a 1978 memoir in which Moose's father forwards a radical argument for communal care and responsibility for the intellectually disabled. Other forms of life writing yield other possibilities: Priya Lalvani (2019) describes her edited collection of essays as narratives of resistance to patriarchal conceptions of motherhood and the devaluation of disability. Michael Bérubé's (1998) and Chris Gabbard's (2019) memoirs weave their experiences of caregiving with scholarly debates about normalcy, humanity, rationality, and citizenship; they move from personal experiences to the political realm, beyond individual overcoming to deconstructing the logic of ableism. And philosopher Eva Feder Kittay has thought and written through raising her daughter Sesha in many forms; her work on care labor and the centrality of dependency to the human condition has challenged the very possibility of "individual over-

coming,” elevating feminist and disability scholarship and activism (2003; 2010; 2019; 2020).

In each of the three memoirs discussed in this chapter—*The Boy Who Loved Tornadoes: A Mother's Story* (2010), by Randy Davenport; *The Still Point of the Turning World* (2014), by Emily Rapp; and *Schuyler's Monster: A Father's Journey with His Wordless Daughter* (2008), by Robert Rummel-Hudson—parents similarly stray from the conventions. I read these memoirs as examples of disruptions to the genre, as memoirs that refuse to replicate “overcoming,” and which gesture towards more expansive ways to imagine cultural belonging (c.f. Minich 2016). Each memoir resists rehabilitation narratives, in which the problem of disability is mitigated through productive and reproductive futurity; indeed, each grapples explicitly with the normal/better future and how their disabled children figure within it. In different ways, each memoir detangles gender and sexuality from normative development. They do not reclaim recognizable, able, cisgender childhoods for their children; and the future, in these memoirs, is hardly a given, let alone straight and able. Instead, these memoirs offer alternatives: a dignified picture of adulthood dependence; an anti-future developmentalist presentism, a temporally askew queer interdependence. They are narratives of resistance, born through the challenges of parenting disabled children in a world not built for them, and which gesture to new ways to narrate futures of *becoming*, rather than becoming straight and able.

## ENTANGLEMENTS

The temporality of an able-bodied, heterosexual adult self originating in a sexually pure child abides by what queer disability studies theorist Alison Kafer calls “straight time” (2013, 34). Drawing on J. Halberstam’s work on queer temporality, Kafer explains, “normative narratives of time presume a linear development from a dependent childhood to an independent adulthood defined by marriage and reproduction” (35). Writing about autistic subjects, Willey et al., note that to the failure to make the passage from “presumed innocence to that of compulsory sexuality” amounts to not growing up (2015, 382). Since this narrative takes the normative development of human experiences and embodiments for granted, framing them as “natural, common-sense” (Kafer 2013, 35), time is a key factor in producing

normalcy (cf. Halberstam 2005, 152). Straight time means normative development; queerness and disability thereby manifest as overlapping categories that have “no future.” In contrast, queer temporalities offer alternative modes of living, growing up, loving, having sex, and making families that defy the logics of straight/able time (2).

The narratives I describe below reject straight, able-bodied futurity, which can be otherwise known as the shared cultural orientation towards a normal future. Normal here means better, in the same way a “normal baby”—one with ten fingers and ten toes and with no apparent disability—is “better” than a disabled baby. Indeed, elsewhere normalcy implies better: not only in the sense that normalcy represents the portion of the bell curve *above* substandard, but also because according to the cultural commonsense logics of neoliberalism, it is “normal” to expect that what is to come should improve upon the present. The cost should yield benefit; the investment, returns. Things are supposed to get better.

As Lee Edelman (2004) has put it, ensuring a preferred social reality to pass onto to future generations is the fundamental purpose of all politics. In other words, all political actors, parties, and policy are driven towards creating a better future, towards a new normal that has improved upon the present. This better future orientation necessarily implies there will be future people living in it, experiencing its betterness; this is why Edelman argues that all politics are animated by The Child, a figuration of the future generations who justify today’s political work. Edelman argues, however, that centering The Child as the harbinger of the “better future” naturalizes heterosexual coupling, and thus the symbolic realm of the political is inherently implicated in reproductive heteronormativity. In short, every political vision, for Edelman, is a vision of heterofuturity.

Drawing on Edelman, Anna Mollow (2012) argues that the figure of The Child also symbolizes a disability-free future (288). The better future (and the better normal) is the one in which disability has been eliminated or dramatically reduced; or as Kafer puts it, “a future with disability is a future no one wants” (2013, 2). This is why the overcoming narrative makes so much cultural sense, and also justifies the significant financial commitments made by both individuals and governments to technologies of cure. Mollow calls this orientation “rehabilitative futurism,” rather than “ableism,” because it emphasizes the elimination—not merely exclusion—of non-normative bodies, and because the emphasis on rehabilitation signals the relationship

between disability and employability, or the idea that disabled people are “burdens” to society rather than contributing members.

Rehabilitative futurism speaks to the legacy of the eugenics movement as it infuses current day understandings of disability: the broad, often unquestioned response to physical, intellectual, sensory, or neurological atypicality as a loss, 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, free of “defects,” who would not “burden” the nation (financially and socially). To the eugenicist, disability invokes an allegedly terrifying slippery slope by which we might slide away from our perfected future (Snyder and Mitchell 2005, 31). Though following the horrors of World War II, Americans have renounced eugenics, bodily atypicality continues to be viewed by many as defect, disorder, or disease, as well as financial and social burden. 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 framework is also argued 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 2009). Indeed, as Alison Piepmeier notes, nearly ninety percent of fetuses identified with having Down syndrome are in fact terminated (Piepmeier 2013, 159; see also Natoli et al. 2012). These are recent figures, despite over forty years of semi-inclusive education for atypical children and thirty years since the passing of the Americans with Disabilities Act (ADA), which prohibits disability-based discrimination. Discrimination persists, nonetheless, and does so in the name of The Child.

It is against this normative investment in a straight and disability free future that Edelman and Mollow (respectively) articulate a politics of negativity, an oppositional positionality that refuses to be on “the side of the child” (Edelman 2004, 18–19). Edelman positions and celebrates queerness as “futureless” in its rejection of heteronormative reproduction. Similarly, rehabilitative futurism asks disabled bodies and disability theory to resist “getting better” and to reject any logics that frame human worth in terms of employability alone. Moreover, Mollow argues that “queer” is the available and appropriate figuration for all subjects who occupy a social position that threatens the so-called better future (2012, 291); in other words, people with

disabilities are queer, too. Recalling the terms of “straight time,” queers/disabled people have “no future.”

What would it mean, and what would it look like, for a parent of a disabled child to write a narrative of no future? 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 heteroable futurity, a resistance to “contributing to society” when it is understood to be *the* most relevant modern-day characteristic of the subject-citizen? The three memoirs under analysis in this chapter depart from the conventions of the genre in the sense that they claim neither a recognizable childhood nor imagine their children in a productive or reproductive adulthood. In *The Boy Who Loved Tornadoes*, 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, on the cusp of another turn. In doing so, Davenport makes time senseless and disorganized and obscures the distinction between childhood dependence and adult autonomy. Emily Rapp’s *The Still Point of the Turning World* 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. Rapp’s memoir includes the possibility that—in the absence of a fatal disease—Ronan may have one day become a gay man, a possibility not repeated elsewhere in the entirety of the parental memoir genre. 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 as manifest therein. 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 exposes the limits of the existing narratives while allowing for new, queerer, more interdependent futurities to emerge. Unlike the figure of The Child, the disabled child communicates a failure to actualize rehabilitative

and reproductive ideals and thereby threatens the onward march of progress; indeed, these memoirs show that disabled children expose the precarity of these ideals, and compel us to imagine other, more just, possibilities.

## DIAGNOSIS NOS

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 2010, 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. Davenport’s memoir, *The Boy Who Loved Tornadoes: A Mother’s Story*, chronicles her experience raising a child with 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 shuffled between inadequate care placements before he was placed at a safe facility that could meet his needs. Unlike many parental memoirs, Davenport does not gender Chase’s childhood, beyond tenuously connecting Chase’s illness with his father, Zip’s, unpredictable behavior. Davenport does not muse about Chase’s future wife or fatherhood. She does not write about teenage crushes or a lost adult heterosexuality; and while Chase’s interests are gender typical for boys, they do not figure in his mother’s memoir as indicators of “ordinary boyhood.” In contrast, she writes about actively 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 (nor adulthood) shape her narrative of Chase’s life.

At the memoir’s conclusion, Chase is in recovery and lives in a residential care facility for adults with developmental disabilities. He has not recognized his mother in years. After several placements in state and private hospitals, Davenport seeks support from the chancellor at the university where she teaches, and finally, the governor of North Carolina to intervene on Chase’s behalf. She does so while recognizing her privileged position among parents of children with mental illness, and from a place of total desperation to protect Chase. Davenport and Haley have come to visit him, to reintroduce themselves, talk with Chase about his childhood, and walk the grounds. In the final passage, Chase, walking ahead of his mother and sister, stops, turns to Davenport and asks, “Mom?” At first glance, Davenport’s memoir constructs 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 because he is in no way recovered by the memoir’s end. This disconnect is further enabled by Davenport’s uses of nonlinear discourse to narrate her story.

As the passage at the start of this section conveys, Chase was not underdiagnosed. 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 was 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 (200). Without a diagnosis, Chase’s future seems entirely uncertain. Chase’s pediatrician hoped an appropriate diagnosis would “clarify over time” (32). It did not; but later, Davenport comes to know Chase as his not-specified disability, as

"Chase, NOS" (359): "I stopped seeing Chase as a child I had to get back on track and 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 in Zip similar, albeit "milder" symptoms of Chase's fully-bloomed psychosis (200), she nonetheless insists on the unpredictability of Chase's illness; 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 (Canguilhem 1991, 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, not to mention throwing the boundaries of normalcy into question.

Medicine's promise to know the body has a relatively recent history in the Global North, 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 power. Along with prisons and schools, hospitals (or, the medical establishment) monitor and discipline the body to make it knowable and docile. In *Fantasies of Identification* (2014), Ellen Samuels clarifies what this looked like in the United States. She writes that beginning in the mid-nineteenth century, a "crisis of identification" emerged in the United States, demonstrated by an increased effort by scientists and the state to determine knowable identities (2). She means: 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 women, people of color, and disabled people, those which differed from the "recognizable subject of democracy" (1). 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 (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 who is thereby deserving of the benefits and protections of related social policies. But the anxiety that circulates around categories of “difference,” including the constant efforts to claim, specify, measure, and delineate them, demonstrate the instability of the terms themselves.

Importantly, both biocertification and the diagnostic regimes upon 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; 1991, 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: at two months, baby smiles; at four months, baby sits, unassisted. 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 non-normative) 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 nonwhite and non-able-bodied individuals were underevolved. As Douglas Baynton (2001) explains, normality (read: white, male, able-bodiedness) “was intimately connected to the Western notion of progress,” and disabilities (including the diagnoses of defect or feeble-mindedness 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 bio-power 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. And 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. Moreover, Chase never promises to get there. Chase's diagnosis NOS means “to not exactly know” and lacks both etiology and prognosis and, as such, is atemporal. 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, essentialized, 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 (2010, 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, and writes nonchronologically 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 fourteen, 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 (age fourteen) without diagnosis; in chapter 11, Chase is six years old; in chapter 12, Chase is almost 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 nonchronological discourse. H. Porter Abbott explains that narrative discourse—how the events of a story are represented—is not bound by temporal logics (2008, 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 fifteen 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 discussed in chapter 1, Abbott argues that “narrative is the principal way in which our species organizes its understanding of time” (3) 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” (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 futurelessness, 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 preexisting diagnostic categories. Chase is disconnected from normative temporality, and as such, we encounter narrative foreclosure on imagining Chase in the recognizable (productive and reproductive) future.

At the narrative's end, when Chase first re-recognizes his mother, he is walking along a path and literally stops and turns around. Davenport's memoir does not ask readers to understand this moment as the end of the story; there is too much movement, and the direction in which Chase will go is uncertain. In an epilogue following the last chapter, Davenport writes that Chase eventually began to recognize her without fail. Over time, and slowly, Chase begins to reintegrate into the world outside his residential

care facility. Due to the severity of Chase’s illness, at twenty years old he is unable to live independently. And neither is this constructed in Davenport’s memoir as any kind of tragedy. Chase’s story is indeed, emotionally stirring; the unpredictability of Chase’s symptoms certainly caused worry and fear, including in Chase himself. The tragedy in Davenport’s memoir, if there is any, is the utter scarcity of resources to help children like Chase. Davenport’s memoir is not a narrative of overcoming the tragedy of disability according to the conventional terms of the genre. Chase does not become a “productive” member of society, nor is he rewritten into a story of ordinary childhood and heterosexual adulthood. Instead, Chase is becoming, always becoming himself, “arrived into himself completely” (2010, 359) without diagnosis or prognosis. Becoming Chase means living a life dependent on others for his safety and wellbeing, without the promise of one day achieving mastery.

### “FUTURE, FUTURE, FUTURE”

Emily Rapp’s memoir, *The Still Point of the Turning World*, also combines an atypical narrative chronology with the language of futurelessness, albeit under terms profoundly different than those in *The Boy Who Loved Tornadoes*. Rapp’s son, Ronan, has Tay-Sachs, a rare, fatal, degenerative nerve disease (Genetics Home Reference n.d.). 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?” (2014, 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 as 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; lengthening each moment and simultaneously reflecting on Ronan's presentness 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 1–18) creeps slowly through the winter and spring months of 2011. Chapters 6 and 7 begin in February, and with the exception of chapter 10, chapters 8 through 13 weave through March alone. Chapter 10 stands apart 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. Seventeen out of twenty-three chapters begin with a phrase that marks the time of year: "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). 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., 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. And 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 futureless 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. 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 childhood temporality. In other words, these memoirs are instructive in that the legibility of "future" depends on other familiar, entangled, normative scripts of cisgendered development. Rapp demonstrates this when she considers the possibility that Ronan, who will not live, might grow up to be a gay man. In a passage that comprises the entirety of Rapp's narrative exploration of Ronan's existence as a gendered and sexual being, she describes the hopes she harbored for Ronan's future before learning about his condition: "he would be generous and gorgeous. Women *or men* would be falling all over themselves to go out with him" (16, emphasis added).

The singularity of Rapp's queer speculation (in both her memoir and the entire genre) raises interesting questions about the relationship between queer possibility and death. Is Ronan's impending death a stand-in for absent future heterosexuality, thus inviting the possibility of gender failure? In perhaps too neat of an Edelmanian reversal, Ronan's biological death drive constructs the queer figure of the present, a sort of sinthomosexual figuration in the body of a futureless child. As Mairead Sullivan synthesizes Edelman, "the sinthomosexual . . . is imagined to evade this commitment [to the better future], insisting instead on present pleasures. By refusing

the normative logic of futurity, the sinthomosexual opens other avenues of investment and thereby threatens the cohesion of [the singular social structure of heteronormativity]" (2016, 270). I am wary, however, to overlay a (neutered?) figuration of the sinthomosexual onto Ronan, who like all the other children in the genre are narratively constructed as asexual (latent sexuality notwithstanding). Desexualizing child Ronan in relation to the adult, sexual Ronan (who will, tragically, not live to be), Rapp reassures readers she has not challenged the U.S. cultural preference of understanding children as distinctly *not* sexual. If not denied completely, childhood sexuality is tolerated only when "innocent of sexual desires or intentions" (Bruhm and Hurley 2004, ix); or in other words, merely accidental and unknowing. For example, in the memoir *Jesse: A Mother's Story* (2010), Marianne Leone views her son's preteen crush on his beloved, beautiful blonde-haired aide Brandy as asexually pure: a child's infatuation absent of erotic overtones: Brandy appears as "a girl in a fairy tale" (168) whom Jesse innocently "loved with all his heart" (168). 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 seems to briefly overcome his disability through the otherwise mundane narrative of heterosexuality. His boyhood crush affirms his gender and promises adult heterosexual able-bodiedness on the horizon, without making his childhood overtly erotic and thereby deviant (Bruhm and Hurley 2004, x).

The normative regime of heterosexuality is bound to the adult body not simply because childhood sexuality is seen as unnatural (Bruhm and Hurley 2004, x), but also because of the relational construction of childhood-as-dependence to adulthood-as-independence. Moreover, heterosexuality itself is an able-bodied accomplishment (Siebers 2008, 175). Put together, sexuality in childhood/the state of dependency is deviant/queer when opposed to not-queer, not-disabled adult sexuality. The relationship presumes the "naturalness" of able-bodiedness and heterosexuality and indeed underscores the compulsoriness of both. And yet, as Kathryn Boyd Stockton (2004) proposes, all children may indeed be already queer insofar as they are "not yet straight," a quality that estranges them from both adults and non-deviant sexuality (283). It is the not-yetness of childhood sexuality that produces its innocent strangeness. Stockton suggests that if the child is "estranged" from the adult it is to become, that space of strangeness might invite possibilities for non-normative growth. Sheldon calls this "the proliferation of lateral potentialities" (2013). Here, Sheldon invokes Butler's argu-

ment that the limits of gender intelligibility are precisely what brings into relief the proliferation of subversive “gender identities,” which, as discussed in the previous chapter, Butler calls “developmental failures” (1999, 24). If “all children are Q[ueer],” childhood might already call into question the inevitability of a smooth progression towards normative adulthood (Stockton 2004, 278). This seems most certainly applicable 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 (2013, 34–40). Developmental failures, in terms of ability, proliferate against the normative regime as both unintelligible *and* as potentially subversive, as resistance.

This is where Rapp’s truly tragic story can engender radical, recuperative possibilities. Rapp’s contribution to new disability narratives is in no way contingent on Ronan’s death; I pointedly refuse to find a “silver lining” in her loss and risk replicating the very neoliberal investment in improvement so anathema to a politics of interdependence. Instead, what Rapp offers is a picture of love and care divorced from developmental promise: one must feed and wash the baby regardless of what tomorrow brings. Because the baby, Ronan, is today. I read this as a possibility that denies neither a universal human capacity for growth and development *nor* the inevitability, and centrality, of dependence to the human condition. The presentness of Rapp’s memoir, the developmental unraveling, create the narrative conditions for Ronan’s constant arrival, rather than replicating a singular vision of developmental completeness in the (re)productive adult body.

### 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 ways 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 U.S. culture are not universal, but their ubiquity

across multiple domains (e.g., medical, cultural, political) makes them register as common sense. Many in the United States 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 2012, 23). People with disabilities are frequently seen as sexually queer, asexual, and nonreproductive (Siebers 2008, 174–75; Mollow 2012, 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 2001, 3–4). Robert Rummel-Hudson’s (2008) 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 (Ferri 2011, 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 2008, 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 nondisabled 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, as do 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 her 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 in their lives 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 discussed above with a fondness for ladies' hats, 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, a girl named 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). In the absence of naming queerness, Rummel-Hudson presumes heterosexuality. 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 narra-

tive 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 (2004) has argued that tomboyism is commonly a part of a girl’s trajectory toward adult heterosexual womanhood. Tomboys “represent . . . a resistance to adulthood, rather than to adult femininity” itself (194). Halberstam’s alternative teleology allows for a less disruptive queerness; gender transgression vies against adulthood without completely upsetting the dominant temporality, however, only when tomboys are more androgynous than queer (read: butch). This strange alliance between child and adulthood queerness (and child and adulthood “straightness”) accords with the straight-time/queer-time binary of Halberstam’s *In a Queer Time and Place* (2005, 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, because she is noncompliant; she is a gender and ability disrupter. 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 *queerish*, 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. 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 does so 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 perceiving Kephart's experience as true, at 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," children's seemingly universal strangeness masks the *profound* estrangement of children with disabilities from the story of childhood itself. The appeal to heteronormativity in "special needs" memoirs makes disabled childhoods seem ordinary, an attempt at restoration to familiar scripts and paradigms. Heteronormativity 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 (1996) 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 preteen 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 (McRuer 2006, 1) and parent-memoirists have little other recourse to claim a privileged, cherished story of childhood. Given that no existing narrative normalizes disabled experiences, who can blame these parents for trying to

normalize it by other means? As noted in the introduction, normativity is a utopia, "an aspirational site of rest and recognition in and by a social world" (Berlant 2008, 5). We all want to be seen and known.

But perhaps queerness, too, is a utopia. In *Cruising Utopia* (2009), Jose Esteban Muñoz argues that queerness is a "potentiality" (21), a way of seeing and feeling in anticipation and hope (11). Muñoz gets Edelman's critique of heteroreproductive futurism, but argues that Edelman's antisocial approach reproduces a kind of binary logic—a queer "no future" positioned against heterofuturity—that itself forecloses on more radical possibilities. For example, Muñoz notes that The Child who animates the future and thereby Edelman's polemic is coded as white, engendering a privileged focal point unimaginable for racialized, disabled, and poor children. The erasure of kids of color enables Muñoz to imagine the future wherein "queer youths of color actually get to grow up" (96). In refusing the refusal, Muñoz embraces Shoshana Felman's theory of "radical negativity": belonging neither to negation, nor contradiction (cited in Muñoz 2009, 13). Muñoz's queerness/utopia is "not yet." Muñoz suggests that such a framework aligns with Sedgwick's "reparative hermeneutics" (12). A reparative hermeneutics, as Sedgwick explains, can be hopeful; it allows for the possibility that the worst we could imagine might be just one of many possibilities (2003, 146). Muñoz's radical negativity thus gestures to a narrative possibility not yet realized in most stories about raising disabled children wherein neither normativity nor reproductive futurity is compulsory.

Thinking queerness as collectivity and potentiality maybe particularly useful for articulating a crip critique of antifuturity. 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 (2005, 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 *or might not* prove the exception to the rule of identity choice. Disability, in contrast to other subjective essences like gender or race, is usually understood as "not choosable" (Davis 2013, 7); except that it is: prospective parents have cheaper, more readily available tools to choose (against) disability; and both disability and specific disabilities increasingly operate as identity markers in the public sphere (for example, crip; neurodivergent, Autistic, not a "person with autism"). And Edelman might consider how queer disabled subjects, not to mention het-



erosexual disabled subjects queered by heterosexist ableism, might seek to reproduce children that are both viewed as both hopeless and unwanted. 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? And 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 employ aides to help coordinate sex, and intellectually disabled people's sexual expression in many ways requires degrees of support from caregivers and the community? In other words, spectacularly queer and crip interdependence?

Rummel-Hudson's memoir does not beholden its subject, Schuyler, to the wholesale antinormativity sometimes informing queer and crip politics, and especially Edelman's *No Future*. Schuyler appears 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" (2008, 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.

In this Schuyler embodies the radical potential invoked by *The Disabled Child*. While the figure, reiteratively produced in the vast number of parental memoirs to reinforce a binary between childhood and adulthood on the basis of able-bodied development, Schuyler suggests what could be. Growth, according to no standardized and pathologizing timeline but Schuyler's own form; development, not towards mastery but towards the fullness of her capacity; interdependent living, in which dependence is recognized as a fundamental, unexceptional characteristic of human life, and in which Schuyler's inclusion in society depends not on any moral or spiritual benefit her dependence is imagined conferring onto those who support her. The Figure of the Disabled Child is exceptional, the child who never should have grown. A figure produced through neoliberalism's idealiza-

tion of autonomy, degradation of dependency, investment in heterosexual reproductive futurity, and eugenic drive as not a child and never an adult, and whose parents plot a narrative of recuperation into the same logics that produced the exclusions: The Disabled Child overcomes. Except when she does not. When she grows despite the charts, develops regardless of the timeline, and fails, spectacularly, to master speech, another possibility appears. Capacitation and dependency, flourishing and support. Schuyler, radically, will not overcome.

## Conclusion

### Nothing About Them, Without Us

Parent narratives occupy a special place in disability studies. Many parental memoirs have been analyzed, for example in Alison Piepmeier's "Saints, Sages, and Victims" (2012), Cindee Calton's (2010) essay on memoirs and class status, and G. Thomas Couser's work. Many memoirs have been analyzed multiple times (e.g., *The Siege* [1982] by Clara Claiborne Clark; *The Child Who Never Grew* [(1950) 1992] by Pearl S. Buck). Parental memoirs are the subject of numerous scholarly book reviews. As noted in the introduction, many authors of parental memoirs are academics; parent narratives however also appear frequently in scholarly work in disability studies (e.g., Davidson [2020]; Savarese [2009]; Vaughan and Super [2019]; Ryan and Runswick-Cole [2008], to name only a few). Recently on Twitter, one academic noted that a fictional essay titled "My Disabled Child: A Parent's Story," could be counted among a reductionist (and amusing) typology of essays in disability studies.<sup>1</sup>

The role of nondisabled parents themselves in disability scholarship and activism is fraught. On the one hand, some parents are fierce advocates for the advancement of disabled people's rights (see Carey, Block, and Scotch 2020). On the other, for many people with disabilities, parents are a primary source of rejection. As I write this today, OurTism, an online resource for autistic people by autistic people, is selling tickets for this week's event titled "What I Wish My Parents Did Differently" (n.d.). Collections of essays by

adults with disabilities ask parents to accept their children, to love them as they are (Klein and Kemp 2004), to believe their children, to resist over-determining the meaning or shape of their children's lives ("14 Things Adults with Disabilities Wish Their Able-Bodied Parents Had Known" n.d.), and to be optimistic and eliminate shame (Janhely 2021; Ballou, daVanport, and Onaiwu 2021). These point to the pain disabled children felt, perhaps still feel, growing up with a sense that they have failed to meet their parents' expectations. Legacies of more overt rejection—institutionalization, physical abuse, infanticide—pull at the edges of parental expressions of disappointment and quests for normalization. Parents have not always been the most trustworthy of advocates.

Perhaps *The Disabled Child* stirs the pot. I have shown throughout this book that parental narratives are sites of recuperation and of possibility. That many parents write of their disabled children's burgeoning sexuality is hugely resistant to a widely held notion that people with disabilities (especially intellectual and developmental disabilities) are asexual. Parents reconfigure what counts as a meaningful social participation and "valuable" contribution. They insist readers encounter stereotypes about disability and provide narrative templates for reimagining human variation. They write, over and over, of their deep love for their children. They also write these things in problematic ways. I have argued throughout this book that parent narratives—as a genre—overwhelming, if inadvertently, (re)frame impairment as an obstacle to social inclusion. Specifically, disability is understood as discursively at odds, indeed, totally incompatible with cultural notions of "normal childhood," based as it is on gendered developmental achievement; and by extension, "normal adulthood," based as it is on autonomy, productivity, and (potential) reproductivity. I showed how parent memoirists challenge their children's presumed exclusion by writing them into normative gender and heterosexual scripts and into neoliberal narratives of contribution: their children are not "burdens," as people with disabilities are often said to be; they impart moral, spiritual, and sometimes intellectual benefit on those who care for them. Parents and others in a disabled child's orbit become "better" people through proximity. Aurora Levins Morales writes, however, that "the last thing [disabled people need] is more opportunities to [keep] the interlocking wheels of class, white supremacy, hetero-males supremacy, and imperialism turning" (2019, 51). In these memoirs, parents rely on settler colonial logics of belonging and reproduce neoliberalism's demands for self-governance and individual responsibility for health

and wellness. In sum, parent narratives reproduce the logics of whiteness, neoliberalism, and heterosexuality, the very same discourses that marked their children as deviant in the first place. The Disabled Child thus emerges in parental memoirs as exceptional while the ableist world order remains intact. Kittay's (2020) inevitable dependencies proliferate in the margins.

Moreover, a problem of authorship remains. In addition to the troubled relationships between nondisabled parents and their disabled children and the problematic generic narrative is what critics would call the decentering of the disabled person's "voice" that occurs in parental memoirs. What rights do parents have to tell these stories? First-person narratives by people with disabilities have made significant impacts to cultural understandings of disability, not to mention disability law and policy. Narratives and academic work by disabled people are part of a legacy of resistance to medical and academic objectification, to a historical cultural preference for the insights of a nondisabled "expert" over a disabled person's lived experience. To many, parental narratives violate the disability rights mantra, "nothing about us, without us," by presenting parents themselves as spokespeople for disability experience (and presumably thereby the experience of ableism) through proximity (see Ryan and Runswick-Cole 2008). In this accusation, parents reenact a strict paternalism by telling a story that is not theirs to tell. As Amy Shuman argues, the question of story ownership is one of epistemological authority (2015, 42), of whose memory, vantage, narrative, is truly true. In "special needs" parental memoirs, the question of authority is particularly problematic, as the narratives concern children not only made vulnerable by disability stigma, but who are also, in relationship to their parents, in positions of extremely diminished power to consent (see Couser 2003). From this perspective, parental memoirs are sites where unequal relationships of power—between children and adults, between disabled and nondisabled people—are reproduced.

The issue, then, is with nondisabled parental authority, or with the constraint on disabled children's autonomy. Adult authority over children's lives is fundamental to children's survival, especially during the "inevitable dependency" of infancy and young childhood. Yet, it is sometimes upsetting to disability activists, especially, perhaps Deaf adults and the autists/people with autism noted above, that children have little say in their parents' approach to disability. The upset is largely due to the dearth of resources available to families of children with disabilities that would offer alternate pathways and models of acceptance instead of medicalization and an

emphasis on normalization. Still, I wonder if the denial of children's autonomy is upsetting because it also reminds us of the ways many adults with disabilities are denied opportunities for independent decision-making. We are reminded of not only the distinction between independence and dependence, but of a cultural preference for autonomy despite what we already know about autonomy's ableist underpinnings—both that the autonomy of people with disabilities has been restricted and that the myth of individual autonomy obscures inevitable dependencies and relations of care.

The restriction on children's autonomy, moreover, does not (necessarily) exploit a power differential between adults and children; rather, in the best-case scenario, it is a part of a relationship whereby children are capacitated through the provision of care. In addition to basic survival, most children, disabled and nondisabled alike, require guidance and support in decision-making to ensure their safety and wellbeing. In other words, a child's access to opportunities for flourishing depend on the care of others. To reject this is to deny infants their states of diminished capacity, which makes little sense. To accept this *only* in infancy or early childhood is to draw a line based on ableist developmentalism or an arbitrary moment in time. If we can accept that dependency catalyzes relationships of care and enables flourishing in childhood, we are forced to reconsider the cultural disdain for adult dependency. Why is what is seen as acceptable, and even precious, about children, so disparaged when present in relationships between adults? Perhaps the broadscale repulsion for dependency is actually directed at the feminized labor of care itself. Care labor, including dependency care, emotional labor, affective labor, and reproductive labor are both profoundly undervalued and largely understood to be the work of women. We do not actually hate children in their states of dependency, but we hold them to a promise to grow out of it and to one day no longer require care. The carer cares without reluctance knowing the labor is temporary. Do we despise adult dependence because of a broken promise? Because of the way dependency care constrains the autonomy of the carers? Because dependency care weakens the myth of the autonomous citizen subject, not only manifest in the body of the dependent, but in the labor of care? Because dependency, care, and non-autonomy are all coded as feminine?

Of course, there are adults who wield their authority over children in harmful and abusive ways. But doing so is decidedly not a practice of care. The distinction is between a constraint on autonomy as an act of care, versus a constraint on autonomy as an act of violence. Parent memoirists write that

they make decisions for their children with the best interests of their children in mind. Margaret Price (2015) writes that care “must emerge between subjects considered to be equally valuable (which does not necessarily mean that both are operating from similar places of rationality), and it must be participatory in nature, that is, developed through the desires and needs of all participants” (279). Things get messy, however, as one parent’s act of care is one disabled adult’s memory of violence. Parents make choices that affect their children’s lives long into adulthood, choices that sometimes hurt the disabled community and slow the advancement of disability justice. They may forestall a more radical future of interdependence for inclusion today (Mingus 2011). This is a disagreement about what care looks like and how to deliver it. Suggested alternatives offer nothing better: community care would expose queer children to painfully queerphobic violences enacted in religious faith and love; state-managed care would only hasten the separation of children of color from their families and overextend the state’s control over all our lives. Leah Lakshmi Piepzna-Samarasinha wonders if changing the narratives of care would change the outcomes of disabled folks’ lives (2018, 131). Despite the shortfalls of representation, I too turn to narratives: a proliferation of stories and possibilities, of alternatives.

This of course brings me squarely back to the question of authorship. Even if we accept that a degree of parental authority over children is fundamental to children’s wellbeing, does a relationship of care entitle parents to their children’s stories? The criticism that parents are telling a story that is not theirs to tell implies that their disabled children are the true “owners” of their stories. And of course they are, as we all are owners of our experiences. I am wary of the implications of this criticism, however, as it suggests that the only permissible life-narrative form is autobiography. Autobiography, no matter its sophistication, requires a degree of self-reflection and reciprocal communication, including the ability to access a shared framework (linguistic, or narrative, for example) by which one’s story can be received. I worry that an autobiographical requirement would render some stories untellable, and we would be without, for example, opportunities to engage with stories of caring for and living with individuals with profound cognitive and/or developmental impairments. The autobiographical requirement, while clearly intentioned to privilege first-person narratives and reduce paternalism, also seems to necessitate a degree of autonomy that is premised on developmental achievement, even if slight. I am thinking here about Katherine, who stared deeply at her sister’s drawing of a yellow bear, yet of whom

whose mother wrote asked for nothing and wanted nothing (Zimmermann 2004, 215, 228). I am glad to have learned of Katherine's interest in the drawing of the yellow bear, an interest Katherine herself would not have had an opportunity to tell me about, and which I would never witness on my own.

Moreover, parental memoirs are not biographies about their disabled children. Couser describes parental memoirs as oscillating between autobiography and biography, and that this movement makes them "inherently unstable" in terms of genre (2003, 56). This suggests of course that autobiography and biography are distinct categories, even as Couser writes elsewhere that the categories are blurred: "one person's *autobiography* is inevitably someone else's *biography*" (2011, 34). Parental memoirs are indeed about their children, but they are fundamentally the parent's understanding of that child (see also Mills 2009), and the parent's response to their child's impairment. The bulk of the content in the genre is moreover about the process of learning to care for a child the parent had not prepared for. They are about processes, about growth and change, about prompt and response. In this way, parental memoirs are more than auto/biographical, they are relational life-writing. Sidonie Smith and Julia Watson (2010) offer "filiation narrative" as a subgeneric distinction for life writing that "memorializes" relationships between those with longstanding affiliations (parents and children, siblings, and ostensibly others, 270). Parental narratives are also in relation to readers because as memoir they promise to be true. They are thus texts of relationality and circulation: between the parent and the child, between the parent and the reader, between the reader and cultural notions of childhood and ability.

Children's dependency catalyzes a relationship of care, and parental memoirs are narratives of relations of care. Sometimes, the care parents describe feels careless. Sometimes the narratives accomplish both radical love and reproduce gender normativity; sometimes gender normativity is a radical utopia for disabled children. The narratives arc from tragedy to overcoming, from grief to acceptance. They produce a figure who is exceptional, a wanted and loved child, an adult who belongs, even as the conditions of belonging are limited. The Figure of the Disabled Child brings into relief the fictions against which it is produced: the myth of autonomy, the alleged avoidability of dependency. In illuminating these fictions, it creates an opening—the possibility to write a different story. Perhaps nondisabled parents should not be the ones to fill this gap. But, they will. They will because they are compelled to account for their disabled child's life; because a baby



like theirs demands a story (Adams 2013, 108). And so, we must read them and critique them as cultural projects that produce meaning about disability and gender and race and economy. I propose that we read them as narratives about parenting and about childhood, and most especially, as relational. I suggest we locate parental narratives as proximal to disability life-writing, in an unstable relationship to the genre, and I suggest we embrace that instability, along with the tensions produced in the body of narratives—the inevitability of care, of failure, of recuperation, of reiteration—as productive in the possibilities to which they point: the margins.

# Notes

## INTRODUCTION

1. I use d/Deaf to refer to the audiological status of diminished or absent hearing (deaf), and individuals who identify as members of a cultural and linguistic community (Deaf) (see Stapleton 2015). A d/Deaf child's parents are often the first to choose the label for their child. 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 become coded by the brain to translate to meaningful words and sounds.

## CHAPTER 1

1. This insight is inspired by Phelan ("Analepsis/Prolepsis," 250).

## CHAPTER 3

1. 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 in XY bodies ("Rett Syndrome Fact Sheet | National Institute of Neurological Disorders and Stroke" n.d.).

2. In my research on parent memoirs, the mirror metaphor has been used to describe intellectually disabled people who are also non-speaking. 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" (2005, 10). Ian Brown describes his "severely disabled son" Walker as like a mirror reflecting Brown's own choices and perceptions (2011, 286).

3. Sean Yeager, neuroqueer physicist-turned-literary theorist points out that for Pauli, “‘not even wrong’ was the ultimate dismissal reserved not just for people who disagreed with him, but for folks who were purporting eccentric or impractical theories. It’s not just that they were working in a different framework, but that their framework was actively counterproductive” (personal communication).

4. 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 (McClintock 1995; Said 1979). 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 eighteenth 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 2005, 1429).

5. 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* (1976).

6. Bettelheim was a self-educated psychoanalyst who established and ran a clinic for autistic children in Chicago during the 1950s, despite having no training or education in developmental psychology or the treatment of disabled children.

7. Collins rightly points out that Bettelheim was not actually a doctor of psychology. His doctorate was in art history. Collins also notes that after Bettelheim’s death his methods were scrutinized, and his theories largely rejected by psychological and medical communities.

8. Grandin is one of three females with autism mentioned in the text. The other two were unnamed girls brought from their homes to live in Bettelheim’s clinic (Collins 2005, 79). These girls figure only peripherally in Collins’s story.

9. Kanner’s paper on “infantile autism” was published in 1943 in the United States, and 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” (2005, 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 (2015) and Robison (2016).

10. 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). M. Remi Yergeau (2018) also challenges the basis of prevalence data, noting that autistic population studies in the United States often only include autistic children. Yergeau notes that other populations (e.g., non-diagnosed autistics) are also absent from the numbers and autistic prevalence may indeed be much higher than currently recognized (2018, 163–64).

11. 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)*, 2007).

12. 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.

13. In addition to her masculine-coded 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*. Jake Pyne (2021) draws together a number of autistic self-advocate perspectives on gender, which collectively challenge the very possibility of gender non-conformity among autistics. Many autistic adults disidentify with gender altogether, or understand autism itself as "a neurology of queer nature" (344; see also Yergeau 2018).

14. 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.'"

15. Matthew 24:13 "But the one who endures *to the end* will be saved."

16. For Christians, this "brokenness" means the fundamental separation of humans from God due to sinful nature, remedied only by belief in Jesus as the savior of humanity.

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

## CHAPTER 4

1. Girls participate in a different ritual called a bat mitzvah.

2. Nakamara presented this idea as the keynote speaker for UCLA's *Disability as Spectacle* conference in 2016.

3. See Barrie Thorne, *Gender Play* (1993) for a detailed analysis of the organizational uses and impact of gender in childhood.

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

## CONCLUSION

1. Also included: "It's not Queer, its Crip," and "LOL DS is Literally So Fucking White." <https://twitter.com/jlsmilges/status/1389605211761614852?s=20>



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