Constructing Childhood Disability: Autism and Down Syndrome in America, 1943-2000

By

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ABSTRACT OF THE DISSERTATION

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Since the publication of Dale Evans Rogers’s memoir about her daughter with Down syndrome, *Angel Unaware,* in 1953 and Clara Claiborne Park’s 1968 memoir, *The Siege*, about her autistic daughter, parent memoirs have shaped the public meaning of each of these conditions. The genre of memoir has allowed parents to advocate for their children’s rights, influence the public understanding of life with disabilities, challenge scientific authority, develop biosocial kinship with other families, and establish expertise over the care, treatment, and meaning of disability. This dissertation uses memoirs as an access point into the construction of the meaning of autism and Down syndrome over the latter half of the twentieth century, examining the shifting trajectory of each diagnosis in the public sphere through the analysis of scientific literature, guidebooks, media coverage, and memoirs by parents and disabled adults.

Down syndrome was the paradigmatic developmental disability in midcentury America, as its immediate physical visibility and chromosomal legibility established it as the model for other genetic conditions. Against the paradigm of Down syndrome’s characteristic facies, physicians and parents articulated difference for autism from other developmental disabilities in the 1950s and 1960s, identifying physical beauty as a characteristic component of the diagnosis. Over time, autism gained prominence, scientifically and culturally, as prevalence increased, parent activism against psychogenic mother-blaming etiological theories gained power, and a complex etiological and therapeutic landscape emerged against which parents asserted their authority. By the end of the twentieth century, autism had become the paradigmatic childhood developmental disability for the next century. In contrast, the advent of amniocentesis and legalized abortion made Down syndrome inextricably associated with prenatal diagnosis and selective termination, reordering the condition as a decision made in pregnancy rather than a valuable part of the fabric of human diversity. This thesis reveals how parents, scientists, and adults with Down syndrome and autism have shaped and responded to these shifts in the meaning of these disabilities.

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Colloquium have been supportive environments for sharing work, and I am grateful to all attendees for the community that they have cultivated.

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CONTENTS

INTRODUCTION

In 1953, Dale Evans Rogers wrote a memoir, *Angel Unaware*, about the life of her daughter Robin, who had Down syndrome and died shortly before her second birthday. Rogers was an actress and singer known as the "Queen of the West" for her roles opposite husband Roy Rogers in Westerns in the 1940s and 50s. By publicizing her daughter's diagnosis, Rogers challenged the stigma against children with intellectual disabilities. *Angel Unaware* presented Robin as a gift from God, sent to Earth to teach the world about love, patience, and the acceptance of God's will. It became the third-bestselling book of 1953.[1]

In 1981, Rogers updated the book with a new preface. She wrote about the effect that *Angel Unaware* had on the experiences of children with Down syndrome in American society:

> Prior to the advent of [Robin's] little book, children with Down's syndrome were seldom, if ever, seen in public by curious eyes. Six months after Fleming H. Revell published *Angel Unaware*, these little children, by the score, were brought to theaters where we appeared, to see us. We saw them in the crowds of parade spectators, in stores—in many public places. Churches began Sunday-school classes for these special little ones, who have been called "those nearest to the heart of God." … Indeed, we appreciate the confidence God placed in us, to send Robin our way. Every time I see a Down's syndrome child at work in school, sheltered workshops, or in routine jobs offered to many organizations, I can almost see Robin's beautiful, beautiful smile…[2]

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[1] James W. Trent Jr., *Inventing the Feeble Mind: A History of Mental Retardation in the United States* (University of California Press, 1994), 234.

[2] Dale Evans Rogers, "Preface," in *Angel Unaware: A Touching Story of Love and Loss*, 50th anniversary ed. (Grand Rapids: Fleming H. Revell, 2004 [1981]), 10-11.

Rogers credited her work, her daughter's legacy, and God's will, along with the efforts of the Special Olympics and the expansion of special education, with bringing people with Down syndrome into the mainstream and establishing institutional services for them. Rogers had depicted Robin as an angel, and she saw this blessedness in all children with Down syndrome as God's special blessings, shaping the perception and expectation of people with Down syndrome to the general public.

Rogers was not alone in crediting her writing for helping to transform the status of children with Down syndrome and other intellectual disabilities in American society. Parents and disability scholars Michael Bérubé and Janet Lyon write that the birth of their son and their advocacy on his behalf has made them "the unwitting heirs of people and movements we never knew we were related to. We saunter with our [son] Jamie publicly largely thanks to Dale Evans who, in 1953, wrote Angel Unaware."[3] Anthropologists Rayna Rapp and Faye Ginsburg describe the disability narratives written by disabled people and/or their family members as influential in "mobiliz[ing] an extraordinary and rapid transformation since the 1970s in the way such notions as rights, entitlement, and citizenship are conceived—a transformation that is shaping public policy in areas such as health care, education, transportation, and access to built, aural, and visual environments."[4]

Parent memoirs both indicate and shape contemporary anxieties and understandings about family life, parenthood—especially motherhood—and disability. As Alison Piepmeier,

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[3] Michael Bérubé and Janet Lyon, "Living on Disability: Language and Social Policy in the Wake of the ADA," in *The Visible Woman: Imaging Technologies, Gender, and Science*, ed. Paula A. Treichler, Lisa Cartwright, and Constance Penley (New York: NYU Press, 1998), 274.

[4] Rayna Rapp and Faye D. Ginsburg, "Enabling Disability: Rewriting Kinship, Reimagining Citizenship," *Public Culture* 13, no. 3 (2001): 537-38. Rapp and Ginsburg identify in this piece as anthropologists and as parents of disabled children.

English professor and mother to a daughter with Down syndrome, noted in her survey of parent memoirs, these works “demonstrate that the family can be a site that both bolsters oppressive cultural models of disability and profoundly challenges them.”[5] For parents of disabled children since the 1950s, memoir has been a space for what Rapp and Ginsburg describe as “meaning-making, whether through the acceptance of ‘God's special angels’ or the infanticide of offspring deemed unacceptable.”[6] This thesis will examine the meaning created for two paradigmatic developmental disabilities, Down syndrome and autism, by parent memoirs, guidebooks, scientific literature, and, ultimately, the writings of disabled adults in the second half of the twentieth century.

Parent memoirs for both Down syndrome and autism share certain purposes and features. Their authors have had the aim of improving services for their children, including proving their educability and challenging professional insistence upon institutionalization; removing stigma around the diagnosis; and demonstrating their children’s value within their families and communities. Narratives within both subgenres extol the worthiness of the disabled children whose lives they describe and explore complicated relationships with the physicians and professionals that parents encounter. However, the particular histories of each diagnosis have afforded parents distinct opportunities for meaning-making according to the etiology, therapy, and diagnostic methods of the time.

While Dale Evans Rogers and *Angel Unaware* initiated the genre of parent memoirs about children with Down syndrome, the history of autism has its own pioneer in Clara

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[5] Alison Piepmeier, “Saints, Sages, and Victims: Endorsement of and Resistance to Cultural Stereotypes in Memoirs by Parents of Children with Disabilities,” *Disability Studies Quarterly* 32, no. 1 (January 25, 2012), https://doi.org/10.18061/dsq.v32i1.3031.
[6] Rapp and Ginsburg, “Enabling Disability,” 536.

Claiborne Park and her 1967 memoir, *The Siege: The First Eight Years of an Autistic Child*. Historian of science Marga Vicedo describes *The Siege* as “a bible for parents of autistic children, who continued, generation after generation, to rediscover the book.”[7] Park’s work established an expected pattern for autism memoirs that distinguished these narratives from Down syndrome memoirs. Park wrestled with finding an appropriate diagnosis for her daughter, developing methods of treatment that would prove effective, and challenging the refrigerator mother theory of autism causation, which blamed a lack of maternal affection for inducing autism in the child. Park’s claims of effective therapy for her daughter—the metaphorical siege of the book’s title—established a tradition of recovery narratives for autism that differ from the accepted narratives of Down syndrome. Although Park did not claim her daughter to be cured, later parents did assert that they had found the miraculous key to solving the problem of their child’s autism. Throughout autism’s history as a discrete diagnosis, parents and professionals have not agreed on a clear etiology for the condition, and treatment for autistic children has varied widely. The lack of stability for autism’s meaning has shaped parents’ ability to construct their authority using narrative genres including memoir. Over the course of the second half of the twentieth century, the plasticity of autism’s meaning contributed to its rise in prominence in the American cultural imaginary, replacing the image of a child with Down syndrome to become the paradigmatic childhood developmental disability of the twenty-first century.

A key aspect of this project is placing the histories of autism and Down syndrome in communication. The work begins within the medical literature’s development of autism as a novel diagnosis, namely using the site of physical beauty for the articulation of difference from

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[7] Marga Vicedo, *Intelligent Love: The Story of Clara Park, Her Autistic Daughter, and the Myth of the Refrigerator Mother* (Boston: Beacon Press, 2021), 137.

the physical features that characterized Down syndrome. Through their writings, parents of autistic children contrast their children's looks, behaviors, and disabilities against the accepted paradigm of childhood developmental disability, Down syndrome, until autism becomes a broadly understood and meaningful diagnosis in its own right. By the 2000s, autism was poised to exist as the paradigmatic childhood developmental disability of the new century, replacing Down syndrome in American culture. Examining Down syndrome and autism in tandem reveals this shift as it illuminates essential aspects of the histories of both conditions.

The status of Down syndrome and autism as paradigmatic childhood developmental disabilities is central to the argument of this thesis. Paradigmatic operates in several ways throughout this work: as a marker of visibility, as a reflection of prevalence, and as a structure of interpretation. The phrase marks the disability against which doctors, researchers, parents, and the public measured other diagnoses. Down syndrome became the paradigmatic childhood developmental disability in mid-century America through its immediate physical identification coupled with its chromosomal legibility. For researchers into genetics, Down syndrome became the model for investigating further chromosomal and genetic anomalies, as scientists sought to determine ties between physical differences and specific genetic causes in other diagnoses.[8] Down syndrome was and remains the most common chromosomal anomaly within the American population.

The visibility of Down syndrome extended beyond the lab. Parent memoirists write about their awareness of Down syndrome as a cause of developmental disability throughout the

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[8] Andrew J. Hogan, *Life Histories of Genetic Disease: Patterns and Prevention in Postwar Medical Genetics* (Baltimore: Johns Hopkins University Press, 2016), 4-5; Daniel Navon, *Mobilizing Mutations: Human Genetics in the Age of Patient Advocacy* (Chicago: University of Chicago Press, 2019), 62.

twentieth century, particularly noting the specific physical features that characterized the condition. Assigning the status of paradigmatic childhood developmental disability to Down syndrome reflects how the diagnosis shaped the expectations for the broader category of such disabilities in American culture. Parents of children with other diagnoses compared their children's development, appearance, and growth to their knowledge of Down syndrome, using both their general awareness of the condition and the specific comparison of their children to children with Down syndrome in their classrooms or doctors' waiting rooms.

Autism overtook Down syndrome as the paradigmatic childhood developmental disability of note by the twenty-first century. Autism's position in the American imagination reflects the diagnosis's rapidly growing prevalence in the American population, widespread visibility throughout American culture, and increasing dominance over the expectations of disability and meaning of disability as a broader category. The autism spectrum became an immediately recognizable construct within American culture, as parents reordered their awareness of disability among children to place autism as the foremost concern. How and why this restructuring of the meaning of developmental disability took place is a primary concern of this thesis.

By paying particular attention to the public writings of parents and their influence on popular understandings of Down syndrome and autism, this thesis reflects a point of tension within the history of and scholarship on disability activism. While relationships between parents and disability activists are complex—and the two categories not mutually exclusive—the history of parent activism and disability activism reflects friction over conflicting goals and differing understandings of disability. Disability studies scholars Allison C. Carey, Pamela Block, and Richard Scotch's book *Allies and Obstacles* analyzes parent activism and its relationship to disability activism and disability activists. Carey, Block, and Scotch examine the ways in which disability activists have directly challenged the authority of parent activists, who have held a belief in their authority over their own children along with economic and political power.[9] Their work intervenes in the historiography of disability self-activism, which has often avoided the discussion of parents, and in parent activism historiography, where work has primarily focused on specific organizations and diagnoses, rather than a cross-disability analysis.

The tensions between parent activists and disability self-advocates reveal a core tenet of parent activism: parents tend to focus on the specific needs of their child and their family, according to the parents' understanding of such needs. This creates activism that can be in opposition both to other parents, who pursue different ends, and to the wishes of disability self-advocates, as it remains focused on parental authority and family needs rather than the rights and decision-making authority of the disabled person or the pursuit of justice for all disabled and marginalized people. Carey, Block, and Scotch use the concept of "embodiment by proxy" to describe the manner in which parents who assert that they are speaking for their children may "displace the subjective experience of those with disabilities and nullify their voices and abilities while emphasizing parents' own perspectives and needs."[10] Parent memoirists, in speaking on behalf of their children and in place of their children, routinely contribute to a tendency for the cultural prioritization of parents' needs over the stated needs of disabled self-advocates. The emergence of memoirs and writing directly from disabled authors later in the twentieth century counters these parent voices in ways that both complement existing parent narratives and, particularly in the case of autism, rupture them. Autistic activists and parents have a particularly

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[9] Allison C. Carey, Pamela Block, and Richard Scotch, *Allies and Obstacles: Disability Activism and Parents of Children with Disabilities* (Philadelphia: Temple University Press, 2020).
[10] Carey, Block, and Scotch, *Allies and Obstacles,* 17.

contentious history involving disagreements over whether autism should be cured, what treatments are permissible, and who should be the trusted authoritative voice for nonverbal autists: parents or other autistic people.[11]

In this thesis, I argue for the importance of parent writings in constructing meaning for the disabilities of their children. Analyzing parent memoirs and guidebooks reveals the power that parents have held and the ways that parents have used writing as a medium for establishing their authority within the autism and Down syndrome communities. At the same time, I pay close attention to the circulation of writings by people with autism and Down syndrome and how their voices navigate a narrative landscape created by their parents. By the 1990s, even as parent memoirs remained popular, memoirs by adults with autism and Down syndrome implicitly challenged the preeminence of parent voices, revealing the differing motivations, intentions, and interpretations of these conditions by the people who have them in contrast to their parents.

The most common genetic cause of intellectual disabilities is Down syndrome. Since John Langdon Down's identification of what came to be known as Down syndrome in 1866, the diagnosis has been tied to the specific, characteristic facies that distinguishes Down syndrome from other disabilities. The identification of trisomy 21 as the chromosomal anomaly causing Down syndrome in 1959 led to the ability to diagnose Down syndrome via chromosomal analysis, but the appearance of the infant or child being diagnosed remained key to clinical diagnosis.[12] Historian of medicine Andrew Hogan has argued that the identification of Down

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[11] Carey, Block, and Scotch, *Allies and Obstacles,* 100-106.

[12] Jérôme Lejune, Marthe Gautier, and Raymond Turpin, "Etude de chromosomes somatiques de neuf enfants mongoliens," *Comptes rendus hebdomadaires des séances de l'Académie des Sciences* 248 (11): 1721-22.

syndrome with this physical dysmorphia shaped the expectations for genetic disabilities in post-war America, leading geneticists to search for other physical markers of difference.[13] By then, Down syndrome was the paradigmatic childhood developmental disability, due in no small part to its immediate legibility through its characteristic facies.[14]

In 1943, child psychiatrist Leo Kanner first used the term "autism" as a discrete diagnosis. He described eleven children, patients at his clinic at Johns Hopkins, who were emotionally distant and had "an obsessive desire for the maintenance of sameness."[15] From these two traits, Kanner described the diagnosis of autism. A year later in Vienna, Hans Asperger published a paper describing four children whom he diagnosed with autistic psychopathy. These children, like Kanner's patients, seemed emotionally distant but, unlike Kanner, Asperger described his cases as having advanced language skills and particular interests in science and math.[16] These two autisms developed in parallel, with Kanner's work becoming widely known in the English-speaking world and internationally, while Asperger's contributions were primarily limited to German scientific literature until the 1970s. Child psychiatrist Lorna Wing's 1981 paper on Asperger's work brought discussion of the two diagnoses to a wide audience, and Wing

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[13] Hogan, *Life Histories*, 4-5.

[14] Developmental disability is a legal category created in the 1970s, primarily through the 1975 Developmental Disabilities Assistance and Bill of Rights Act. The DD Act defined developmental disability as any disability that a person was born with or acquired before age twenty-one that involved significant social, physical, and/or educational differences. In practice, autism, intellectual disabilities, and cerebral palsy were most commonly described under this categorization. For more, see Carey, Block, and Scotch, *Allies and Obstacles*, 91-93.

[15] Leo Kanner, "Autistic disturbances of affective contact," *Nervous Child* 2 (1943): 217-250. Reprinted in Leo Kanner, *Childhood Psychosis: Initial Studies and New Insights* (Washington, D.C.: V.H. Winston, 1973), 37.

[16] Lorna Wing, "Asperger's Syndrome: A Clinical Account," *Psychological Medicine* 11, no. 1 (February 1981): 115–29. For more on Hans Asperger, see Edith Sheffer, *Asperger's Children: The Origins of Autism in Nazi Vienna* (New York: W. W. Norton & Company, 2018).

popularized the concept of an autism continuum or spectrum, spanning a complex dimension of differences on which Kanner's patients and Asperger's patients both existed.

While Kanner and many of his contemporaries viewed autism as a rare condition, Wing's work reflected a broadening of the diagnosis. In the decades following Kanner's initial paper, researchers estimated autism prevalence to be around two to four children per 10,000.[17] Due to a varied set of reasons including changing diagnostic criteria and increased awareness of the condition, autism prevalence increased significantly beginning in the 1990s.[18] By 2000, the Centers for Disease Control estimated autism prevalence to be one in 150. As of 2020, the CDC's estimate was one in fifty-four.[19] The popular construction of autism rates since the early 2000s has been that of an epidemic, of uncontrolled—and alarming—growth.[20]

The question of why autism rates have increased significantly over the late twentieth and early twenty-first centuries has been of considerable popular and academic interest, including to historians, anthropologists, and social scientists interested in the history of the condition. Roy Grinker's cross-cultural anthropological study of autism challenged the popular assertion of an autism epidemic, finding the increase in diagnoses in the growth of psychiatry, advocacy, and education and insisting that the meaning of autism is contingent on local understandings of disease and identity.[21] Sociologist Gil Eyal has argued that the deinstitutionalization movement

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[17] Lorna Wing and David Potter, "The Epidemiology of Autistic Spectrum Disorders: Is the Prevalence Rising?," *Mental Retardation and Developmental Disabilities Research Reviews* 8, no. 3 (2002): 151–61.

[18] Bonnie Evans, *The Metamorphosis of Autism: A History of Child Development in Britain* (Manchester: Manchester University Press, 2017)*;* Gil Eyal et al, *The Autism Matrix: The Social Origins of the Autism Epidemic* (Cambridge: Polity, 2010).

[19] CDC, "Data and Statistics on Autism Spectrum Disorder," Centers for Disease Control and Prevention, September 25, 2020, https://www.cdc.gov/ncbddd/autism/data.html.

[20] Eyal et al., *The Autism Matrix.*

[21] Roy Richard Grinker, *Unstrange Minds: Remapping the World of Autism: A Father, a Daughter, and the Search for New Answers* (New York: Basic Books, 2007).

of the 1960s and 70s has resulted in the increasing prevalence of autism, as new networks of expertise centered on child development emerged that linked psychiatrists, psychologists, therapists, and parents in producing meaningful diagnoses of autism.[22] Historian Bonnie Evans's book *The Metamorphosis of Autism* stresses that the rise of children's rights and the refashioning of child development in the UK in the 1960s produced the current global interpretation of the autism diagnosis and the corresponding growth in autism rates.[23] Journalist Steve Silberman examined the history of autism with a particular focus on the rise of the neurodiversity movement in his popular work *Neurotribes*. Arguing for the increase in autism's prevalence as a function of changing diagnostic categories, Silberman asserted the value of the "spectrum-making" of autism that emerged when Lorna Wing introduced Hans Asperger's work into English in 1980 and the potential benefits that earlier adoption of Asperger's interpretation of autism characteristics and exceptionalism could have had for individuals and families with autism.[24]

In this same period, the population of people with Down syndrome has also increased in American society. While the CDC has studied autism prevalence since 1998 via population sampling, there is neither a corresponding sampling system for Down syndrome nor a population-based registry as exists in other countries. One 2017 study estimated that the number of people with Down syndrome living in the United States has grown from 49,923 in 1950 to 206,366 in 2010, with a prevalence of one in 1,499 in 2010.[25] Another study estimated the

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[22] Eyal et al, *The Autism Matrix.*

[23] Evans, *The Metamorphosis of Autism.*

[24] Steve Silberman, *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity* (New York: Penguin, 2015).

[25] Gert de Graaf, Frank Buckley, and Brian G. Skotko, "Estimation of the Number of People with Down Syndrome in the United States," *Genetics in Medicine* 19, no. 4 (April 2017): 439.

population at 250,700 in 2008.[26] These estimates reflect changes in the birth rate of Down syndrome, including maternal age over time and the availability and frequency of amniocentesis and selective abortion, as well as changes to life expectancy for people with Down syndrome resulting from improvements in medical care from birth and deinstitutionalization. In 1950, the mean life expectancy for someone with Down syndrome was twenty-six years; the median life expectancy was just four years. In 2010, the mean life expectancy was fifty-three years and the median life expectancy was fifty-eight.[27] Over these years, the growing availability and acceptability of both prenatal diagnosis and abortion access have shaped a cultural expectation that Down syndrome is under imminent threat of being eliminated.[28] The belief that soon, all cases will be identified prenatally and terminated informs articles like "The Last Children of Down Syndrome."[29] These narratives of changing prevalence for autism and Down syndrome—that autism grew to epidemic proportions, and Down syndrome is soon to be rendered obsolete—form the backdrop to the history examined in this thesis. Awareness of and concern over autism grew at the same time that diagnostic technologies for Down syndrome shifted the cultural meaning of the diagnosis to a decision made during pregnancy. Memoirs from parents and people with Down syndrome and autism contended with these understandings of each diagnosis in their writings.

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[26] Angela P. Presson et al., "Current Estimate of Down Syndrome Population Prevalence in the United States," *The Journal of Pediatrics* 163, no. 4 (October 1, 2013): 1163.
[27] de Graaf et al, "Estimation," 446.
[28] Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (New York: Routledge, 1999).
[29] Sarah Zhang, "The Last Children of Down Syndrome," *The Atlantic*, November 18, 2020, https://www.theatlantic.com/magazine/archive/2020/12/the-last-children-of-down-syndrome/616928/.

This work engages with several literatures in the history of medicine and disability studies. Methodologically, the use of memoirs and parent-authored guidebooks as sources draws upon scholarship on disability life writing and, more broadly, illness narratives. The study of illness narratives has illuminated the ways that patients make sense out of their experiences with sickness and make meaning out of the process of symptoms, diagnosis, and treatment.[30] Psychiatrist and anthropologist Arthur Kleinman defines illness as "the innately human experience of symptoms and suffering… how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability."[31] The narratives that are available to patients reveal cultural expectations of illness, while the production of such narratives into monographs imposes the conventions of book-length storytelling on the complexity of lived experience, shaping such narratives and influencing the lived experience.[32] Illness narratives have been of particular interest to certain elements of the medical profession, such as psychiatry, as well as scholars in the medical humanities.[33]

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[30] Rita Charon, "Narrative Medicine: Attention, Representation, Affiliation," *Narrative* 13, no. 3 (2005): 261–70; Kathlyn Conway, *Beyond Words: Illness and the Limits of Expression* (Albuquerque: UNM Press, 2013); Arthur Frank, "Five Dramas of Illness," *Perspectives in Biology and Medicine* 50 (February 1, 2007): 379–94; Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995); Rebecca Garden, "Disability and Narrative: New Directions for Medicine and the Medical Humanities," *Medical Humanities* 36, no. 2 (December 1, 2010): 70–74; Rebecca Garden, "Who Speaks for Whom? Health Humanities and the Ethics of Representation," *Medical Humanities* 41, no. 2 (December 2015): 77–80; Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Ind.: Purdue University Press, 1993); Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (Boston: Basic Books, 1988).
[31] Kleinman, *The Illness Narratives*, 3.
[32] Rebecca Garden, "Telling Stories about Illness and Disability: The Limits and Lessons of Narrative," *Perspectives in Biology and Medicine* 53, no. 1 (2010): 121–35.
[33] For example, Susan K. Cahn, "Border Disorders: Mental Illness, Feminist Metaphor, and the Disordered Female Psyche in the Twentieth-Century United States," in *Disability Histories*, eds. Susan Burch and Michael Rembis (Urbana: University of Illinois Press, 2014), 258-283.

While illness narratives can concern disabled subjects, and Kleinman's argument for a distinction between illness and disease hinges upon the experiential expansiveness of illness, illness, with its connotation of suffering, is not inherently or necessarily an aspect of disability.[34] As English professor Rachel Adams notes, "Disease is, by definition, an unwanted, pathological state, whereas disabilities are more ambiguous."[35] Disability narratives thus have points of intersection with illness narratives; however, I would not describe the memoirs analyzed within this thesis as illness narratives, but disability narratives. The historiography analyzing disability narratives is informed by additional literature from disability studies.[36] English professor G. Thomas Couser has been particularly influential in his examinations of life writing, as literary scholars identify the genre, concerning disability and illness.[37] Couser's work argues that the rise of life writing concerning disability, a category that includes obituaries and documentaries as well as literary memoirs, is "the most important development in American life writing in the last three decades or so and thus a cultural and historical phenomenon of great significance."[38] Literary scholar Anne Hunsaker Hawkins identifies pathography—autobiographies by an author with a particular illness—as a genre that was "uncommon before 1950 and rarely found before

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[34] For more on the distinction between being healthy or unhealthy disabled, see Susan Wendell, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," *Hypatia* 16, no. 4 (2001): 17–33.

[35] Rachel Adams, "The Special, the Inclusive, and the Universal," in Alison Piepmeier, *Unexpected: Parenting, Prenatal Testing, and Down Syndrome* (New York: NYU Press, 2021), 133.

[36] Susannah B. Mintz, *Unruly Bodies: Life Writing by Women with Disabilities* (Chapel Hill: University of North Carolina Press, 2007).

[37] G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: University of Wisconsin Press, 1997), 4; Couser, *Signifying Bodies: Disability in Contemporary Life Writing* (Ann Arbor: University of Michigan Press, 2009); Couser, *Vulnerable Subjects: Ethics and Life Writing* (Ithaca: Cornell, 2004).

[38] Couser, *Signifying Bodies*, 3.

1900."[39] As Couser notes, "Although it is often not recognized as such, eluding most critics' radar, disability has become one of the pervasive topics of contemporary life writing."[40] Couser argues that disability life writing as a genre coheres around the purpose of destigmatizing the condition that the work concerns, and aligns the genre with the postcolonial autoethnography as defined by Mary Louise Pratt: "instances in which colonized subjects undertake to represent themselves in ways that engage with [read: contest] the colonizer's own terms."[41]

Parent memoirs diverge from other disability life narratives in important ways. In her analysis of parent memoirs, Alison Piepmeier finds that Couser and Susannah Mintz's arguments that disability memoirs offer liberatory challenges to conventional, tragic depictions of disability do not necessarily hold true within the genre of parent memoirs. Piepmeier argued in 2012 that parent memoirs had been largely ignored by studies of life writing and disability studies, arguing that such works "reveal the powerful hold that formulaic narratives have, but they also offer glimpses of the ways they can and should be resisted and overturned."[42] Since Piepmeier's work, Allison C. Carey has examined the relationship of parents to professionals and the medical establishment as expressed through memoirs about a child with intellectual disability, revealing the complexity that parents faced in navigating the changing rights and therapies available to their children from the 1950s to the 1980s.[43] Amy C. Sousa analyzes the memoirs of mothers of intellectually disabled children to find a shift in maternal symbolism from mother blaming in the

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[39] Hawkins, *Reconstructing Illness*, 3.

[40] Couser, *Signifying Bodies*, 3.

[41] Mary Louise Pratt, *Imperial Eyes: Travel Writing and Transculturation* (London: Routledge, 1992), 7, quoted in Couser, *Signifying Bodies*, 8.

[42] Piepmeier, "Saints, Sages, and Victims."

[43] Allison C. Carey, "Parents and Professionals: Parents' Reflections on Professionals, the Support System, and the Family in the Twentieth-Century United States," in *Disability Histories*, eds. Susan Burch and Michael Rembis, (Urbana, Chicago, and Springfield: University of Illinois Press, 2014), 58-76.

post-war period to the dominance of the fighting warrior figure in the late-twentieth and early-twenty-first centuries.[44] In this thesis, I examine the ways that parents of children with autism and Down syndrome reinscribed and resisted the formulaic narratives identified by Piepmeier, Couser, Frank, and others, arguing that the narratives available to autism and Down syndrome shaped the meaning that parents brought to each condition and to the role of parents in creating authority for that meaning. By examining parent memoirs alongside scientific literature, guidebooks, media coverage of the diagnoses, and writings by disabled adults, this work expands upon the historiography on parents of developmentally disabled children, revealing how parents have navigated the changing cultural attachments to the terms autism and Down syndrome and how the particularities of each diagnosis shaped parent experiences.

Over the second half of the twentieth century, the genre of disability memoirs, and disability life narratives more broadly, blossomed in the American publishing landscape. The definitions of and distinctions between memoir and autobiography are historically contingent and lack universal coherence.[45] Couser delineates a distinction between memoir and autobiography in *Signifying Bodies:* "Memoir is a notoriously vague term. It generally is understood to refer to a first-person narrative in which someone or something other than the narrator is central—the narrator's parent, child, spouse, partner, or career... In the case of illness narrative the key distinction has to do with whether the narrator is ill or a witness to another's illness."[46] The

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[44] Amy C. Sousa, "From Refrigerator Mothers to Warrior-Heroes: The Cultural Identity Transformation of Mothers Raising Children with Intellectual Disabilities," *Symbolic Interaction* 34, no. 2 (2011): 220–43.

[45] Sidonie Smith and Julia Watson, *Reading Autobiography: A Guide for Interpreting Life Narratives,* Second Edition (Minneapolis: University of Minnesota Press, 2010), 1-19; Margaretta Jolly, ed., *Encyclopedia of Life Writing: Autobiographical and Biographical Forms*, 1st edition (London: Routledge, 2001).

[46] Couser, *Signifying Bodies,* 16.

former, in Couser's explanation, was an autobiography, the latter, a memoir. In this work, I have tended to use memoir as a broader category than autobiography, strictly referring to the latter for works of self-narrative, while memoir includes narratives of self and narratives of witnesses, particularly works that focus on a particular period or a precipitating event rather than a full life history. In this way, the language reflects the broadening of memoir as a term for life writing. In 2011, Couser identified memoir as "the preferred term for literary life writing," noting the decline of the autobiography in the twenty-first century.[47]

Autism has been a subject of considerable recent historical scholarship. The role of parents, particularly parent activism, has been a particular focus. Historian of medicine Chloe Silverman has argued for the significance of love in shaping parental organization and activism, paying particular attention to parents' pursuit of alternative medical treatments for autism.[48] Gil Eyal's sociological study of the autism epidemic argues for the significance of parent organizations and scientific researchers who were also parents to an autistic child in attempting to create a clear definition and diagnostic criteria for autism.[49] The growth of autism parent advocacy and the "Autism wars" between parents and autistic self-advocates over the questions of whether to pursue a cure for autism or accept autism as a valuable aspect of human diversity are one focus of *Allies and Obstacles*.[50] Journalists John Donovan and Caren Zucker’s *In a Different Key: The Story of Autism* argues that the failures of autism research and treatment led to parental advocacy and rejection of the medical establishment, particularly in the rise of theories about the role of vaccines in causing autism. Sociologist Jennifer Singh examines the

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[47] Couser, *Memoir: An Introduction* (Oxford University Press, 2011), 9.
[48] Chloe Silverman, *Understanding Autism: Parents, Doctors, and the History of a Disorder* (Princeton: Princeton University Press, 2012).
[49] Eyal et al, *The Autism Matrix.*
[50] Carey, Bloch, and Scotch, *Allies and Obstacles*.

roles parents have played in constructing genetic and genomic explanations for autism and pushing autism research towards those ends.[51] Rhetorical scholar Jordynn Jack's *Autism and Gender: From Refrigerator Mothers to Computer Geeks* studies the relationship between gender and autism discourse in history, considering shifting gendered roles for mothers and fathers along with the specifically gendered ways that autism as a diagnosis has taken.[52] Historian of science Marga Vicedo's recent book, *Intelligent Love*, examines the history of autism through a prism created by Clara Park and her writing about her daughter, arguing for Park's influence in resisting and rejecting the refrigerator mother theory of autism causation.[53]

The history of Down syndrome is significantly less studied than the history of autism. David Wright's book, *Downs: The History of a Disability*, which follows the social and scientific history of what became known as Down syndrome from before the naming of the diagnosis, remains the only monograph on the subject.[54] Wright traces the shifting scientific understanding of Down syndrome and the consequences of such knowledge for the experiences of people with the condition. The broader history of intellectual disability encompasses works that address the history of parent activism around Down syndrome.[55] Sociologist Allison C. Carey's *On the Margins of Citizenship* is a particularly valuable history of the fight for civil rights for people with intellectual disabilities. Carey analyzes how parents have understood the rights that they

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[51] Jennifer S. Singh, *Multiple Autisms: Spectrums of Advocacy and Genomic Science* (Minneapolis: University of Minnesota Press, 2016).
[52] Jordynn Jack, *Autism and Gender: From Refrigerator Mother to Computer Geek* (Champaign-Urbana: University of Illinois Press, 2014).
[53] Vicedo, *Intelligent Love*.
[54] Wright, David. *Downs: The History of a Disability*. Oxford: Oxford University Press, 2011.
[55] Katherine Castles, "'Nice, Average Americans': Postwar Parents' Groups, and the Defense of the Normal Family," in *Mental Retardation in America: A Historical Reader*, eds. Trent and Steven Noll and James W. Trent (New York: New York University Press, 2004); Trent, *Inventing the Feeble Mind*.

believe their children to deserve and how their depictions of intellectual disability shape the establishment and instability of rights.[56] In *Allies and Obstacles*, Carey, Pamela Bloch and Richard Scotch examine parents of children with Down syndrome as part of their study of parents of children with intellectual disabilities, finding the ways that parents both collaborate and reject alliances with disability activists.[57] This thesis argues for the particular ways that parents of autistic children distinguished themselves from the parents of children with Down syndrome through their responses to mother-blaming and ability to construct recovery narratives for the condition, creating a position of parent expertise and authority over the autism diagnosis that transcends what was available for other parent advocates. As autism incidence rates have grown, so has the authority of parents within the cultural meaning of autism. Meanwhile, despite Down syndrome having a clear etiology in its chromosomal origin, something that many parents continue to seek for autism, its legibility prenatally has cultivated Down syndrome's cultural attachment to pregnancy, rather than a broad meaning that incorporates people with Down syndrome and their families across the lifespan.[58]

Another historiography with which this work engages is on disability as a source of public fascination and a site for cultural identity formation. While these questions have been examined for a variety of specific disabilities and disability categories, the cultural representation of Down syndrome specifically is not a well-studied subject.[59] In contrast, autistic representation

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[56] Allison C. Carey, *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-Century America* (Philadelphia: Temple University Press, 2009).

[57] Carey, Bloch, and Scotch, *Allies and Obstacles*.

[58] For more on genetic and genomic research on autism and parent advocacy, see Singh, *Multiple Autisms* and Navon, *Mobilizing Mutations*.

[59] For works on disability and representation, see Sander L. Gilman, *Seeing the Insane* (Hoboken, N.J.: Wiley, 1982); Martin Halliwell, *Images of Idiocy: The Idiot Figure in Modern Fiction and Film* (London: Ashgate, 2004); Paul K. Longmore, *Why I Burned My Book and Other Essays on Disability* (Philadelphia: Temple University Press, 2003); Paul K. Longmore,

and identity and identity formation is a topic of scholarship. Philosopher Ian Hacking has written about the relationship between autism and the internet, suggesting that the popular interest in fiction concerning autism reflects how the internet shapes autistic styles of communication for neurotypical persons while it facilitates opportunities for non-interactive communication for autistic people.[60] Professor of Literature Stuart Murray's work explores the relationship between autism and popular culture, analyzing the metaphorization and narrativization of autism in literature, media, and the arts and offering the concept of an "autistic presence" as a means of recentering the material experiences of autism within its cultural paradigm.[61] The edited collection *Autism and Representation* examines historical and contemporary depictions and constructions of autism, including through memoir, film, and clinical discourses.[62] This thesis argues that placing the histories of autism and Down syndrome in communication and examining the specific ways the discourse around each diagnosis developed over the second half of the twentieth century illuminates the cultural representations of each condition.

Post-war disability activism and parent activism have been the subjects of a growing literature in disability history and the history of medicine. Parent memoirists often have political and activist aims for their work, placing memoirs within a broader set of actions of parent advocacy. Parent activism has not operated as a singular, cross-disability movement throughout

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Telethons: Spectacle, Disability, and the Business of Charity (New York: Oxford University Press, 2016); Rosemarie Garland Thomson, 'Disability and Representation," *PMLA* Vol. 120, No. 2 (Mar., 2005), pp. 522-527; Rosemarie Garland Thomson, *Extraordinary Bodies*; Joseph P. Shapiro, *No Pity: People with Disabilities Forging a New Civil Rights Movement* (New York: Crown, 1994).

[60] Ian Hacking, "Autism Fiction: A Mirror of an Internet Decade?," *University of Toronto Quarterly* 79, no. 2 (Spring 2010): 632–55, https://doi.org/10.3138/UTQ.79.2.632.

[61] Stuart Murray, *Representing Autism: Culture, Narrative, Fascination* (Liverpool: Liverpool University Press, 2008).

[62] Mark Osteen, ed., *Autism and Representation* (New York and London: Routledge, 2008).

its history, but encompasses a variety of goals and actions, often focusing on specific disabilities and disability categories. The historian Katherine Castles argues that in the postwar period, "the American preoccupation with the idealized middle-class family, with a mother at home raising psychologically healthy children, led to a rising concern for mental retardation as a problem of young children and their families."[63] A significant animating factor for parent advocacy has been the care their children received in state-run institutions for the disabled. In the mid-twentieth century, institutionalization dominated the professional disability landscape, as doctors advised parents that early institutional placement was the appropriate action for an intellectually disabled child.[64] For children with Down syndrome, often diagnosed as newborns on the basis of their distinctive physical features, doctors often recommended institutionalization from birth.[65] According to Castles, in her study of postwar parent groups, the institutionalization of children with intellectual disabilities under age six doubled in the period between 1945 and 1955, a

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[63] Castles, "Nice, Average Americans," 353. For more on motherhood, see Rima Apple, *Perfect Motherhood: Science and Childrearing in America* (New Brunswick, N.J: Rutgers University Press, 2006); Linda M. Blum, "Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities," *Gender and Society* 21, no. 2 (2007): 202–26; Molly Ladd-Taylor and Lauri Umansky, eds., *Bad Mothers: The Politics of Blame in Twentieth Century America* (New York: New York University Press, 1997); Gail Heidi Landsman, *Reconstructing Motherhood and Disability in the Age of "Perfect" Babies*, (New York: Routledge, 2009); Rebecca Jo Plant, *Mom: The Transformation of Motherhood in Modern America* (Chicago: The University of Chicago Press, 2010); Sousa, "From Refrigerator Mothers to Warrior-Heroes"; and Deborah Weinstein, *The Pathological Family: Postwar America and the Rise of Family Therapy* (Ithaca, NY: Cornell University Press, 2013).

[64] For more on institutions for disabled children and adults, see Carey, *On the Margins of Citizenship;* Deborah Blythe Doroshow, *Emotionally Disturbed: A History of Caring for America's Troubled Children* (University of Chicago Press, 2019); Sarah F. Rose, *No Right to Be Idle: The Invention of Disability, 1840s–1930s* (Chapel Hill: UNC Press, 2017); Trent, *Inventing the Feeble Mind.*

[65] Castles, "Nice, Average Americans," 363.

change borne out of lowering the age of eligibility for institutional residency and increasing community pressure for placements for young children.[66]

Institutional care was marked by neglect, abuse, disease, and overcrowding. The appalling treatment within institutions led Pennsylvania Governor George H. Earle to comment in 1937 that he "found conditions [in public institutions] that were so lacking in humaneness as to be almost unbelievable in a great civilized Commonwealth."[67] Families felt immense shame over having a child with an intellectual disability. Throughout the early twentieth century, the structure of institutionalization left parents disempowered to improve their children's living conditions. Many gave up their legal parental rights when their children entered state care. Parents' attempts to advocate for their children were often met with abusive retaliation against the child. One parent wrote in 1948, "Parents with this type of child are handicapped by the fact that there is no other way to care for them and if they state their belief that something is wrong with the manner in which an institution is managed, the child may not even get what attention he is receiving."[68] Institutionalized children and adults received little-to-no services, education, or training. As a result, they became more disabled over time, without hope for a return to their families and communities.

Beginning in the 1940s, parents of children with intellectual disabilities, including Down syndrome, were among the earliest parent activists to organize and effect change in disability policy at the state and national levels. As one mother of a child with an intellectual disability wrote in a newspaper ad in 1949, "Surely there must be other children like him, other parents

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[66] Castles, 362.
[67] Quoted in Carey, Block, and Scotch, *Allies and Obstacles,* 36.
[68] Quoted in Carey, Block, and Scotch, 37.

like myself. Where are you? Let's band together and *do something* for our children!"[69] Castles recounts that this mother's ad resulted in the foundation of the Association for the Help of Retarded Children (AHRC), with a thousand members within a year, an outcome that is consistent with the growth of parent organizations in this time.[70] In 1950, the AHRC and other local groups joined together to form the Arc. According to Castles, "by 1960, [the Arc] had 681 local affiliates and a membership of 62,000."[71] Parents joined together, forming parent groups that challenged the stigmatization of intellectual disability, offered support to families in their communities, and established services that would aid the members of their groups.

In the same moment as this early parent-led activism, foundational works for the genre of parent memoirs about disabled children emerged. Parent memoirists including Nobel Prize-winning novelist Pearl Buck and Dale Evans Rogers shared the love they felt for their children, demanding societal recognition of their children's humanity and insisting upon improved care whether in institutions or in the community. Buck's daughter lived in a residential school in New Jersey, which Buck had chosen because of the quality of care she saw there, with staff who treated residents kindly and humanely.[72] She supported the reform of institutions and a high standard of care for all who lived there. Buck's work was soon followed by John Frank's *My Son's Story*, which described the middle-class law professor's experience finding an institutional placement for his toddler with intellectual disabilities, and *Angel Unaware,* the most popular

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[69] Quoted in Castles, "Nice, Average Americans," 351.

[70] Castles, 351.

[71] The Arc has had several names in its history, beginning with the National Organization for Retarded Children. For simplicity's sake and in recognition of the organization and other disability activists' rejection of the term "retarded" as a slur, I will consistently refer to it as its contemporary name, the Arc. Castles, 351.

[72] Carey, *On the Margins of Citizenship*, 110.

parent memoir of its time.[73] Parent narratives like these shifted the meaning of a child with an intellectual disability away from being a shameful mark on their family into a valued family member whose life should be cherished.

As their activism grew in the 1960s, parents asserted their children's rights. Court cases that mandated the right to an education, including 1971's landmark victory, *PARC v. Commonwealth of Pennsylvania*, "affirmed parents' right to due process in relation to educational decision and to participate in such decisions."[74] In 1975, building on the legal victory of *PARC*, Congress passed the Individuals with Disabilities Education Act (IDEA), originally titled the Education for All Handicapped Children Act, which legislated the right of all children to a public education. By 1984, over ninety-three percent of disabled children in the United States were being educated in mainstream schools.[75]

Parents were not united in opposition to institutionalization. Many parents remained committed to institutionalization and demanded reform, rather than closure. As institutions closed in the 1970s and 80s, residential placement options grew to replace them. The Arc's position, as the largest parent organization, changed over the decades, moving from support for improved conditions and treatment in institutions to support for deinstitutionalization and the right of all disabled people to receive services in the community by 1982.[76] Other parent organizations formed in opposition to the Arc's support for community integration. Parents formed the first autism-specific organization, the National Society for Autistic Children, in 1965. Down syndrome-specific organizations grew in the 1970s.

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[73] Carey, 111-12.

[74] Carey, Block, and Scotch, *Allies and Obstacles,* 44.

[75] Margret A. Winzer, *The History of Special Education: From Isolation to Integration* (Washington, D.C.: Gallaudet University Press, 1993), 382.

[76] Carey, Block, and Scotch, *Allies and Obstacles,* 46.

In the same period, disability activists mobilized, inspired by the civil rights movement in Black activists’ demands for equality and effective forms of non-violent protest. While disability activism in the early- to mid-twentieth century had involved organization around specific disabilities, such as the League of the Physically Handicapped and the National Association of the Deaf, the disability activism of the 1960s and 70s marked the development of cross-disability organization. Efforts included the 504 Sit-in, in which disabled activists demanded the enforcement of the 1973 Rehabilitation Act’s prohibition of disability-related discrimination by federally funded services, programs, and agencies; the Independent Living Movement’s actions to create services to support community inclusion for disabled people; and ADAPT activists blocking buses that were not wheelchair accessible.[77] The history of disability activism is vast and complex and cannot be adequately represented here. Disability activists fought for their right to be recognized culturally and politically as the authority on disability policy and the needs of the disability community.

This history shapes the development of parent memoirs and guidebooks and the publication of memoirs by adults with autism and Down syndrome over the post-war period. The changing rights of children and responsibilities of parents established parent motivations for their writing, informed parents' models for good parenting—especially good mothering—of a disabled child, and structured parents' and children's experiences. Parent memoirists were typically

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[77] For more on the disability rights movement and disability activism, see Lennard Davis, *Enabling Acts: The Hidden Story of How the Americans with Disabilities Act Gave the Largest US Minority Its Rights* (Boston: Beacon Press, 2015); Doris Zames Fleischer and Frieda Zames, *The Disability Rights Movement: From Charity to Confrontation* (Philadelphia: Temple University Press, 2011); Kim E. Nielsen, *A Disability History of the United States* (Boston: Beacon Press, 2012); James I. Charlton, *Nothing About Us Without Us: Disability Oppression and Empowerment* (Berkeley: University of California, 1998); Fred Pelka, *What We Have Done: An Oral History of the Disability Rights Movement* (Amherst: University of Massachusetts Press, 2012); and Shapiro, *No Pity.*

engaged with local, if not national or international advocacy for their children, whether their memoir was the beginning of such work or a reflection of it. For example, Clara Park channeled the responses she received from other parents into her work with the nascent National Society for Autistic Children.[78] When Jason Kingsley and Mitchell Levitz, both of whom have Down syndrome, wrote *Count Us In* as teenagers in the 1990s, they were both experienced as self-advocates. They had begun their careers as babies on *Sesame Street* and accompanying their parents to meetings and events for Down syndrome, progressing to congressional appearances and television interviews. Memoirs reveal changing experiences, rights, and meanings for autism and Down syndrome while also shaping these cultural changes through their circulation.

The language used to describe disability is controversial. Conventions and preferences vary individually, by disability community, geographically, and historically. Throughout the history of disability activism, disabled people have fought for the right to define their own identities, recognizing the importance of language to how we understand and interpret disability.[79] In contemporary usage, the conventions around *person-first* language or *disability-first* language are tied to specific individual and group preferences. In the United States, person-first language—e.g. a man with Down syndrome—is generally preferred by parents, professionals, and self-advocates within the intellectual disability community, including within the Down syndrome community. Person-first constructions emphasize the individual, rather than the disability in recognition of disability as only one aspect of life and the complex humanity of

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[78] Vicedo, *Intelligent Love.*

[79] Paul Longmore writes about the longer history of disability language in his essay on the League for the Physically Handicapped, an advocacy group during the Great Depression that fought to identify as handicapped, rather than crippled, paralytic, or invalid. Longmore, *Why I Burned My Book*, 69.

each person. Many disability activists and certain disability communities, including the autistic community, prefer disability-first language, as in autistic person or autist. Disability-first language politicizes disability as an identity, as its proponents insist that disability is a central aspect to the lived experience of the disabled person and argue that person-first language divorces the person from the impairment.[80]

In this work, I have relied on the general contemporary preferences of the Down syndrome and autism communities for person-first and disability-first language as much as possible. At times, my language has varied (e.g., writers with Down syndrome and autism; disabled children; adults with disabilities) according to clarity and ease and as a reflection of the fact that there is no singular consensus on this subject. My intention has always been to respect the identity of my actors and their varied views on language and disability identity. Given that the conventions around disability language and the diagnoses of Down syndrome and autism have changed over time, I tend to use the language of contemporary diagnoses. Certain terms—specifically, variations on "mental retardation" and "mongoloid"—were common in the past, whether used neutrally or intentionally as offensive. These terms are highly offensive slurs today.[81] At times throughout the dissertation, I have selectively chosen and edited quotes to

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[80] John Swain and Sally French, "Whose Tragedy: Towards a personal non-tragedy view of disability," in *Disabling Barriers – Enabling Environments: An Introduction to Disability Studies*, 2nd ed., eds. John Swain et al. (London: Sage, 2004), 34-40.

[81] Use of Down syndrome, previously Down's syndrome, has been preferred in English since the 1960s, although use of "mongolism" did continue for some time. The intellectual disability community has objected to the use of "retard[ed]" throughout the twenty-first century. See Wright, *Downs*, 115-119; Neda Ulaby, "Rethinking 'Retarded': Should It Leave The Lexicon?," *WBUR*, September 8, 2009, https://www.wbur.org/npr/112479383/rethinking-retarded-should-it-leave-the-lexicon; "About Spread the Word," Spread the Word, February 7, 2019, https://www.spreadtheword.global/about.

refrain from gratuitously quoting these phrases, as I recognize their potential to cause harm. However, such language does appear.

In the first chapter, I examine the ways that beauty in autism discourse and joy for Down syndrome offer aestheticized constructions of each diagnosis. For parents and professionals working to construct a meaningful diagnosis of autism, the physical beauty of autistic children offered a site for the articulation of difference for the condition in comparison to the expectation of childhood developmental disability, namely the particular physical features of Down syndrome. Parents of children with Down syndrome used their memoirs to challenge the stigmatization of the diagnosis by creating an expectation for children with Down syndrome as happy, well-loved members of the family. In their descriptions of physicality and temperament, parents contrasted autism with Down syndrome.

Chapter two looks at the differing opportunities afforded to parent narratives of Down syndrome and autism regarding the etiological understanding of each diagnosis. As Down syndrome became fixedly attached to the chromosomal anomaly trisomy 21 and prenatal testing made selective abortion possible, parents were forced to wrestle with a cultural narrative that a child with Down syndrome was a deliberate choice that required justification. Theories on autism’s etiology have been inconsistent and controversial throughout its history. Parents have capitalized on autism’s plasticity to promote their own treatments, establish their own authority over the diagnosis, and challenge popular understandings of the condition and motherhood.

Parent guidebooks on autism and Down syndrome are the focus of chapter three. Throughout these works, parents as authors, as contributors to professionally-authored books, and as intended audience shape the messages of imagined community and parental expertise that such books contain. Guidebooks on Down syndrome indicate the potential for quality professional care alongside the need for asserting parental authority over care for a child with Down syndrome. Parents of autistic children use guidebooks to amplify the authority over autism and over their children's futures that they convey in memoirs. Rather than a collaborative effort between parents and professionals, the parents of autists warn the reader about the threat that the medical establishment poses to their families and insist that no one can be trusted about autism—except another parent.

In the fourth chapter, I analyze the voices of people with Down syndrome and autism through their own life narratives. Looking at significant memoirs and autobiographies between the 1960s and 1990s reveals the ways that these disabled authors have challenged the expectations and understandings for people with Down syndrome and autism at the time of publication as well as the changing opportunities and self-created meaning for each diagnosis over time. While memoirs by writers with Down syndrome emphasize their success at assimilating into mainstream institutions and society, the rise of the neurodiversity movement ruptured the expectation of a recovery narrative for autism. Autistic autobiographies by the end of the twentieth century focused on the specificities of autism and underscored the condition as a different, yet no less valid way of being human.

The epilogue looks to the growth of disability life narratives for autism and Down syndrome in the twenty-first century. A brief analysis of two exemplary parent memoirs from the 2000s reveals the diverging paths of autism and Down syndrome in cultural prominence, as well as the competing constructions of developmental disability found in neurodiversity and in the medical model.

CHAPTER ONE

Beauty and Joy: The Aestheticization of Autism and Down Syndrome

In her 1967 memoir, Clara Claiborne Park described her daughter Jessy at age two as "a bronzed, gold baby of unusual beauty…. Many people are looking at her because she is so pretty, but she is looking at no one."[1] With this short description, Park identified the key aspects of her daughter's diagnosis of autism: beautiful and alone. According to Park, Jessy was an unusual and self-contained but attractive child, qualities which caused Park to set Jessy apart from other children with developmental disabilities. While other children's physical dysmorphia called attention to their disabilities, Jessy and other autistic children stood out for their beauty. Yet this was a beauty that their particular patterns of autistic behavior, defined as the child's "extreme aloneness" in the 1943 paper that first utilized autism as a discrete diagnosis in children, made strange and otherworldly.[2] Autism's aestheticization thus synthesized the condition's diagnostic meaning with the appearance of the children being diagnosed.

Park's description of her daughter's appearance as beautiful and unusual became a trope within the genre of parent memoirs about raising an autistic child through the end of the twentieth century. Parents saw in the ethereal appearances of the children signs of the latter's distant, detached behavior. Through the 1980s, the consistent description of autistic children as beautiful reflects parental rejection of the mother-blaming to which the psychiatric community at large subjected parents. Parents refused to accept any role for their behavior in the child's condition, seeing the child's physical beauty as disproving the implications of psychological

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[1] Clara Claiborne Park, *The Siege: The First Eight Years of an Autistic Child* (Boston: Little, Brown, and Company, 1967), 5.
[2] Kanner, "Autistic disturbances of affective contact," 37.

damage in the child. The children's attractive appearance additionally served as a distinguishing marker from other developmental and intellectual disabilities, as parents insisted that their children's beauty proved that they could not be classified as intellectually disabled. Down syndrome's distinctive facies and dysmorphia defined that condition, for example, which established expectations for identifying developmental disabilities. By contrast, beauty defined autism.

The scientific community joined parents in proclaiming the unusual beauty of autistic children. Beginning with Leo Kanner's initial identification of autism as a discrete diagnosis in 1943 and continuing through the 1970s, autism researchers considered beauty to be a constitutive element of the diagnosis. Like parents, researchers compared the characteristic attractive appearance of autism with other developmental disabilities, distinguishing autism with this beauty. The emphasis on dysmorphia as the defining aspect of Down syndrome shaped expectations for genetic disabilities in post-war America, as geneticists looked for similar signs of physical difference to indicate genetic anomalies.[3] Autism thus offered a contrasting paradigm within a broad category of mental retardation: closely associated with physical beauty, psychogenic in etiology, resolutely unlike Down syndrome. The identification of children with autism as unusually beautiful, as expressed by parents and professionals, created for autism a space for the articulation of difference with respect to other childhood developmental disabilities that was vital to the formation of the diagnosis between the 1940s and the 1970s.

Against the medical establishment's constructions of autism and Down syndrome, parents of children with these diagnoses published memoirs that offered their own understandings of these conditions. Beginning in the 1940s, parents of children with Down

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[3] Hogan, *Life Histories*, 5.

syndrome used memoirs to support political and social goals, including reducing stigma, deinstitutionalization, access to public schooling, and increased support for community integration. Parents of children with intellectual disabilities in the 1940s and 50s created narratives of exceptionalism for their children—such as eternal innocence for the intellectually disabled child, who was vulnerable, a gift from God, and deserving of support throughout life from society and the state.[4] Making disabled children exceptional formed a basis for parent advocacy through the medium of memoir.

Alongside offering narratives that supported the work of parent advocates, memoirs of Down syndrome gave parents positive interpretations of their children's condition. Portraits of Down syndrome focused on the loving personality of children with the diagnosis, leading parents such as Martha Moraghan Jablow to proclaim that that "a child with Down's syndrome is a joy."[5] Parents recounted the love, humor, and happiness of their children and report that their children teach them the true meaning of life. Such understandings of Down syndrome created a compensatory narrative to counter the negative, tragic depictions of disability that shaped the meaning of Down syndrome in popular culture and pushed parents to institutionalize their children. While the loving nature of Down syndrome allowed parents to interpret a diagnosis with hope, its aesthetic particularities continued to distinguish the condition. Parents often found their children with Down syndrome to be beautiful, but their children's appearance signaled their diagnosis. Their parents could reclaim dysmorphia as beauty but could not deny the features that identified their children's condition.

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[4] Carey, *On the Margins of Citizenship.*

[5] Martha Moraghan Jablow, *Cara: Growing with a Retarded Child* (Philadelphia: Temple, 1982), 181.

Beauty made autism unique. Parents and physicians did not protest that they found an individual child beautiful despite the diagnosis, but marveled at the unusual beauty of autistic children, a beauty that separated their children from other developmentally disabled individuals. For the parents, recognizing the exceptional beauty of their autistic children served as a redemptive component to the diagnosis, although the power of beauty was not wholly positive. The parent's relationship to the child's beauty ambiguously reflected both consolation and tragedy, as parents considered the life the child might have lived had he or she not been autistic. Their children were beautiful and autistic, two features that amplified each other, reified each other, and frequently defined the child. Beauty thus offered parents a complex site upon which to understand autism and understand their children.

Exceptional Children, Exceptional Parents: Memoirs of Disability

The genre of memoirs on parenting exceptional children, or children with exceptional needs, began with Pearl S. Buck's short book, *The Child Who Never Grew*. Originally an article published in *The Ladies' Home Journal* that Buck expanded into a book in 1950, the book details the challenges of Buck's life with her daughter Carol, who was born in 1920 with phenylketonuria. Phenylketonuria, or PKU, is a rare inherited condition that causes an inability or a difficulty in metabolizing the amino acid phenylalanine; untreated, as was at Carol's time of birth, it can result in developmental delays and intellectual disability.[6] Buck's experiences as a highly intelligent, accomplished woman—she had won the Nobel Prize for Literature in 1938—who had to learn to accept her developmentally disabled daughter was the centerpiece of her work. Making her experience public after decades of keeping Carol a secret, Buck affirmed the

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[6] For more on the history of PKU, see Diane B. Paul and Jeffrey P. Brosco, *The PKU Paradox: A Short History of a Genetic Disease* (Baltimore: Johns Hopkins University Press, 2013).

value of disabled children and established an expected narrative for the memoirs of their parents: the child will teach the parent about love, acceptance, and human dignity, and the parent will come to value the child for the exceptional qualities that their disabilities afford them. By the end of the memoir, the parent has grown, while the child remains disabled. Buck found in her daughter an inspiration for recognizing the worth and dignity of people with disabilities: "It was my child who taught me to understand so clearly that all people are equal in their humanity and that all have the same human rights."[7] As the title of her work suggests, Buck described her daughter as forever a child, innocent, vulnerable, and dependent on others, making her into the "eternal child" discussed by Allison Carey in her work on intellectual disability and the exceptionalizing of disabled children in post-war America.[8] Buck also serves as a model for the parents who typically wrote memoirs. Although unusual in her success and talent among any group—Buck is the only woman ever to have won both the Nobel and Pulitzer prizes—many of the authors of memoirs of autism and Down syndrome would share her status as a well-educated, middle- or upper-middle-class white woman.

Three years after Buck's ground-breaking work, another celebrity-parent memoir captivated the public. In 1953, Dale Evans Rogers, actress, celebrity, and wife of singing cowboy Roy Rogers, published *Angel Unaware: A Touching Story of Love and Loss*. Rogers was America's sweetheart, the "Queen of the West," starring in dozens of films and a long-running television show with her husband. The public reacted to her reveal of a daughter with an intellectual disability with deep sympathy.[9]

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[7] Pearl S. Buck, *The Child Who Never Grew* (New York: J. Day Co., 1950), 78.

[8] Carey discusses *The Child Who Never Grew* in much greater detail, focused on the ways that Buck's narrative of the eternal child demanded state and social support for disabled individuals throughout their lives. See Carey, *On the Margins,* 109-119.

[9] Carey, *On the Margins,* 112.

Rogers wrote *Angel Unaware* about the life and death of her daughter Robin, who was born with Down syndrome in 1950 and died two years later. Rogers framed the book from Robin's perspective as an angel in Heaven speaking to God about her life. Robin described her mission in life as showing all those around her the importance of faith in God's will and spreading love, crediting her parents' refusal to institutionalize her as one sign of their love for her. Overtly religious, the clear message throughout is that children with Down syndrome and other disabilities are gifts from God, deserving of reverence, who can teach the people around them about love, patience, acceptance, and Christian faith. Published by Christian publishing house Fleming H. Revell, *Angel Unaware* was the third best-selling book in 1953.[10]

Angel Unaware differs significantly from *The Child Who Never Grew*. Buck wrote simply about her own vulnerability and maternal failings throughout the challenges of raising a child with an intellectual disability, ultimately choosing for her daughter to live in a residential school that she found well-run and suited to her daughter's needs. Rogers refused to institutionalize her daughter. She wrote little about experiences that did not fit an idealized vision of faith in God's will and love for their daughter. Buck characterized her daughter as an eternal child. Rogers cast Robin as a literal angel in heaven. However, both works shared a purpose in asserting the value of the disabled population to their able-bodied families and communities. In the preface to the 1981 edition of the book, Rogers wrote about the effect *Angel Unaware* had on American culture: "Prior to the advent of [this] little book, children with Down's syndrome were seldom, if ever, seen in public by curious eyes… Every time I see a Down's syndrome child at work in school, sheltered workshops, or in routine jobs offered in many organizations, I can

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[10] Trent, *Inventing the Feeble Mind,* 234.

almost see Robin's beautiful, beautiful smile."[11] Rogers saw the influence of her work in the greater visibility of children with Down syndrome socially, while her characterization of her daughter as an angel, whose life God intended to benefit the world, influenced the broader perception of children with Down syndrome.

The genre of parent memoirs in the 1950s and 1960s grew alongside increasing organization by parents to advocate for their children. Seeking public sympathy for middle-class families with intellectually disabled children, parents fought for better medical care and public services and the right for children with disabilities to live at home and attend mainstream schools.[12] Local and national parent groups grew beginning in the late 1940s. By 1964, membership in the National Association for Retarded Children (now known as the Arc) had reached over one hundred thousand people nationwide, nearly all parents.[13] Throughout this growth in activism, parent activists used narratives in which a child with a disability was considered a blessing, in a religious sense, or a valuable member of the family and society, in a secular one, to shape public perceptions of the importance of improving the lives of the disabled. Parent memoirists, including Buck and Rogers, along with parent activists, used narratives in which a child with a disability was considered a blessing, in a religious sense, or a valuable member of the family and society, in a secular one, to shape public perceptions of the importance of improving the lives of the disabled.[14]

As Paul Longmore argues in his history of telethons, the expectation of disability in late-twentieth-century America centered on the archetype of Tiny Tim, the subject of pity and source

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[11] Rogers, "Preface," in *Angel Unaware*, 10-11.
[12] Castles, "Nice, Average Americans," 351-370.
[13] Carey, *On the Margins,* 124.
[14] Castles, "Nice, Normal Americans"; Paul Longmore, *Telethons*; Carey, *On the Margins of Citizenship*.

of burdens for his family in Dickens' *Christmas Carol*. According to Longmore, "A disabled person was a vulnerable child, one of 'the most weak.'"[15] Parent memoirs created a space in which the depiction of disability remained frozen in childhood, with the disabled person dependent on the ability of their parents to care for them, advocate for them, act as their expert, and literally write their story. Parents attempted to complicate the positioning of disability as a burden by insisting on the joy that their child created, but the parents' hard work in supporting that joy was never ignored. The vulnerability of their children remained a defining aspect of these narratives of Down syndrome and autism. As a genre, parent memoirs shaped particular meanings for each condition that aligned with the existing archetype of Tiny Tim and mediated the expectations the public held for these diagnoses. People with autism or Down syndrome had limited opportunities to participate in the construction of each diagnosis throughout this period, while their parents took on an influential role through work including memoirs.

Beauty, Inaccessible: The Aesthetics of Disability

An expectation that disability will be hideous pervades disability history. Often, studies of the aesthetics of disability have focused on physical disabilities. Beginning in the 1860s, "ugly laws" prohibited visibly disabled Americans from moving freely in public places, as Susan Schweik has explored.[16] Disability activist and scholar Harlan Hahn asks the question, "Can disability be beautiful?" in a 1988 article that sought instances of disability being considering exceptionally attractive throughout history as a challenge to the "asexual objectification" that disabled adults faced. Hahn argues that this process has rendered the disabled aesthetically outside of the possibility of attractiveness, making disability and beauty's coexistence

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[15] Longmore, *Telethons*, 159.

[16] Susan M. Schweik, *The Ugly Laws: Disability in Public* (New York: New York University Press, 2010).

unthinkable.[17] Rosemarie Garland Thomson gives the example of a woman who is both beautiful and uses a wheelchair, who experiences people's pity over being beautiful and disabled, "as if this combination of traits were a remarkable and lamentable contradiction."[18] In *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Thomson argues that the construction of disability is not based exclusively on function, but on form. The aesthetic expectations that make disability into the other have monstrousness as their history, a past that Thomson explores in the context of nineteenth-century freak shows and the spectacle-making of physical difference.

The aestheticization of disability has not been limited to physical disabilities. In the introduction to her ethnographic study of psychiatry, *Of Two Minds: The Growing Disorder in American Psychiatry*, T.M. Luhrmann writes about her surprise at the attractive appearance of the mentally ill patients presented to her introduction to psychiatry class, contrasting one patient's beautiful face and "long, golden Baywatch hair" with the palpable misery of the patient's deep depression.[19] Literary historian Sander Gilman examines the history of depictions of the mentally ill in Western art in *Seeing the Insane*, arguing that the stereotypes of madness as visually ugly have shaped the treatment of mental illness.[20]

In 1866, John Langdon Down defined mongolism on the basis of its specific facies and physical characteristics. As historian David Wright has argued, Down had identified a pattern in the physical features of some of his patients at Earlswood Asylum which he compared to the

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[17] Harlan Hahn, "Can Disability Be Beautiful?" *Social Policy* 18.3 (1988): 26-32.
[18] Thomson, *Extraordinary Bodies,* 25.
[19] T. M. Luhrmann, *Of Two Minds: The Growing Disorder in American Psychiatry* (New York: Knopf, 2000), 4-5.
[20] Gilman, *Seeing the Insane*.

appearance of the population of Mongolia.[21] Down's racist understanding of human progress led him to interpret the facies of these patients as a sign that they had regressed evolutionarily to a lesser race, inspiring the name Mongolian idiocy or mongolism, which endured for over a century.[22] Down categorized these patients' appearance as "typical Mongols," describing distinctive physical features in clearly negative terms:

> The face is flat and broad, and destitute of prominence. The cheeks are roundish and extended laterally. The eyes are obliquely placed, and the internal canthi more than normally distant from one another. The palpebral fissure is very narrow. The forehead is wrinkled transversely from the constant assistance which the levatores palpebrarum derive from the occipito-frontalis muscle in the opening of the eyes. The lips are large and thick with transverse fissures. The tongue is long, thick, and is much roughened. The nose is small. The skin has a slight dirty yellowish tinge, and is deficient in elasticity, giving the appearance of being too large for the body.[23]

Physicians continued to reference Down's description of patients with this condition for the next century. The identification of trisomy 21 as the chromosomal anomaly causing Down syndrome in 1959 led to the ability to diagnose Down syndrome via chromosomal analysis, but the appearance of the infant or child being diagnosed remained key to clinical diagnosis.[24] The historian Andrew Hogan argues that this identification of a physical dysmorphia that defined a syndrome, as happened with Down syndrome, shaped the expectations for genetic disorders in

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[21] Wright, *Downs,* 9-10.

[22] Wright, *Downs*, 115-119; Norman Howard-Jones, "On the Diagnostic Term 'Down's Disease,'" *Medical History* 23.1 (1979): 102–4.

[23] John Langdon Down, "Observations on an Ethnic Classification of Idiots," *London Hospital Reports* (1866) 3:259-262.

[24] Lejune, Gautier, and Turpin, "Etude de chromosomes somatiques, 1721-22.

post-war America, leading geneticists to search for other physical markers of difference.[25] Sociologist Daniel Navon quotes a researcher in medical genetics writing in the 1970s that the discovery of trisomy 21 led to "'funny looking' kids [becoming] the prime targets of inquiry."[26] By then, Down syndrome was the paradigmatic childhood developmental disability, due in no small part to its immediate legibility through its characteristic facies.

Defining autism through beauty ruptured the expected disability paradigm. Rather than pathologize disability or psychiatric illness as hideous, the aesthetics of autism incorporated the physical beauty with the alienating behavior of the condition, classifying autistic beauty as ethereal and unearthly. David Barnes argues that the tuberculosis-suffering female heroine in nineteenth-century French literature made disease the means by which the idealized feminine figure could be attained: beautiful, spiritual, vulnerable, tragic. Tuberculosis made the female ideal possible.[27] In mid-twentieth-century America, autism made otherworldly beauty possible. The appearance of children with autism depended on their autistic behaviors: the beauty that parents claimed for their children existed as a reflection of their children's aloneness and the unattainability of such beauty without the cost of the condition of autism. Just as the tragedy of tuberculosis was intrinsic to the beauty of the nineteenth-century literary heroine, the tragedy of autism—the child's extreme aloneness, the parents' inability to access the child within, the possibility of a normal child trapped within the beautiful facade—became intrinsic to the unusual beauty of the autistic child.

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[25] Hogan, *Life Histories,* 4-5.

[26] Navon, *Mobilizing Mutations*, 62.

[27] David S. Barnes, *The Making of a Social Disease: Tuberculosis in Nineteenth-century France* (University of California Press, 1995), 48-73.

Attractive, Beautiful, Intelligent Appearance: Autism Aesthetics in Medical Discourses

Beginning with child psychiatrist Leo Kanner's work in the 1940s classifying autism as a distinct diagnosis and continuing through the 1970s, the discussion of the appearance of autistic children in scientific literature took several forms. Throughout this period, autism was typically diagnosed within well-educated, upper-middle-class, white families, and the prominent psychogenic etiology for the diagnosis attributed its causation to maternal coldness, popularized as the refrigerator mother theory.[28] The attractive appearance of autistic children distinguished autism in the medical literature from other diagnoses, defining autism through beauty, rather than dysmorphia.

One recurring theme is how physicians discussed children with autism being unusually attractive as a rule. In addition to individual autistic children described in case studies as attractive and beautiful, researchers addressed beauty in cases of autism as a standard aspect of the condition.[29] In 1949, Kanner described the fifty-five patients he had diagnosed as autistic as uniformly "well formed, well developed, rather slender, and attractive."[30] The research psychologist and parent advocate Bernard Rimland wrote in *Infantile Autism,* his 1964 compilation of evidence for a biological basis of autism, "the [autistic] child is usually exceptionally healthy and attractive."[31] Later researchers knew of the longstanding nature of this

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[28] For more on the development of autism as a diagnosis, see Evans, *The Metamorphosis of Autism;* Silverman, *Understanding Autism*; and Verhoeff, "Autism in Flux."

[29] S. Robert Lewis and Shirley Van Ferney, "Early Recognition of Infantile Autism," *The Journal of Pediatrics* 56.4 (April 1960): 511; John Money, Nanci A. Bobrow, and Florence C. Clarke, "Autism and Autoimmune Disease: A Family Study," *J. Autism and Childhood Schizophrenia* 1.2 (June 1971): 149.

[30] Leo Kanner, "Problems of Nosology and Psychodynamics of Early Infantile Autism," *Amer. J. Orthopsychiatry*, 19.3 (1949): 420.

[31] Bernard Rimland, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (New York: Meredith, 1964), 7.

connection between autism and beauty. One physician in 1977 explained that “autistic children have since Kanner’s early enunciations been described as well-formed, beautiful, attractive children free of obvious defect.”[32] This statement takes the attractive, even beautiful appearance of children with autism as universally recognized and understood. Such comments from scientists continued to appear through the 1970s and early 1980s.[33]

This acceptance of beauty as a defining aspect of autism circulated in popular accounts of the condition during this same period. Reporters routinely commented in articles about autism on the beauty of individual children and the typical attractiveness of autism. In 1973, Lael Morgan wrote in the *Los Angeles Times*, “for some strange reason, autistic children are unusually beautiful.”[34] Helen B. Callaway wrote in the *Dallas Morning News* in 1975: “autistic children look normal, are usually attractive or even beautiful.”[35] In 1981, the education reporter G. K. Hodenfield drew a clear distinction between the appearance of autistic children with that of children with Down syndrome in a syndicated series for the Associated Press:

> Perhaps the cruelest form of mental retardation is autism, because there are few if any outward signs of the handicap. A child born with Down's Syndrome, for example (mongolism) shows physical evidence of the problem, and parents know immediately that they have an exceptional child who needs extra special care and love. Although autism

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[32] Harry A. Walker, “Incidence of Minor Physical Anomaly in Autism,” *Journal of Autism and Childhood Schizophrenia* 7.2 (June 1, 1977): 174-75.

[33] For examples, see Marie M. Bristol, “Family Resources and Successful Adaptation to Autistic Children,” in *The Effects of Autism on the Family,* eds. Eric Schopler and Gary B. Mesibov (New York: Plenum Press, 1984), 289-310, quotation on 291; David L. Nelson, *Children with Autism and Other Pervasive Developmental Disorders: Therapy Through Activitie*s (Thorofare, NJ: Slack, 1984), 14; Michael Rutter, “Diagnosis and Definition,” in *Autism: A Reappraisal of Concepts and Treatment*, eds. Michael Rutter and Eric Schopler (New York and London: Plenum Press, 1978), 1-26, quotation on 1.

[34] Lael Morgan, “The Uncharted Path of the Autistic Child,” *Los Angeles Times,* Mar 18, 1973.

[35] Helen B. Callaway, “The Mystery of Autism,” *Dallas Morning News,* Jun 8, 1975.

> becomes evident during the first three years of a child's life, most parents of autistic children find it difficult to accept the fact that he is handicapped because their child appears normal.[36]

These articles provide a few examples of the regular discussion of the appearance of autistic children in newspaper accounts of the diagnosis throughout this period, showing the ongoing association of autism with beauty and its aesthetic positioning as unique from other diagnoses of developmental disability.[37]

Given that autism was not associated with any physical anomalies until the 1970s and the children who were diagnosed with autism appeared physically normal, the commentary that children with autism were beautiful might be unsurprising – do we not think of all children as beautiful? However, descriptions of these children as unusually attractive, and of autism as a condition that affects the unusually beautiful, suggest a belief in the children's beauty that surpassed the physically normal child. The combination of individual children identified as

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[36] G. K. Hodenfield, "Autism May Be Cruelest Form of Retardation," *Eau Claire Leader Telegram*, November 16, 1981.

[37] Joan Beck, "Hearing Loss Hard to Detect," *Chicago Tribune,* April 26, 1970; Lorraine Bennett, "An Artful Language for the Handicapped," *Los Angeles Times,* May 4, 1978; Anatole Broyard, "Books of The Times," *New York Times*, June 9, 1972; Helen B. Callaway, "Autistic Boy's Parents Doggedly Seek Answers," *Dallas Morning News,* July 7, 1968; Helen B. Callaway, "Daniel, 7 Years Later," *Dallas Morning News,* June 8, 1975; "Dallasite leads convention crowd," *Dallas Morning News,* June 30, 1973; Dorothy Gaiter, "Relationships; Siblings Who Help Disabled," *New York Times*, July 2, 1984; Emma Harrison, "Plight of Girl, 7, Told to Analysts," *New York Times,* May 8, 1960; Ann Japenga, "Autistic Adults Ignored, Left to Face Pain Alone," *Los Angeles Times,* September 30, 1983; John J. O'Connor, "TV: Solid C.B.S. Fare," *New York Times,* October 11, 1973; Vernon Scott, "Actor Helps Fight Mysterious Disease," *Eau Claire Leader Telegram*, May 17, 1974; Jane Smiley, "Someone's in the Kitchen With Freud," *New York Times*, April 22, 1990; Meri Svoboda, "Forurn School at Waldwick Offers 'Attic Children' Hope," *New York Times*, June 4, 1972; Ursula Vils, "Lloyd Nolan Recalls Tragedy of Autism," *Los Angeles Times,* March 11, 1973; "'Wild Child' Show to Aid Autistic Group," *Dallas Morning News,* April 6, 1971.

attractive and the references to a general understanding that autism occurred in beautiful children indicates the role of beauty in the formation of the diagnosis.

An insistence on the beauty of autistic children persisted even when researchers found evidence of higher rates of minor physical anomalies in children with autism. As one researcher wrote in 1978, “among the beautiful children in this study, there were four autistic children who displayed absolutely no stigmata or any other distortion of physical form. Most of the children, including the majority of stigmata, had the attractive features described in most patients with Class I autistic syndrome.”[38] Minor physical anomalies observed in children with autism included morphological differences in the head, hands, ears, and mouth. Such features are typically of no large cosmetic difference, but they are characteristic of developmental disabilities and could potentially call for a reordering of the conception of beauty. The discussion of physical anomalies did not preclude researchers from maintaining the connection between autistic children and beauty. As another researcher wrote in 1977, “it was readily observed that most of the children in the study, many with high stigmata scores, had the attractive features sometimes described of the classic autistic child.”[39] That this insistence that the minor physical anomalies in autistic children did not negate the beautiful appearance of these children suggests the importance of beauty to the differentiation of autism from other developmental disabilities. Minor physical anomalies occur at a higher rate among populations with schizophrenia, intellectual disabilities, and Down syndrome, but the discussion of beauty alongside these physical anomalies within the medical literature was specific to autistic children.

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[38] “Class I” refers to the criteria for autism Kanner identified in 1943, sometimes referred to as Kanner-type autism. Mary Coleman, “A Report on the Autistic Syndromes,” in Rutter and Schopler, *Autism: A Reappraisal*,192.

[39] Walker, “Incidence of Minor Physical Anomaly,” 174-75.

An alternative thread running through the scientific literature is the reference to autistic children's "intelligent physiognomies." Researchers drew a distinction between the appearance of autistic children and the expected appearance of children with mental retardation, as Kanner did in 1949.[40] This intelligent appearance did not exclude a diagnosis of autism from a concurrent diagnosis of mental retardation. In 1960, researchers described fifty children diagnosed with autism and severe mental retardation as possessing "a superficially intelligent appearance at initial inspection."[41] Although distinct from physical beauty, which it sometimes appeared alongside, the intelligent appearance of autistic children acted as an additional basis for differentiation from other developmentally disabled children, particularly children with Down syndrome, even as children with autism exhibited severe intellectual disabilities, contributing to the discourse on the aesthetics of autism.

Researchers ceased to discuss beauty in scientific literature after the early 1980s, following the growing belief in an organic etiology for autism and the declining belief in a connection between autism and higher socioeconomic status. The relationship between a psychogenic etiology for autism and physical attractiveness can be seen in a comment from a therapy assistant at the 1977 Summer Intensive Program for Autistic Children, compiled in a dissertation that examined the meaning of autism present among people involved in the camp:

> I'd come into the program with some very strange ideas of what the parents of autistic kids were like, and when the co-director said during Orientation that autism is probably a brain disease for which the parents could not be held responsible, I didn't really accept

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[40] Kanner, "Problems of Nosology," 420; Harry Bakwin, "Psychologic Aspects of Pediatrics: Early Infantile Autism," *J. Pediatrics* 45 (1954): 493.

[41] Richard Schain and Herman Yannet, "Infantile autism: An analysis of 50 cases and a consideration of certain relevant neurophysiologic concepts," *J. Pediatrics* 57.4 (Oct 1960): 562.

> that. After all, I'd read about autism myself. Maybe the biggest thing, though, in making me think the kids' problems were emotional rather than physical was that they looked so apparently healthy and attractive. They just don't look as if parts of their bodies could be malformed somehow.[42]

For this therapist, the physical perfection and attractiveness of children with autism seemed to deny the possibility that their condition was biologically based. A psychogenic understanding of the condition, in which parents' rejection of the child caused the development of autism, fit with the physical appearance of the children—no child this beautiful could be organically disabled, therefore the cause must be psychological. An organic etiology would suggest the expectation of a disabled appearance for autistic children, as would be consistent with other developmental disabilities, such as Down syndrome. As the belief in the biological causation of autism increased, the logic of the physically perfect, psychologically damaged autistic child ceased to make sense. Parents would argue the exact opposite: the unusual beauty of autistic children was evidence of the biological nature of the condition.

The perception of beauty among children diagnosed with autism reflects the particular class status and race of their parents. Kanner's initial discussion of the high social class of autistic children, judged both by the professional statuses and the educational attainments of parents, established a long-lasting pattern for a linkage between higher social class and the diagnosis of autism. In 1949, Kanner wrote that he had looked for children with autism with "unsophisticated" parents and found none, suggesting to him a possible connection between the behavior of this type of parent towards the child and the child's condition. Kanner described the

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[42] David Nelson, "The Experience of Working in the Summer Intensive Program for Autistic Children" (Ph.D. diss., Union Graduate Institute, 1978), 195.

fathers of his patients as successful professionals. The mothers were college-educated women who had pursued careers before, and some after, marriage. He characterized the parents as sharing "an indisputably high level of intelligence" as well as being perfectionistic, emotionally aloof, undemonstrative, withdrawn from their children, obsessive, and lacking the warmth that their children needed.[43] Although not discussed as a causal factor like social class, all of these parents in Kanner's studies were white. In 1969, Dr. Robert Zaslow, professor of psychology at San Jose State University, described the division of autistic mothers by ethnic and economic stereotypes:

> There's little autism in Italy, where mothers are outgoing, responsive, not afraid to be emotional. There's a lot of autism in England, the United States, France, Norway, Sweden, Israel. In one specific kind of autism, thirty percent of the children are from Jewish families, although only three percent of the population are Jewish. But Jewish families comprise thirty percent of the highly placed professional class.[44]

In *Infantile Autism*, Bernard Rimland defended Kanner's assertion that autistic children came from well-educated, professional families against accusations of referral bias.[45]

Through the 1960s, following Kanner, scientific literature on the parents of autistic children consistently described the families as upper- or upper-middle-class. The refrigerator mother theory of causation accused women of causing their children to develop autism by being intellectually superior but emotionally withholding, denying the child needed love and

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[43] Kanner, "Problems of Nosology," 421-425.

[44] Ursula Vils, "New Therapeutic Concept Sparks Response in Children," *Los Angeles Times,* Nov 2, 1969.

[45] Rimland, *Infantile Autism,* 23-38.

affection.[46] This maternally derived, psychogenic explanation for autism traded on the stereotype of the college-educated woman who had lost her feminine, nurturing side. This aligned with the importance of the family intertwined with the growth of psychoanalysis in postwar America, which blamed middle-class white mothers for a variety of society's ills.[47] The "refrigerator mother" was consistent with the schizophrenogenic mother theory, which attributed maternal causation to the development of adult schizophrenia.[48] Within the construction of autism as a condition that developed in upper-class, white families, the description of children seeking this diagnosis as beautiful reflects the longstanding associations between beauty, race, and status in the United States. Historian Elizabeth Haiken sees the connection between whiteness and the standard of beauty in the development of cosmetic surgery, arguing that plastic surgeons reproduced and replicated a definition of beauty that clearly derived from and relied on Caucasian, even Anglo-Saxon, traditions and standards.[49]

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[46] For one definition, see J. Louise Despert, *The Emotionally Disturbed Child: Then and Now* (New York: Robert Brunner, 1965), 203.

[47] Philip Wylie's essay on "momism" in *Generation of Vipers* (1942, republished New York: Holt, Reinhart, and Winston, 1955) popularized the belief that middle-class white mothers were responsible for raising sons who were inadequate in a variety of ways. Texts that developed this theory include Helene Deutsch, *The Psychology of Women,* vol. 2 (New York: Grune and Stratton, 1945); Ferdinand Lundberg and Marynia F. Farnham, *Modern Woman: The Lost Sex* (New York: Harper and Brothers, 1947); and Edward R. Streker, *Their Mothers' Sons: The Psychiatrist Examines an American Problem* (Philadelphia: J. B. Lippincott, 1946, 1951). For more, see Ladd-Taylor and Umansky, *Bad Mothers*; Plant, *Mom*; and Weinstein, *The Pathological Family.*

[48] Anne Harrington, "The Fall of the Schizophrenogenic Mother," *The Lancet* 379, no. 9823 (April 7, 2012): 1292–93; Carol Eadie Hartwell, "The Schizophrenogenic Mother Concept in American Psychiatry," *Psychiatry* 59.3 (Fall 1996): 274-97.

[49] Elizabeth Haiken, *Venus Envy: A History of Cosmetic Surgery* (Baltimore: Johns Hopkins University Press, 1997), 10. Haiken discusses the use of Northern European white features as the standard of beauty for cosmetic surgery, finding evidence of Jewish and black patients getting rhinoplasty and Asian patients altering the shape of their eyes, describing such transformations as "caucasianizing." Cultural historian Sander Gilman describes similar processes of cosmetic surgeries and body modifications aimed at allowing Jewish, Irish, Black, and Asian patients to

Studies published through the early 1970s supported Kanner's association between social class and autism.[50] However, as early as the 1950s, researchers challenged Kanner's assertion of autism as a specifically class-based condition. Child psychiatrist Lauretta Bender alleged that the families Kanner saw at Johns Hopkins consisted of "his colleagues, professors and intellectual sophisticates," rendering his analysis of the significance of familial backgrounds flawed.[51] Bender wrote that the "unselective services of large city and state public facilities" found autistic behavior in children from a wide variety of backgrounds.[52] In *The Empty Fortress*, popular child psychologist Bruno Bettelheim denied any causal association between autism and social class, but attributed Kanner's findings to selection bias in the parents who seek out a psychiatrist to diagnose a child with autistic symptoms.[53] However, Bettelheim remained consistent in maintaining his theory of maternal rejection for the causation of autism. In *Infantile Autism*, Bernard Rimland defended Kanner's assertion that autistic children came from well-educated, professional families against accusations of referral bias. Rimland insisted that Kanner saw patients from all backgrounds, and he argued that Kanner's ability to distinguish the parents of

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pass as white in late-nineteenth- and early-twentieth-century Europe and America; Sander L. Gilman, *Making the Body Beautiful* (Princeton: Princeton University Press, 1999), 85-118.

[50] Victor Lotter, "Epidemiology of Autistic Conditions in Young Children," *Social Psychiatry* 1.4 (March 1, 1967): 163–73; D.A. Treffert, "Epidemiology of Infantile Autism," *Arch. General Psychiatry* 22.5 (May 1, 1970): 431–38; I. Kolvin, C. Ounsted, L. M. Richardson, and R. F. Garside, "The Family and Social Background in Childhood Psychoses," *British Journal of Psychiatry* 118.545 (April 1, 1971): 396–399.

[51] Lauretta Bender, "Autism in Children with Mental Deficiency," *Amer. J. Mental Deficiency* 64.1 (July 1959): 82.

[52] Bender, "Autism in Children," 82. Bender's article was in opposition to the use of autism as a particular "clinical or etiological entity," as Kanner proposed, but to recognize autism as one form of behavior and developmental stage that could be seen in a variety of diagnoses. For more on autism as a shifting concept, see Evans, *The Metamorphosis of Autism* and Berend Verhoeff, "Autism in Flux: A History of the Concept from Leo Kanner to DSM-5," *History of Psychiatry* 24.4 (December 1, 2013): 442–58.

[53] Bruno Bettelheim, *The Empty Fortress* (New York: The Free Press, 1967), 420.

autistic children from children with other diagnoses indicated the validity of Kanner's observation: "if there were nonintellectual parents of autistic children, why did they bring only their non-autistic children to Kanner, leaving it only for the highly intellectual parents to bring their autistic children?"[54]

Rimland's protestations did not stop other researchers from investigating the relationship between autism and social class. In the *Journal of Autism and Childhood Schizophrenia* in 1971, child psychiatrist Edward Ritvo and his colleagues analyzed the social class of 148 patients diagnosed with autism between 1961 and 1970, finding no significant association between social class and a diagnosis of autism.[55] Through the 1970s and 1980s, evidence mounted that disproved any class component to autism incidence.[56]

In the same period, evidence for an organic etiology of autism grew. Bernard Rimland's 1964 work *Infantile Autism* offered the first monograph arguing for the biological basis of autism and challenging parental psychogenic etiology. In 1971, child psychiatrist Stella Chess identified a higher incidence of autism among children exposed to congenital rubella, marking the first clear evidence suggesting an organic causation of autism. Chess explicitly rejected any

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[54] Rimland, *Infantile Autism,* 28.
[55] Edward R. Ritvo et al, "Social Class Factors in Autism," *Journal of Autism and Childhood Schizophrenia* 1.3 (September 1, 1971): 297–310.
[56] For articles that disproved a class component to autism, see Christopher Gillberg and Helen Schaumann, "Social Class and Infantile Autism," *J. Autism and Developmental Disorders* 12.3 (September 1, 1982): 223–228; Sukhdev Narayan, Barbara Moyes, and Sula Wolff, "Family Characteristics of Autistic Children: A Further Report," *J. Autism and Developmental Disorders* 20.4 (December 1, 1990): 523–535; Eric Schopler, Carol E. Andrews, and Karen Strupp, "Do Autistic Children Come from Upper-middle-class Parents?" *J. Autism and Developmental Disorders* 9.2 (June 1, 1979): 139–152; Luke Tsai, Mark A. Stewart, Michael Faust, and Steven Shook, "Social Class Distribution of Fathers of Children Enrolled in the Iowa Autism Program," *J. Autism and Developmental Disorders* 12.3 (September 1982): 211-221; Lorna Wing, "Childhood Autism and Social Class: a Question of Selection?" *British Journal of Psychiatry* 137 (November 1980): 410–417.

psychogenic etiology for autism in her study.[57] Chess's work, among others, reflected the growing belief among researchers for autism's biological causation.[58]

The National Society for Autistic Children's diagnostic criteria, published in 1978, included the caveat that autism occurred in all cultures, among all classes, and in people of every race. Since the NSAC's purpose was to advocate for autism, emphasizing the universality of the occurrence of autism benefitted its cause. However, its diagnostic criteria reflected the influence of its Professional Advisory Board, which included Edward Ritvo, whose work challenged any connection between class and autism.[59] Autism was no longer dependent on the social class of an individual's parents and could be found within any family. At the same time, beauty ceased to be a constitutive aspect of the diagnosis for physicians and researchers.

The Changeling: Parent Memoirs of an Autistic Child

Despite a general decline of beauty in medical discourse after the 1970s, parents continued to reference the unusual beauty of their children. In 1991, Bernard Rimland wrote that autistic children were unusually attractive and lacking in physical stigmata in the afterword to a parent memoir: "Autistic children tend to be quite attractive and well developed physically. Their physical attractiveness is frequently commented upon, and is especially surprising, because virtually all other conditions characterized by severe 'mental' problems also show a number of physical anomalies (stigmata)."[60] Rimland's insistence on the beauty of autistic children reflected the importance of beauty in constructing the difference between autism and other

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[57] Stella Chess, "Autism in Children with Congenital Rubella," *J. Autism and Childhood Schizophrenia* 1.1 (March 1971): 44.

[58] Silverman, *Understanding Autism*, 35.

[59] Frank Warren, "The Role of the National Society in Working with Families," in Schopler and Mesibov, *The Effects of Autism,* 104-107.

[60] Bernard Rimland, "Afterword," in Annabel Stehli, *The Sound of a Miracle: A Child's Triumph over Autism* (New York: Doubleday, 1991), 222.

developmental disabilities. By the 1990s, Rimland was not active in mainstream medical research circles working on autism, but he remained prominent as one of the founders of the National Society for Autistic Children (now the Autism Society of America) and as an advocate for alternative therapies for autism.[61] His acceptance of the unusual attractiveness of autistic children reflects the endurance of beauty as a central aspect to the autism parent community.

Parents wrote about their children's beauty as a reflection of the specific symptomatology of autism. The aloof, withdrawn nature of the child along with his unusually beautiful appearance became signs of the child's otherworldliness. Clara Claiborne Park titled the first chapter of her memoir after the changeling, the mythical fairy child left in exchange for the human child the fairies had stolen. Park described Elly as a fairy child, seeing her daughter's golden hair, blue eyes, and graceful body along with her daughter's innocence as fairy-like: "There was a fairy lightness in her movements, a fairy purity in her detached gaze. As time passed and she grew taller, leaner, older, her face seemed to record time's passage. She carried none of the stigmata of the defective; nothing distinguished her from other children except that in some undefinable way she looked younger…Elly's eerie imperviousness, her serene self-sufficiency, belonged to those who, like the fairies, can live somehow untouched by the human experience."[62] Park saw in Elly's youthful appearance a reflection of her detachment from humanity, sharing with fairies a distance from the concerns, passions, and compassion of humans. Park was not alone in seeing her child as a changeling. English professor Jane Taylor McDonnell recalled her husband describing their son Paul in the same way at age three: "Paul looks like an otherworldly child, a child strayed into our world from a different order of being.

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[61] Silverman, *Understanding Autism,* 133-136.

[62] Park, *The Siege,* 5-6.

The changeling was always a very beautiful child, perfect in every way, but somehow disconnected. Paul is so beautiful, so perfect, yet he doesn't seem to be with us, of us."[63]

For parents, autistic children, like fairies, stayed youthful through their lack of human worries, which kept them innocent and their beauty fresh. As parent memoirist Josh Greenfeld said of autistic children in general, they "are invariably beautiful, as if their untouchable imperviousness to the usual course of human events keeps them so."[64] Echoing the eternal child narrative of earlier parent memoirs, parent advocate Charles A. Hart, in his memoir of life with an autistic son and an autistic brother, described his older brother as aging slowly, retaining his handsome, classical features and clear skin into his middle-age.[65] The beauty of the autistic child reflected, in their parents' and families' minds, the absence of normal human responsibility and worry, keeping the child youthful and unearthly. Parents sought meaning in their children's autistic behavior, which beauty provided.

Parental insistence on the beauty of their children with autism reveals a space for the articulation of difference between autistic children and other developmentally disabled children, clearly seen in parent memoirs about the experience of raising a child with autism. Universally, parents described their autistic children as attractive. Some discussed a belief in the superior beauty of autistic children. Jacques May, medical geographer, physician, and early parent advocate wrote about his autistic sons in 1958: "They were indeed unusually beautiful. We found out later that these children often are, for reasons that are not understood. There is probably in

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[63] Jane Taylor McDonnell, *News from the Border: A Mother's Memoir of Her Autistic Son* (New York: Ticknor & Fields, 1993), 54.
[64] Josh Greenfeld, *A Child Called Noah: a Family Journey* (New York: Holt, Rinehart, and Winston, 1972), 5.
[65] Charles A. Hart, *Without Reason: A Family Copes with Two Generations of Autism* (New York: Signet, 1989), 21.

the genes that predispose them to this sickness also something that guides them to the most graceful accomplishment one may dream of."[66] According to May, beauty was a universal and biological symptom of autism which had implications for the prevailing psychogenic etiology of the diagnosis. His belief in the organic beauty of autistic children supported May's belief that autism was a biologically-based disability and that he and his wife had not caused their children to turn autistic by rejecting them.[67] May, and other memoirists, used their memoirs as evidence of their love for their children, refuting the refrigerator mother theory as they grappled with the meaning of autism in their children's lives. Beauty became evidence of the biological basis of autism, as well as a reflection of their affection towards their children.

Other parents made no claims to universality, but confidently claimed that their child was beautiful. As Clara Park claimed that her daughter's beauty turned heads on the beach, journalist and writer Josh Greenfeld described people coming up to him in the supermarket to exclaim over his son Noah's beauty. Greenfeld explained Noah's appearance is due to being autistic: "He looks like that because he is pure. He is not touched by anything in this world. Everything he feels, everything he is, comes from inside himself. That's what autism means. It means being locked in the confines of the self, being one's own entire world."[68] Greenfeld's interpretation of his son's appearance reflected his understanding of autism: innate, unknowable, and resolutely unrelated to the outside world. Attesting to strangers' recognition of the attractive appearance of children with autism allowed parents to claim an objective superiority for their children's good looks, while also tying autism's specific attributes to the presentation of beauty.

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[66] Jacques M. May, *A Physician Looks at Psychiatry* (New York: J. Day Co., 1958), 47.
[67] For a discussion of changing etiological understandings and parent responses to autism etiology, see Chapter Two.
[68] Greenfeld, *A Child Called Noah,* 3.

Parent memoirists often emphasized their children's fair skin, blue eyes, and delicate features, descriptions that pointed to traditional signifiers of whiteness. As Catherine Maurice, pseudonymous memoirist and mother of two children with autism, described her daughter at her third birthday party, "Anne-Marie's delicate face, with its porcelain skin and faint roses in the cheeks, was framed by wispy brown curls. Her blue-green Irish eyes gazed solemnly at the cake."[69] The emphasis placed on blue eyes and fair skin, shared by Charles Hart, James Copeland, Jane Taylor McDonnell, and Clara Park, underscores the whiteness of the typical family in which autism was diagnosed.[70] The characteristically Northern European features of these children with autism, as described by their parents, suggests the universal beauty of autistic children has a basis in the equation of whiteness with beauty in the United States, aligned with the class status of autistic children throughout this period.[71] The parents who wrote memoirs, in particular, represented the well-educated, intellectual, high socioeconomic status families that Kanner had described in his early writings on autism. In *Recovering Bodies*, G. Thomas Couser argues that despite lofty claims about the universally accessible nature of autobiography—he quotes William Dean Howells's comment that "autobiography is the most democratic province in the republic of letters"—the authors of "narratives of illness and disability are not diverse in terms of race and class. They tend to be white and upper-middle class. Before they became ill or

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[69] Catherine Maurice, *Let Me Hear Your Voice: A Family's Triumph Over Autism* (New York: Alfred A. Knopf, 1993), 3.

[70] James Copeland, *For the Love of Ann: Based on a Diary by Jack Hodges* (London: Arrow Books, 1973), 100; Hart, *Without Reason*, 40; McDonnell, *News from the Border*, 70; Park, *The Siege*, 5.

[71] Josh Greenfeld's son Noah was an outlier among the subjects of parent memoirs, as he is half-Japanese, which indicates that whiteness was not necessary for the diagnosis of autism in the 1960s. Greenfeld was an Academy Award-winning screenwriter and journalist and his wife, Fumiko Kometani, was an artist and writer, so the family was part of the upper-middle-class, intellectual milieu that found most autism diagnoses of the period.

impaired, many were already professional writers or worked in professions where writing was part of the job."[72] While Couser refers here to illness and disability narratives about the self, the pattern of white, upper-middle-class professional autobiographers and memoirists is generally consistent with the parents who write narratives about their children's disabilities.[73] One outlier is Carolyn Betts, a young Black mother. In her memoir, Betts described her difficulty in getting a diagnosis of autism for her son.[74]

Beauty became a consoling aspect to autism. Karl Taro Greenfeld, Josh Greenfeld's older son and Noah's brother, has written his own memoir about being the brother to an autistic child whose life consumed the family. Taro Greenfeld recognized the subjective and biased view of a parent on his own child's looks in his discussion of the "family myth" of Noah's beauty, explaining his parents' insistence on the fact that Noah was exceptionally lovely as a response to the lack of other positive memories. "Noah's beauty keeps coming up because what else do my parents have as memories? His *not* doing things?"[75] Noah's beauty was a central theme of the three memoirs his father wrote, regularly mentioned in reviews and press about the books.[76] The beauty of an autistic child may have been the only unequivocally positive memory the Greenfelds had. Greenfeld expressed the bittersweet quality of Noah's beauty in the sequel to *A Child Called Noah*: "My neighbor told me that he and his wife keep remarking to each other how

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[72] Couser, *Recovering Bodies, 4*.
[73] Cindee Calton, "The Obscuring of Class in Memoirs of Parents of Children with Disabilities," *Disability & Society* 25, no. 7 (December 1, 2010): 849–60.
[74] Carolyn Betts, *A Special Kind of Normal* (New York: Charles Scribner's Sons, 1979).
[75] Karl Taro Greenfeld, *A Boy Alone: A Brother's Memoir* (New York: Harper, 2009), 20.
[76] D. Keith Mano, "A Child Called Noah," *New York Times,* June 11, 1972; "New and Recommended," *New York Times,* July 2, 1972; Thomas J. Cottle, "A Special Person," *New York Times,* April 23, 1978.

good-looking Noah is. I said, 'Noah doesn't have anything else to do but be good-looking.'"[77] Jane Taylor McDonnell wrote that she found solace in the knowledge of her children's beauty when she lacked any other comfort. Describing her autistic son and her daughter, who was born with mild cerebral palsy, she wrote, "it surprised me a little that this physical beauty should mean so much to me. At the same time, I felt it was my one small compensation for the damage done to their minds. I took a fierce pleasure in these two small bodies, as if the sheer perfection of their physical selves was all I could ever hope for."[78] McDonnell and the Greenfelds found their children's beautiful appearances to be a consolation for the otherwise painful experience of raising a child with autism. Without other positive advantages to the diagnosis, beauty became the singular benefit to autism.

Parental discussion of beauty takes on an ambivalent meaning as it encompassed both a redemptive component to the beauty of the child and the parent's lament at the distance between their expectation for the child and the reality of autism. As Judy Barron wrote about her son as a baby, before any signs of autism, "he was so tiny, a perfectly formed human being with the potential to be or do anything in the world."[79] Seeing the child as physically perfect cast his unusual behavior in stark contrast, emphasizing the unrealized potential of the autistic child had he been neurotypical.

Often, the parent-memoirist directly compared the child with autism to children with different conditions, using the child's beauty as a point for the articulation of difference between the autistic child and other disabled children. As Annabel Stehli wrote when seeing her daughter

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[77] Josh Greenfeld, "A Father's Agony: What Place for an Autistic Child?" *Chicago Tribune*, April 18, 1978.

[78] McDonnell, *News from the Border,* 111.

[79] Judy Barron and Sean Barron, *There's a Boy in Here* (New York: Simon & Schuster, 1992), 3.

among a group of disabled children, “as a child who was physically intact, she was completely out of place among the other children in the room.”[80] Stehli considered the other children, disabled by thalidomide exposure, cerebral palsy, and neurological impairments, to be frightening for her exceptionally physically beautiful daughter and felt a need to find an alternative place for Georgie. Likewise, Jane McDonnell refused to accept a diagnosis of mental retardation on account of her son’s physical appearance, continuing to search for something more fitting.[81] Seeing Paul among other children being evaluated for developmental disabilities, McDonnell wrote about how different she found him and tried to understand her impulse not to categorize Paul with the other children and her perception of their suffering. She recalled being at the hospital with Paul at two years old when they accidentally wandered into the pediatric ward. Seeing a sick child of Paul’s size, visibly bandaged and hospitalized, brought McDonnell feelings of compassion and gratitude: compassion over the child’s suffering, gratitude that her child did not share it. Even as she struggled with Paul’s behavior, the comfort she found in Paul was in his appearance: “here beside me is my own child, my boy who can’t speak, but is just now running back down the hall. His golden hair is gleaming, his creamy skin is shining with a beauty that every day takes my breath away.”[82] For McDonnell, Paul’s beauty offered a compensatory order of difference from other disabled children. She insisted on his beauty not merely as a mother’s affectionate assessment of her son, but as something remarkable and distinctive that she acknowledged at difficult moments. Clara Park positively noted her daughter’s differences from the children in her inclusive preschool class, describing Jessy as “not even the most severely handicapped child in the school; she functioned far more ably than the

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[80] Stehli, *Sound of a Miracle,* 60.
[81] McDonnell*, News from the Border,* 19.
[82] McDonnell*,* 126-127.

overgrown, affectionate Mongoloid who moved clumsily about among the toys," adding that the child with Down syndrome's only contribution to the classroom was "helplessness."[83]

Josh Greenfeld wanted to see his son Noah as different from other children with developmental disabilities but could not allow himself the relief that difference would bring. He lamented Noah's kinship to other disabled children: "When I look at Noah's fellow day campers at the hospital I simply do not want to associate Noah with them: I mean, their braces and their rolling heads and their anguished sounds. But he—emotionally disturbed or organically retarded—is one of them."[84] Greenfeld considered his acceptance of his son as both beautiful and disabled to be a paradox, offering him one possible positive aspect to his son's condition while also obscuring the truth of his son's reality with autism, the condition that makes his child appear more beautiful. Greenfeld found the beauty of children with autism to be deceptive, bringing further tragedy to the family: "And not the least victims of this common but rarely foreseen malady will be the child's parents and family. They may delight at first in the tranquil docility or uncommon beauty of their child…Then, however, there will be months and years of anguish, roller coaster cycles of elation and depression as the parents try to deny the evidence before their eyes that their child is less than ordinary or normal, is indeed 'exceptional' to use one of the medical euphemisms."[85] Greenfeld's sadness about his son's fate colored his view of his beauty, transforming it from a bittersweet consolation into a cruel twist of fate for the parents of the child with autism.

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[83] This description of a child with Down syndrome in the early 1960s illustrates the widespread belief at the time that children with the condition were not educable. See Chapter Four of this dissertation for more on educability. Park, *The Siege*, 171.

[84] Greenfeld, *A Child Called Noah,* 65.

[85] Greenfeld, 5.

Joy Straight Up: Parent Memoirs of Down Syndrome

Parents of children with Down syndrome did not find consolation in their children's uncontested beauty, but in a tradition of children with Down syndrome being considered especially loving, caring, and joyful. The most prominent early parent memoir of Down syndrome is Dale Evans Rogers' 1953 bestseller *Angel Unaware*. Although the book is unusual for its literary framing of Rogers's daughter as an angel telling her life story to God, Rogers writing about Down syndrome and the love that her daughter brought the world was consistent with later memoirs. Within the story, Robin regularly reflects on how God was able to work through her, showing love to those around her: "[My nurse] used to say that I had 'such loving hands...always stretched out to give... not earthly, grasping hands, and that's heavenly! Of course, my hands grew loving. They were filled with [God's] love, so they could bless those around me."[86]

Like Rogers, other parents found the happiness and sweetness of their children a comfort. The popularity of Rogers's book shared this expectation widely, countering narratives of tragedy and suffering for individuals with Down syndrome and their families. In her 1963 memoir, Edna Moore Schultz recalled a friend's comment about Kathy, Schultz's daughter with Down syndrome: "'I had never heard that a defective child could be a joy until I read Dale Evans' book and later saw Kathy. You didn't have to tell people what she meant to you. Everyone could see it. We all loved her, too, and she was definitely a joy.' That was what the Lord had promised when He gave Kathleen to us."[87] Kathy had died at age eight, leaving her mother to use memoir as the medium to explore the meaning of her daughter's short life and premature death.

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[86] Rogers, *Angel Unaware,* 44.
[87] Edna Moore Schultz, *They Said Kathy Was Retarded* (Chicago: Moody Press, 1963), 119.

Comparing Kathy to Robin Rogers, the angel unaware of her mother's book, cast both girls, and all children with Down syndrome, as heavenly gifts.

The overt religiosity of *Angel Unaware* is not unusual among Down syndrome memoirs, in which parents often describe their children as gifts from God or as supernaturally endowed. In one of the stranger entries in the genre, *Expecting Adam*, sociologist Martha Beck wrote about receiving divinely guided telepathic messages from her son while in utero and regularly being visited by angels because of Adam's presence in her life.[88] In a more ordinary way, Douglas Hunt, father of a son with Down syndrome, stated in the 1967 preface to his son's autobiography, "without being pompous or over-pious, I think we can both truly say that we accepted Nigel as a gift from God which we were greatly honored to receive. He is an individual soul, as precious as any other, and we deemed it a great privilege that we were entrusted with this precious soul in this somewhat handicapped body, who needed especial care and understanding."[89] In her memoir on raising a son with Down syndrome, Vicki Noble suggested her son and others with Down syndrome were divinity manifested in ways not understood by modern Western society: "It is indeed the hand of the Divine on this child, and apparently on others with Down syndrome. Every person with Down syndrome whom I have ever met seemed happier, friendlier, more congenial and kindhearted than the rest of us, and I've heard other people say this as well."[90] In his work on families with children different from their parents,

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[88] *Expecting Adam* received glowing reviews, including from the *New York Times*, and was a national best-seller. Susan Cheever, "What Visions Have I Seen!," *New York Times*, May 16, 1999, 11.

[89] Douglas Hunt, "Preface," to Nigel Hunt, *The World of Nigel Hunt: The Diary of a Mongoloid Youth* (New York: Garrett Publications, 1967), 33. A similar message would be found in Schultz, *They Said Kathy Was Retarded.*

[90] Vicki Noble, *Down Is Up for Aaron Eagle: A Mother's Spiritual Journey with Down Syndrome* (Harper: San Francisco, 1993), 3.

Andrew Solomon saw this insistence on the positive qualities of Down syndrome ranging from an effort to obscure sadness to a genuine expression of joy. The varying reasoning behind the efforts to construct Down syndrome positively did not negate the importance of this action for these families.[91]

A frequent trope in these memoirs is one physician who tells the parents that this diagnosis is a tragedy, while another physician or nurse offers parents hope in the form of the redemptive aspects of the condition. In these recountings, a trusted doctor or someone intimately familiar with a family member with Down syndrome tells parents expect a joyful personality after receiving the diagnosis. Until the 1980s, doctors routinely advised parents to institutionalize a child with Down syndrome soon after birth, as the physical features of Down syndrome made diagnosis of a newborn possible.[92] Passive infanticide was common until the 1970s, as doctors refused to repair the esophageal and heart problems that are common among infants with Down syndrome.[93] Even after deinstitutionalization, in many hospitals new mothers continue to be offered foster or adoption placements for a child after the diagnosis of Down syndrome, as hospital policy presumes that parents will not always want to bring such a child home.[94] For memoirists, some reassurance about the promise of a bright future was a highly significant moment. As journalist Martha Moraghan Jablow's physician told her after confirming the diagnosis of Down syndrome for her daughter, "the doctor has to let the parents know about the positives, too. And that's why I told you that Down's syndrome children are loving and

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[91] Andrew Solomon, *Far From the Tree: Parents, Children and the Search for Identity* (New York: Scribner, 2012), 191.

[92] Katherine Castles, "Nice, Average Americans;" Carey, "Parents and Professionals."

[93] Martin S. Pernick, *The Black Stork: Eugenics and the Death of "Defective" Babies in American Medicine and Motion Pictures since 1915* (New York; Oxford: Oxford University Press, 1996).

[94] Rapp and Ginsburg, "Rewriting Kinship," 546.

affectionate and fit in easily with family life."[95] Jablow and others used their writing to challenge the conventional narratives that deemed children with Down syndrome tragic, uneducable, and valueless. Emphasizing their children's positive qualities allowed parents to insist upon the validity of their decisions to raise their children at home and to encourage other parents to do the same. Jablow's memoir offered support for this interpretation of Down syndrome: "Cara has enriched my life with her outgoing, sweet, generous self. She has a spunky style that I find amusing and, occasionally, trying. She has proven, and I am sure will continue to prove, that low expectations about retarded people are outdated bunk. That is particularly satisfying to me as a parent."[96] The affectionate nature of children with Down syndrome directly opposed the emotionally distant, unreachable autistic child.

Parents of children with Down syndrome found their children beautiful, but unlike autism parents, they made no claims to objectively recognized superior physical appearance. Dale Evans Rogers wrote about how people seeing Robin as beautiful was another sign of God's work: "I heard [my nurse] say many times, 'God is good to have made her so beautiful.' Beautiful? I guess I was, although when I was born nobody would have thought it, except my parents. Isn't it funny, Father, that the first thing people worried about was my slanted eyes—and by the time I was a year old they were saying, 'Hasn't she beautiful eyes?' … Even ugly things can be changed into beautiful things, under [God's] hand."[97] While parents of children with autism attested to the beauty of their children as something objective and aligning with conventional standards of beauty, Rogers saw the acceptance of her daughter as beautiful as a way that her daughter has been accepted by her family and society. Robin's beauty has none of the tragedy of the

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[95] Jablow, *Cara*, 9.
[96] Jablow, 171.
[97] Rogers, *Angel Unaware*, 66.

otherworldly beauty of autism but reflects a divinely-inspired commitment to loving the disabled that Robin has taught those around her.

Like Rogers describing Robin's eyes as beautiful, other parents attested that the specific symptomatology and dysmorphia that categorized Down syndrome made their children particularly beautiful in their eyes. In her 1999 memoir *Expecting Adam*, Martha Beck described her son in a mixture of figurative and clinical language: “The genetic weakness of his muscles (hypotonia, the doctors call it) lets his body fall into strange shapes, as though he has been dropped out of a plane to his death; legs twisted under him, undersize head bent too far back, chunky little arms flung wide… Watching him, I think he is the most beautiful child I have ever known.”[98] Beck and Rogers argued for the beauty of these children on the basis of their dysmorphia, recharacterizing disability as a thing of beauty. Beck recounts a pediatrician who describes babies with Down syndrome, whose features are smaller than non-disabled children's, as "the cutest babies on earth. I have a cousin who works for Mattel. I told him they should make a Down syndrome newborn doll."[99] In this way, both autism and Down syndrome parents asserted that their children are beautiful and challenged the negative physical connotations of developmental disability. While parents with Down syndrome acknowledged their children's particular facies and symptoms and argued that these features are beautiful, autism parents argued that their children are beautiful not on the basis of dysmorphia, but due to the combination of an absence of dysmorphia, the presence of unusual beauty, and the social aloofness characteristic of autism.

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[98] Martha Beck, *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic* (New York: Berkeley Books, 1999), 19.

[99] Beck, *Expecting Adam*, 323.

The cultural understanding of dysmorphia still mediated parents' expectations for their children with Down syndrome. English professor Michael Bérubé worried about how his infant son Jamie would appear to strangers and how his appearance would influence their expectations for him, anticipating future problems: “Jamie would be judged first by his appearance, and up to this point, one couldn't tell from a casual glance that he had Down syndrome. We didn't expect him to look like any other child with Down's, of course; but we also didn't want him to look too 'normal,' lest people expect too much of him.”[100] Bérubé was conscious of not wanting his son to look too different while wanting him to look different enough that Down syndrome would be legible in his son's physical appearance. For a condition identified by its aesthetic presentation, to fail to meet the expectations of a Down syndrome appearance would place Jamie in a liminal netherworld of disability in which he would not receive the benefits that clear identification of his diagnosis could offer him.

While the autistic child was notable for a lack of engagement with strangers, children with Down syndrome would charm the public, garnering attention through their personalities. Jablow's daughter exemplified this personal magnetism while at a school evaluation: “Cara emerged from the room in [the psychiatrist] Dr. Rabinowitz's arms. She had rarely been carried like that since she was a toddler. I knew instantly that she had become queen for the day. She pulled two small candies from her pockets and gave me a triumphant grin. "She's won a lot of hearts around here this morning," Dr. Rabinowitz said, explaining that someone else in the office had given her the candy.”[101] Cara's ability to win over the school district's staff reflects the positive qualities of Down syndrome in which parents took comfort. According to her mother,

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[100] Michael Bérubé, *Life as We Know It: A Father, a Family, and an Exceptional Child* (New York: Pantheon Books, 1996), 118-119.
[101] Jablow, *Cara,* 152.

her sense of humor, work ethic, and joyful spirit enriched her family's life and the lives of those around her. Martha Beck described her son as an exceptional guide to living life with joy:

> Adam takes his joy straight up, in purer form than most of us can handle. He was the person who, at two years of age, spent enough time experimenting to learn that his four-month-old sister was capable of laughter, and determining exactly what would make her laugh. He is the one who goes into transports of delight over clean sheets, or packaged waffles, or batteries. He is the one who taught me to appreciate rainbows—not only in the sky, but 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.[102]

The child with Down syndrome thus becomes a channel for joy, inspiring those around them to live fully, find happiness, and appreciate life. Although some parents resist this reductive interpretation of an individual with Down syndrome, this illustration of the condition pervades the literature of parent memoirs.[103]

The value of family members with Down syndrome lay in their ability to teach others through their beautiful spirits. Parents of children with autism and children with Down syndrome characterized both groups as otherworldly. However, the distant, unearthly changeling with

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[102] Beck, *Expecting Adam,* 327.

[103] Bérubé's work offers a more complex interpretation of the "live in the moment ethos" of a child with Down syndrome: "Occasionally it will occur to Janet or me that Jamie will always be 'disabled,' that his adult and adolescent years will undoubtedly be more difficult emotionally—for him and for us—than his early childhood, that we will never *not* worry about his future, his quality of life, whether we're doing enough for him. But usually these moments occur in the relative comfort of abstraction, when Janet and I are lying in bed at night and wondering what will become of us all. When I'm *with* Jamie, by contrast, I'm almost always fully occupied by taking care of his present needs rather than by worrying about his future. When he asks to hear the Beatles because he loves their cover of Little Richard's 'Long Tall Sally,' I just play the song, sing along, and watch him dance with delight… Jamie is entirely sui generis, and as long as I'm with him I can't think of him as anything but Jamie." Bérubé, *Life As We Know It,* xi.

autism and the spiritual, divinely aided soul with Down syndrome shared little. Parents found unique, positive qualities in each diagnosis upon which to create meaning for each condition.

Conclusion

The aestheticization of autism and Down syndrome offered a way for the articulation of difference for each condition. The discussion of beauty in the discourse on autism aided parents and professionals in establishing autism as a distinct diagnosis. Beauty served as a space for signaling difference between autism and other developmental disabilities, which was particularly crucial for the scientific literature in the psychogenic etiology-dominated period before the 1970s. The decline in attribution of autism to psychogenic causes and in the association of autism with parents from higher socioeconomic backgrounds occurred simultaneously with the decline in the attribution of unusual beauty as constitutive of the diagnosis. Researchers persisted in identifying individual children as beautiful after the expansion of the diagnosis beyond the upper social strata, but beauty ceased to be essential to autism. The growing acceptance of an organic etiology for autism and a rejection of a connection between autism and socioeconomic status challenged the association between beauty and autism in the scientific literature. As autism became biological, its beauty ceased to be medically significant.

For parent memoirists, beauty held both a redemptive quality and exposed the tragedy of the autism diagnosis. The recognition of the unusual and distinctive beauty of children with autism allowed space for parents to distinguish autism from other developmental disabilities as well as wrestle with the meaning of autism for their child’s life. Examining the use of beauty reveals both its productive quality and its ambivalence. Parents found their children’s beauty to be a bittersweet consolation for the otherwise devastating diagnosis of autism, as well as a tragic suggestion of what might have been had the child been normal. Beauty remained a salient feature to the parent memoirist in crafting the story of life with a child with autism as it remained central to the parent community in understanding and accepting the diagnosis.

Parents of children with Down syndrome found their own compensatory and hopeful narrative through descriptions of the joyful and loving personalities of children with the condition. Insisting on the benefits that a child with Down syndrome brings to the family and the broader community allowed parents to refuse to institutionalize their children and demand support from the state for the lifespan of the disabled individual. Parents constructed the meaning of Down syndrome as an eternal innocence and their children as angelic blessings, forcing others to reconsider the belief that a disabled child was only ever tragic.

The portraits that parents created of their children allowed them to find compensatory aspects to their children's disabilities. While children with Down syndrome were angelic and Heaven-sent, children with autism by definition were socially inaccessible and detached. Children with Down syndrome would charm strangers, engaging people through their joyful personalities. Children with autism, however, remained distant and beautiful, like Clara Park’s daughter, who did not look at the crowd drawn by her beauty, their aloofness keeping them unsullied by the realities of modern life. Instead of an angel, an autistic child was a changeling, mysterious and beautiful, strange and estranged.

CHAPTER TWO

The Etiological Question

In her 1967 memoir, *The Siege: The First Eight Years of an Autistic Child,* Clara Claiborne Park described the process of seeking a diagnosis for her toddler daughter, Jessy. Jessy's remote affect, her independence, her lack of speech, and her physical beauty made her seem to Park as "a fairy child," strikingly different in her development from her three older siblings.[1] Searching for understanding, Park and her husband brought Jessy to a renowned pediatrician who was "abreast of the most recent developments in mental and physical illness."[2] Facing the possibility that Jessy was intellectually disabled, Park expressed her concerns in her memoir, writing, "I had thought that retardation was the worst thing that could happen to a baby, to a family, and to me. But apparently this was not the worst possibility. There was another. The worst diagnosis [the doctor] could give us would be a different word altogether—autism."[3] The introduction of this new fear—autism—marks a reordering of the list of parental concerns. In this moment in the early 1960s for Park, autism became the worst diagnosis, the primary childhood disability that parents fear might affect their child, a shift that occurred for American culture more broadly during the late twentieth century.

In outlining her fears, Park distinguished between autism and other disabilities by defining autism as distinct from, and, as her doctor presented it, worse than, mental retardation. This articulation of difference was an essential element of the medical literature and parental discussion of autism, which required clear separation from other developmental disabilities. In

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[1] Park, *The Siege,* 5.
[2] Park, 31.
[3] Park, 33.

Park's memoir, her daughter's "essential aloneness" contrasted with her physical beauty, prompting commentary such as, "many people are looking at [Jessy] because she is so pretty, but she is looking at no one."[4] By emphasizing beauty, Park was implicitly contrasting autism with Down syndrome, the most visible diagnosis of intellectual disability, or mental retardation, at the time. As the diagnosis of autism has lacked a stable meaning over the past sixty years, the work of defining what it is, and what it is not, has continually occurred in scientific literature and popular culture, including parent memoirs.

Park constructed a narrative out of the confusing, sometimes frustrating, sometimes joyful, experiences of raising a child with autism. She wrote about her daughter's birth and babyhood, then the recognition of symptoms along with seemingly prophetic statements that appeal to the meaning of autism at the time of the memoir's publication. An unfamiliar pediatrician remarked, "she seems like a child who has been raised very much alone", which offered a clear description of both the extreme self-isolation that defined autism at the time and the then-popular psychogenic etiology of the diagnosis.[5] Park outlined procession of doctors and tests and diagnoses and specialists in the pursuit of the title of autism, followed by ongoing treatments and setbacks and advances in reaching the child within until, finally, some resolution has been reached and the child's autism has, somehow, been mitigated. Park's extended metaphor of laying siege to autism to access the girl within offered a vision of autism as obscuring the real child, who could be revealed even if the autistic traits never disappear.[6] As Park wrote towards the end of her work of the now-eight-year-old Jessy, "Someone who saw her now for the first time and had no knowledge of her history would probably not think her autistic

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[4] Park, 5.
[5] Park, 28.
[6] Later discussions of autism would describe this as the "intact mind."

at all… The autistic isolation itself is very much attenuated."[7] Park did not make claims of her daughter's autism having been cured, but the improvements that came from her daughter being "under siege" had allowed her to reach Jessy. This narrative recurs throughout the genre of parent memoirs about autism, varying according to changes in the diagnosis, treatment, and construction of autism at the time of writing.

The tropes of autism parent memoirs have their roots in Park's book and in the larger genre of memoirs by parents of so-called exceptional children. Since the 1940s, parents have used the medium of memoir to construct the meaning of childhood developmental disabilities for the public. For parents of children with autism and Down syndrome, this work has intersected with advocacy for disability rights, the rise of prenatal testing and selective abortion, and changes in autism and Down syndrome etiology. As parents used the writing and reading of memoirs as a site for the participation in imagined communities of the afflicted, they contributed to the social construction of these diagnoses. While autism has become an expansive and meaningful social category over the past fifty years, Down syndrome has been relegated to a concern expressed through prenatal testing, reduced to a chromosomal anomaly without broad cultural meaning. The incidence rate and prevalence of each diagnosis has grown in the American population, but their cultural positions have occupied inverse trajectories. The narratives presented by parent memoirs have shaped autism's ability to capitalize on controversies, from the refrigerator mother to vaccine causation. Parents have not offered Down syndrome a narrative that challenges its overdetermined identification with the Trisomy 21 anomaly, limiting Down syndrome's prominence culturally, and allowing autism to ascend to its current position as the paradigmatic childhood developmental disability in American culture.

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[7] Park, *The Siege*, 252.

From Refrigerator Mother to Uncertain Cause

Child psychiatrist Leo Kanner first identified autism as a discrete diagnosis in 1943.[8] In his paper, "Autistic disturbances of affective contact," Kanner described eleven children he had seen as patients at the child psychiatry service at Johns Hopkins University hospital, who were emotionally distant and had "an obsessive desire for the maintenance of sameness."[9] Based on these two traits, Kanner described the diagnosis of autism. He concluded that "these children have come into this world with an innate inability to form the usual biologically provided

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[8] Kanner was not the first to use the term "autism." Swiss psychologist Eugen Bleuler had first used it in 1910 to describe symptoms of schizophrenia, and Swiss developmental psychologist Jean Piaget used the term to describe the earliest stage of thought in infancy, in which children were not able to think logically or relate to others socially. Kanner attempted to distinguish autism from these other uses by identifying it as a specific syndrome, a diagnosis that was hotly contested in the 1940s and 50s and remained unsettled for long after Kanner's initial work. Historian Bonnie Evans argues that autism transformed into its contemporary diagnostic category in the 1960s and 70s following the growth of children's rights and epidemiological surveys in the United Kingdom. For more, see Evans, *The Metamorphosis of Autism;* also, Roland Kuhn and Charles H. Cahn. "Eugen Bleuler's Concepts of Psychopathology," *History of Psychiatry* 15.3(2004): 361-66; Verhoeff, "Autism in Flux." Throughout my work, I refer to the diagnosis of autism not to suggest that it has been a stable category in epidemiology or etiology, but in the way that parents and physicians have historically treated it as a stable category. For more on Kanner, see Silverman, *Understanding Autism*. Additionally, the question of whether Leo Kanner plagiarized Hans Asperger, a fellow Austrian child psychiatrist who published "Die 'Autistischen Psychopathen' im Kindesalter," his own description of autism, in 1944, has been the subject of a variety of books and articles. Psychiatrist Michael Fitzgerald has argued that Kanner plagiarized an earlier, 1938 work of Asperger's—see "Autism: Asperger's syndrome—History and first descriptions," In *Asperger's disorder*, eds. J. L. Rausch, M. E. Johnson, & M. F. Casanova (New York: Informa Healthcare, 2008). This remains debatable—see Nick Chown, "'History and First Descriptions' of Autism: A Response to Michael Fitzgerald," *Journal of Autism and Developmental Disorders* 42, no. 10 (October 1, 2012): 2263–65. Journalist Steve Silberman argues in *Neurotribes*, his 2015 book, that Kanner's rescue of Asperger's chief diagnostician from Nazi persecution in 1944 proves a relationship between the two psychiatrists and supports the claim that Asperger influenced Kanner. Historian Edith Sheffer examines Asperger, his role in the development of autism, and his cooperation with the Nazi medical establishment during the Third Reich in *Asperger's Children.* Asperger's work was not widely introduced to the English-speaking world until Lorna Wing's 1981 paper, so before that point, I do not consider Asperger or his influence within this history.

[9] Kanner, "Autistic disturbances of affective contact," 37.

affective contact with people, just as other children come into the world with innate physical or intellectual handicaps."[10] Kanner's description of autism continues to be referenced as a meaningful discussion of the diagnosis.[11] Influential English child psychiatrist Michael Rutter wrote in his 1978 paper defining autism, "Any account of the definition of autism must start with Kanner's (1943) careful and systematic observations on 11 children with a previously unrecognized syndrome."[12]

Although Kanner's first paper identified autism as an innate difference within some individuals, his discussion of specific characteristics of the parents of his patients makes his initial intention regarding parental causation ambiguous. Kanner described the parents of this first group of children as well educated and socially prominent, but cold and formal towards their children: "for the most part, the parents, grandparents, and collaterals are personas strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest in people… The question arises whether or to what extent this fact has contributed to the condition of the children."[13]

Autism was typically diagnosed in children from upper- or upper-middle-class families. Contributing to this particular class aspect of the condition was the psychogenic etiology of autism, which held mothers responsible causing their children to become autistic. Kanner described this process in 1949, as parents keeping their children "neatly in refrigerators which did not defrost. [The child's] withdrawal seems to be an act of turning away from such a

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[10] Kanner, "Autistic disturbances of affective contact," 42-43.

[11] Jan Blacher and Lisa Christensen, "Sowing the Seeds of the Autism Field: Leo Kanner (1943)," *Intellectual and Developmental Disabilities* 49, no. 3 (June 1, 2011): 172–91.

[12] Michael Rutter, "Diagnosis and Definition of Childhood Autism," *Journal of Autism and Childhood Schizophrenia* 8, no. 2 (June 1, 1978): 139.

[13] Kanner, "Autistic disturbances of affective contact," 42.

situation to seek comfort in solitude."[14] From this description, the term "refrigerator mother" emerged to describe the autism-creating mother, as defined by child psychiatrist J. Louise Despert in 1965: "compulsive, perfectionistic, narcissistic, immature, frigid, emotionally detached, frightened by body contact, lacking in sensuousness, and capable of functioning only on an intellectual level."[15]

Investigation into the maternal causation of psychological problems occurred contemporaneously to the development of the refrigerator mother theory. In the 1950s, Harry Harlow, psychologist at the University of Wisconsin-Madison, experimented with the damaging effect of maternal deprivation on rhesus monkeys. When Harlow replaced their mother figure with a wire statue covered in cloth, the infant monkeys behaved in ways similar to autistic children. Harlow's work provided evidence of the importance of the mother-child relationship for healthy psychological development. In her biography of Harlow, journalist Deborah Blum argues that Harlow did not intend for his research to support the mother-blaming etiology for autism. Citing Harlow's critique of Bruno Bettelheim's *The Empty Fortress*, a popular mother-blaming tome from the celebrated child psychologist, Blum argues that Harlow intended his experiments to demonstrate the effect of maternal deprivation on the normal individual, not those with an innate difference.[16] However, Harlow and Kanner's correspondence in 1970 suggests that Harlow believed in the significance of maternal influence on childhood mental conditions more broadly. After Kanner invited Harlow to join the advisory editorial board of the *Journal of*

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[14] Kanner, "Problems of Nosology and Psychodynamics in Early Infantile Autism," *American Journal of Orthopsychiatry*, 19 (1949): 416-426. Reprinted in *Childhood Psychosis,* 61.

[15] Despert, *The Emotionally Disturbed Child,* 203. See Chapter One of this dissertation for more discussion of momism and mother-blaming.

[16] Deborah Blum, *Love at Goon Park: Harry Harlow and the Science of Affection* (Cambridge: Perseus, 2002), 232-33.

Autism and Childhood Schizophrenia, Harlow replied to accept, adding an anecdote from his wife's experience as a psychologist at the Bradley Home in Rhode Island working with children with schizophrenia: "Mrs. Harlow, then Margaret Kuenne, traced the early history of the cases and later told me that all, or almost all, of the children suffered, apparently, from unfeeling mothers, whatever the cause of maternal indifference may have been. My wife-to-be was deeply impressed."[17]

The refrigerator mother theory reached its widest popular audience via the work of child psychologist Bruno Bettelheim. Bettelheim published *The Empty Fortress: Infantile Autism and the Birth of the Self* in 1967*,* his account of his work with children with autism at the Orthogenic School at the University of Chicago, where he claimed to have successfully cured autistic children. An Austrian Jewish refugee released from Dachau, Bettelheim arrived in the United States in 1939 with no formal training in psychology or psychoanalysis. He fabricated a self-aggrandizing personal mythology that included a personal relationship with Freud, training and participation in analysis, multiple degrees from the University of Vienna, and the personal rehabilitation of a young girl with autism. These inventions allowed Bettelheim to establish himself as the country's premier psychoanalyst, a role he played on talk shows and in writing magazine and newspaper columns.[18] Bettelheim used his experiences in Dachau and Buchenwald to establish his authority on the causality of autism, as he compared autistic children to those in

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[17] Correspondence from Harry Harlow to Leo Kanner, 20 October 1970, Box 100695, Folder 3: "Autism and Childhood Schizophrenia, Journal of...", 1970-1973, Leo Kanner Files, American Psychiatric Association, Washington, D.C.

[18] Silverman, *Understanding Autism,* 64. More on Bettelheim can be found in several biographies, including Richard Pollak, *The Creation of Doctor B: A Biography of Bruno Bettelheim* (New York: Simon and Schuster, 1998).

the concentration camps, arguing that autistic children had been rejected by their families and left to emotionally wither as much as children in the camps were psychologically traumatized.[19]

In the 1950s and 1960s, Bettelheim was widely popular, appearing regularly on talk shows as the foremost psychologist in the country. The *New York Times* described Bettelheim as "foremost among the handful of psychiatrists and psychologists who have dedicated themselves to unraveling the puzzle of autistic behavior."[20] Bettelheim was a major supporter of the refrigerator mother theory and explicitly rejected any innate causation of autism, proposing that the significant maternal rejection could occur within the first days of life.[21] Bettelheim's work received rave reviews in the popular press and *The Empty Fortress* became a best seller, contributing to the spread of the refrigerator mother theory outside of scientific literature.[22]

Bettelheim's insistence on maternal blame for autism reflects the experiences many parents had when their children were diagnosed. Some parents refused to accept blame and worked to refute parental causation. The first major attempt to challenge maternal causation was Bernard Rimland's *Infantile Autism: the Syndrome and Its Implications for a Neural Theory of Behavior*, published in 1964. Rimland was the father of an autistic son and a research psychologist with the US Navy who set out to understand whether a biological basis for autism existed.[23] The blame Rimland and his wife experienced over their son's autism motivated his

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[19] Bettelheim's fame and prestige became tarnished in the wake of his suicide in 1990, when several former patients and staff members of the Orthogenic School accused him of physically and verbally abusive behavior and questions arose about plagiarism in his work and the veracity of his claims to cure children of autism at the school**.** Silverman, *Understanding Autism*, 64; Pollak, *Creation of Dr. B*, 61.

[20] "In Brief," *New York Times* Feb 26, 1967, BR23.

[21] Bruno Bettelheim, *The Empty Fortress* (New York: The Free Press, 1967), 399.

[22] Eliot Fremont-Smith, "Books of the Times: Children Without an 'I,'" *New York Times* Mar 10, 1967; Carol Kleinman, "A total commitment to children," *Chicago Tribune* Jan 22, 1967.

[23] Silverman, *Understanding Autism,* 172.

work. Rimland discussed evidence for the biological basis of autism, such as the higher frequency in male children than in female and the lack of autistic siblings among children raised in the same environments by the same parents, while he used this evidence to attack the psychogenic theory of causation.[24] Leo Kanner provided the foreword to Rimland's work, in which he praised Rimland and his research. He cited his own characterization of autism as "innate" in his first paper on the subject as support for Rimland's efforts.[25] Rimland founded the National Society for Autistic Children in 1965 with other parents and continued to pursue non-psychoanalytical causes and treatments for autism until he died in 2006.[26]

Rimland and Bettelheim received very different responses both in the press and among the public. Bettelheim was publicly lauded and widely popular. The parents of autistic children applauded Rimland's work but he lacked wider public recognition. In 1968, a *New York Times* article on psychoanalysis described Bettelheim as "one of the most prominent figures in American psychoanalysis" and Rimland merely as "author of *Infantile Autism.*"[27] Bettelheim had by the 1960s established himself as an authority on psychoanalysis and a media figure, having earned the title of "heir to Freud," as bestowed upon him by the *Times*, through his public work.[28] Bettelheim wrote *The Empty Fortress* in the easily accessible style for the general public that he had cultivated in his work as a public intellectual in magazine columns and public speaking engagements.[29] In contrast, Rimland was a marginal figure in the public, popular

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[24] Rimland, *Infantile Autism,* 51-52.
[25] Leo Kanner, "Foreword," in *Infantile Autism*, p. v. Kanner's statements played both sides of the maternally derived vs. innate question throughout the 1960s.
[26] Benedict Carey, "Bernard Rimland, 78, Scientist Who Revised View of Autism, Dies," *New York Times*, November 28, 2006.
[27] John Leo, "Psychoanalysis Reaches a Crossroad," *New York Times* Aug 4, 1968.
[28] Paul Roazen, "The Children of the Dream," *New York Times* Apr 6, 1969.
[29] Silverman, *Understanding Autism*, 67.

among fellow parents of autistic children for his passionate rejection of psychogenic etiology but dismissed out of hand by the popularly renowned Bettelheim, in *The Empty Fortress* and their personal correspondence.[30] Increasingly through the 1970s, members of the scientific community studying autism also rejected Rimland, dismissing his attempts at research and viewing him as a parent taken with pseudoscientific ideas such as vitamin B6 therapy and, eventually, vaccine-causation of autism.[31]

Despite the widespread popularity of *The Empty Fortress*, by the late 1960s researchers within the scientific community were shifting away from a strict psychogenic etiology for autism. In 1971, child psychiatrist Stella Chess identified a higher incidence of autism among children exposed to congenital rubella, marking the first clear evidence suggesting an organic causation of autism. Chess disavowed a psychogenic etiology for autism in her work, acknowledging that "the hypothesis of the schizophrenogenic mother had to be addressed" as she argued against it.[32]

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[30] Bettelheim, *The Empty Fortress*, 407-418; Bruno Bettelheim, Letter to Bernard Rimland, March 25, 1965, Bettelheim Papers, University of Chicago, quoted in Silverman, *Understanding Autism*, 88.

[31] Edward R. Ritvo, interview with the author, March 26, 2014. Ritvo took a dark view of Rimland and his pseudoscience's lasting influence over NSAC (later the Autism Society of America), telling me he had unofficially ceased working with the organization after attending a conference where Andrew Wakefield was the keynote speaker. In 1998 Wakefield published a study in the *Lancet* linking autism and the measles-mumps-rubella vaccine. In 2010, the *Lancet* retracted the paper, and the British General Medical Council struck Wakefield off the medical register after finding him guilty of serious professional misconduct in his research into autism and the MMR vaccine. Wakefield now lives in the United States. The Editors of The Lancet. "Retraction—Ileal-lymphoid-nodular Hyperplasia, Non-specific Colitis, and Pervasive Developmental Disorder in Children." *The Lancet* 375, no. 9713 (February 2010): 445; James Meikle, and Sarah Boseley, "MMR Row Doctor Andrew Wakefield Struck Off Register," *The Guardian*, May 24, 2010, http://www.theguardian.com/society/2010/may/24/mmr-doctor-andrew-wakefield-struck-off; Carey, "Bernard Rimland."

[32] Chess, "Autism in Children with Congenital Rubella," 44. The collapsing of autism and childhood schizophrenia into one disorder, as Chess appeared to do in this quotation, was not unusual for the period. In the first Diagnostic and Statistical Manual in 1952, autism appears

The shift away from strictly psychogenic thinking that began in the 1960s did not eliminate maternal blame from theories of autism causation. The scientific literature on autism showed a rejection of the Bettelheim-esque exclusively maternal causation. Instead, maternal causation became a possible factor along with biological causes.[33] By the 1976 International Symposium on Autism in St Gallen, experts on autism could claim that owing to the evidence of biological abnormalities in autistic children, few of their colleagues "maintain an exclusively psychogenic position" on causation, which the other papers given at the conference support.[34] In 1984, researchers comparing parent-child relationships and home environments concluded that there was nothing different between the family environment of children with autism and other families, except for the added stress of living with a disabled child.[35] Absent evidence for maternal causation of autism, the scientific community investigating autism ceased to focus on

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under "Schizophrenic reaction, childhood type" as the primary psychotic reaction in children. It maintained this status in the DSM-II, published in 1968, as "autistic behavior" fell into the category of "Schizophrenia, childhood-type." The DSM did not differentiate autism from schizophrenia until the publication of the third edition in 1980, when the criteria for diagnosis were greatly expanded to reflect those established by the National Society for Autistic Children, reflecting the role of parents in the development of the diagnosis of autism. American Psychiatric Association, Committee on Nomenclature and Statistics, "000-x28 Schizophrenic reaction, childhood type," *Diagnostic and Statistical Manual for Mental Disorders*, 1st ed. (Washington: American Psychiatric Association, Mental Hospital Service, 1952), 28; American Psychiatric Association, "295.8 Schizophrenia, childhood type," *Diagnostic and Statistical Manual of Mental Disorders*, 2nd ed. (Washington: American Psychiatric Association, 1968), 35; American Psychiatric Association, "299.0x Infantile Autism," *Diagnostic and Statistical Manual of Mental Disorders*, 3rd ed. (Washington: American Psychiatric Association, 1980), 87-90; Frank Warren, "The Role of the National Society in Working with Families," in *The Effects of Autism on the Family*, 105.

[33] Michael Rutter, "The Development of Infantile Autism," *Psychological Medicine*, 4 (1974): 147-163.

[34] Dennis P. Cantwell, Lorian Baker, and Michael Rutter, "Family Factors," in *Autism: A Reappraisal.*

[35] Dennis P. Cantwell and Lorian Baker, "Research on Families of Children with Autism," in *The Effects of Autism on the Family*, 41-64.

parental causation, although parent memoirs recount experiences of mother-blaming from the psychiatric and psychological communities continuing through the 1980s.[36]

Since the decline of maternal causation, the possible causes for autism have become a wide-ranging and heterodox assortment of biological factors, from genetic and genomic interactions to vaccine-derived brain damage, excess screen time, and vitamin deficiencies. In 1998, Bernard Rimland, who had long advocated for a variety of possible causes for autism, suggested that autism's cause was pollution, which he broadly defined to include "industrial pollution, food additives, and overused pharmaceuticals, including vaccines."[37] Rimland's Autism Research Institute investigated connections between autism and candida yeast infections, autism and vaccines, the benefits of treatments including secretin, dimethylglycine, and auditory integration training.[38] One mother wondered in the New York Times in 2002 if "the Indian Point nuclear power plant, PCB's in the Hudson River or fertilized lawns cause a countywide epidemic."[39] Genetic and genomic causation have been heavily studied since the 1990s, with large amounts of funding coming from parent advocacy organizations.[40] The potential causative relationship between some high amount of television or computer screen access and autism has been a topic of concern scientifically and in media coverage.[41] The etiology of autism remains unsettled.

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[36] Jane Taylor McDonnell, "On Being the 'Bad' Mother of an Autistic Child," In *"Bad" Mothers,* 229.

[37] Elena Conis, *Vaccine Nation* (Chicago: University Of Chicago Press, 2015), 210.

[38] James D. Herbert, Ian R. Sharp, and Brandon A. Gaudiano, "Separating Fact from Fiction in the Etiology and Treatment of Autism," *The Scientific Review of Mental Health Practice* 1, no. 1 (Summer 2002), http://www.srmhp.org/0101/autism.html.

[39] Alice Kenny, "When Autism Strikes," *New York Times*, December 8, 2002.

[40] Navon, *Mobilizing Mutations;* Singh, *Multiple Autisms.*

[41] Tony Hicks, "How 'Secondhand Screen Time' Can Affect Young Children," *Healthline*, January 30, 2020, https://www.healthline.com/health-news/why-secondhand-screen-time-isnt-healthy-for-babies; Victoria Dunckley, "Autism and Screen Time: Special Brains, Special

“We Will Take Matters Into Our Own Hands”

Into the web of mother-blaming and psychological danger that defined autism in the 1960s, Clara Claiborne Park’s memoir stands as a testament to her love for her daughter and the warm family home that Park and her husband created for their children. Park’s ongoing care for her daughter at home, as seen in other parenting memoirs and activism around the deinstitutionalization of the disabled, took on new resonance when she, and other parents, had been told that not only was an institution the best place for their child, but it was the only place suited for their child because the maternal influence was inflicting such damage. The work of psychologist Bruno Bettelheim, particularly his text *The Empty Fortress,* which promoted complete removal of the child from his family environment, emphasized this maternal danger and publicized the refrigerator mother theory to a wide audience. Historian of religion James T. Fisher argues that the best-known autism narratives are conversion narratives: “these texts resuscitate the imperiled humanity of their subjects while confirming the efficacy of therapeutic interventions, which, in the twentieth century, rivaled traditional religious practices as chosen

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Risks,” *Psychology Today*, December 31, 2016, https://www.psychologytoday.com/us/blog/mental-wealth/201612/autism-and-screen-time-special-brains-special-risks; Rebecca Lane and Jenny Radesky, “Digital Media and Autism Spectrum Disorders: Review of Evidence, Theoretical Concerns, and Opportunities for Intervention,” *Journal of Developmental & Behavioral Pediatrics* 40, no. 5 (June 2019): 364–68; Yurika Numata-Uematsu et al., “Attachment Disorder and Early Media Exposure: Neurobehavioral Symptoms Mimicking Autism Spectrum Disorder,” *The Journal of Medical Investigation* 65, no. 3.4 (2018): 280–82; Bruno Harlé, “Intensive Early Screen Exposure as a Causal Factor for Symptoms of Autistic Spectrum Disorder: The Case for «Virtual Autism»,” *Trends in Neuroscience and Education* 17 (December 1, 2019): 100119; Weerasak Chonchaiya, Prapasri Nuntnarumit, and Chandhita Pruksananonda, “Comparison of Television Viewing between Children with Autism Spectrum Disorder and Controls,” *Acta Paediatrica* no. 7 (July 2011): 1033–37; Aviva Must et al., “Comparison of Sedentary Behaviors between Children with Autism Spectrum Disorders and Typically Developing Children,” *Autism* 18, no. 4 (May 1, 2014): 376–84.

vehicles for personal transformation."[42] Fisher analyzes *Dibs: In Search of Self* as the paradigmatic autism conversion text, the best-selling 1964 account of a semi-mute, withdrawn, miserable young boy written by Virginia Mae Axline, who transformed the child through weekly play therapy sessions. *Dibs* fit neatly into the refrigerator mother theory, as Axline saved the boy from his uncaring parents, offering a conversion through nondirective therapy and a soul saved from the darkness of autism.[43] These narratives of recovery draw upon the restitution narrative type described in Arthur Frank in his 1995 examination of illness narratives, *The Wounded Storyteller*. According to Frank, the restitution narrative shapes the experience of illness—or disability—into a meaningful story by interpreting every new development as a step towards regaining health. In this narrative type, the physician is the hero, the patient the object of heroism.[44] For parent memoirs that invoke this narrative structure, rather than the physician as hero, the parent author is the hero-protagonist of their child's disability.

Park was well aware of contemporary psychoanalytical theory. She described child development expert Erik Erikson's theory of psychosocial development and ego failure, Bettelheim's claims of autistic children's recovery under his care, and Beata Rank's insistence on mother-blaming as she described her struggles to understand her daughter and autism.[45] She wrote honestly about how she fit the profile of the refrigerator mother in case it might be significant, describing herself as "an intellectual mother by no means totally accepting of her feminine role, who did not at all want another baby."[46] But Park refused any guilt and rejected

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[42] James T. Fisher, "No Search No Subject? Autism and the American Conversion Narrative," in Osteen, *Autism and Representation*, 51.
[43] Fisher, "No Search," 53-56.
[44] Frank, *The Wounded Storyteller*, 101-123.
[45] Park, *The Siege*, 19.
[46] Park, 23.

the idea that her treatment of Jessy had been different from the loving care she had shown her three older, non-autistic children: “We knew we had been the same kind of parents to [Jessy] that we had been to the others… Experience with three children had taught me that the mind-reading powers of babies are greatly exaggerated. I know that [Jessy] had never guessed that (like so many normal children) I had not really needed another baby.”[47] Park’s rejection of guilt motivated her to write *The Siege*, as she wished to relieve the pain other mothers felt and help them navigate the experience of an autistic child, as well as convince professionals that she had not caused her daughter to become autistic.[48]

Park’s rejection of mother-blaming and secure confidence in her knowledge and experience as the mother of four invokes the role of parent as expert amateur as described by Chloe Silverman in her book, *Understanding Autism*. Park’s lack of guilt was unusual, even among parents who did not believe that they were to blame for their children’s condition. Jane Taylor McDonnell, whose son was diagnosed in the mid-1970s, wrote about her devastation at being told by her son’s physician to read *Dibs*.[49] McDonnell refused to believe that she had harmed her son through any failure to show affection or by continuing to work as an English professor, but the blame of the medical community still weighed on her heavily, as it did for many. The mother-blaming of the post-war period had conditioned her to take the blame for everything that her children experienced: “the guilt was planted… from a thousand other injunctions I had heard all my life. Asthma, hyperactivity, school problems, delayed development, allergies, psychological withdrawal, autism—all came from working mothers.”[50]

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[47] Park, *The Siege*, 131.
[48] Vicedo, *Intelligent Love*, 130.
[49] McDonnell, *News from the Border*, 10-11.
[50] McDonnell, 11.

In a 2019 interview, McDonnell described the mother blame as something that "went so deep. It was so, so hurtful."[51]

The mother-blaming that strongly characterized the 1950s had a long legacy, but researchers were moving away from a strict psychogenic etiology for the diagnosis by the late 1960s, seeking alternative explanations. Autism's etiology remained unsettled and unstable in ways that persist to the present. Its plasticity has opened up space for a variety of explanations to emerge throughout the scientific and parent communities, including genetic and genomic explanations, as Chloe Silverman and Jennifer S. Singh have explored, along with concerns over gut health, auditory functioning, vitamin deficiency, and screen time.[52] The unsettled nature of autism's causes also allowed vaccine causation to take hold in a significant part of the parent community.

Fears within the autism community of the role that vaccines may have played in the increasing prevalence of autism date to the 1980s and continue to the present. The historian Elena Conis has argued that second-wave feminist health activism has shaped vaccine skepticism and refusal, as women questioned the paternalism of the medical establishment and the vaccines they feared were unsafe, and for the centrality of the media in publicizing fears of autism and vaccines.[53] The fear that vaccine damage caused autism, prominently publicized after Andrew Wakefield's 1998 article in the *Lancet* which linked the MMR vaccine with an increased risk of autism, picked up on longstanding fears of vaccine-induced injury along with concern over the

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[51] Jane Taylor McDonnell, oral history with the author, Oct. 17, 2019.

[52] Silverman, 141-66; Singh, *Multiple Autisms.*

[53] Elena Conis, "A Mother's Responsibility: Women, Medicine, and the Rise of Contemporary Vaccine Skepticism in the United States," *Bulletin of the History of Medicine* 87, no. 3 (October 1, 2013): 407–35; Conis, *Vaccine Nation*.

increasing incidence rates of autism.[54] Despite the widespread medical rejection and refutation of Wakefield's work, he remains popular among certain anti-vaxxers in the United States, and the fears of vaccines have not subsided. Furthermore, the explanations that vaccine-refusers and parents alleging vaccine damage offer vary beyond concerns over MMR, from having too many inoculations at one time to the role of mercury in vaccine preservation.

Vaccine-causation for autism combined a skepticism of the medical establishment with roots in feminist health activism with the effects that the refrigerator mother theory and lingering parental blame has had on the relationship of the autism community with the medical establishment. As parents used memoir as a space to respond to the doctors that blamed and shamed them for their children's autism, they created a narrative in which medical authority was unreliable and untrustworthy. Josh Greenfeld, author of several memoirs about his son Noah, wrote in 1972, "It seems to me there is a gulf between the parents of autistic children and most professionals in the field—and that gulf is guilt. We're wary of assigning it; psychologists and psychiatrists and educators are looking to assign it. And I've decided that from now on I'm going to listen only to the consumers in the field, the parents, not the professionals with their own wares to sell."[55] Greenfeld's sentiments were widely shared. Rejecting the medical establishment, parents placed their trust in other parents, fueling the urgency of writing and reading memoirs, which served to grant a parent access to the imagined community of autism and to the ability to shape its meaning. The kinship biosociality that autism parenting created, established through reading memoirs and guidebooks and participating in parent advocacy

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[54] Andrew J. Wakefield et al., "RETRACTED: Ileal-Lymphoid-Nodular Hyperplasia, Non-Specific Colitis, and Pervasive Developmental Disorder in Children," *The Lancet* 351, no. 9103 (February 28, 1998): 637–41.

[55] Greenfeld, *A Child Called Noah; a Family Journey*, 112.

organizations, elevated the status of parents as expert amateurs and solidified the ability of parents to create the meaning of autism within American culture.[56] As Catherine Maurice wrote in 1993, "We parents *are* amateurs, in the true sense of the word: amateurs are lovers. We are lovers of our children, and until the professional community can offer us more effective programs, we will often have to take matters into our own hands."[57] For Maurice, her status as a parent and her ability to show her own children as evidence of her love and knowledge of autism, was the superior credential for understanding autism.

The unsettled etiology of autism allowed parents to use memoirs as a space to assert their own beliefs about autism, its causes, and its treatment. In the 1976 book *Son-Rise*, Barry Neil Kaufman recounted the novel treatment that he and his wife had successfully used with their young autistic son, Raun. The Kaufman spent hours each day mimicking their son's behavior, including spinning and flapping their arms, on the basis that by joining him, they would be able to reach him.[58] By the book's end, Raun was a normal, happy boy of six. Their son's recovery became the basis for the Kaufmans' branded autism therapy program, the Son-Rise Program for Autism, which began in 1983 as well as a 1979 tv-movie, *Son-Rise: A Miracle of Love*.[59]

The validity of the Son-Rise method continues to rely on the evidence of Raun Kaufman as a successful, non-autistic person. In 2006, Kaufman wrote to the *New York Times* to voice his objections to an opinion piece that credited false expectations of recovery with creating a culture

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[56] Rayna Rapp, Deborah Heath, and Karen-Sue Taussig, "Genealogical Dis-Ease: Where Hereditary Abnormality, Biomedical Explanation, and Family Responsibility Meet," in *Relative Values: Reconfiguring Kinship Studies*, ed. Sarah Franklin and Susan McKinnon (Durham: Duke University Press, 2001), 384–412.

[57] Maurice, *Let Me Hear Your Voice,* 307.

[58] Barry Neil Kaufman, *Son-Rise,* First ed. (New York: Harper & Row, 1976).

[59] "The Son-Rise Program at the Autism Treatment Center of America," *Autism Treatment Center of America*, https://autismtreatmentcenter.org/about-us/; John J. O'Connor, "TV: 'Son-Rise,' About Autistic Child," *New York Times*, May 14, 1979.

in which three parents had recently murdered their autistic children. The essay's author, Cammie McGovern, parent of a son with autism, described *Son-Rise* as "a bible of hope" with the message that "If you commit all your time, your money, your family's life, recovery is possible."[60] McGovern decried this message and cautioned other parents that recovery is not the reality— "I've never met a recovered child outside the pages of those old books"[61]— but that life with an autistic child can be delightful on its own merits. Kaufman rejected the notion that his program was dangerous in its false promises, writing that "I know of many children who have recovered using the Son-Rise Program… Raun K. Kaufman, the first Son-Rise Program child, is now a lecturer, teacher and the chief executive of our center."[62] Kaufman insisted that "Autism does not have to be a life sentence," continuing to promote the promise of recovery that he had been publicizing since the 1970s.[63] Since the publication of *Son-Rise*, critics have questioned the validity of Raun's autism diagnosis and the efficacy of the treatment.[64]

Annabel Stehli wrote of the successful use of auditory training with her daughter Georgiana in her 1991 memoir *The Sound of a Miracle: A Child's Triumph Over Autism*. Auditory training, also known as Auditory Integration Therapy (AIT) involves listening to specific tones and sounds of various pitches and volumes. Originally developed for specific auditory disorders, its creator, French physician Guy Bérard, began promoting AIT as a treatment for autism in the late 1970s, suggesting that hypersensitive hearing was a major cause of autistic behavior. *Sound of a Miracle* shares the story of Georgiana's journey from autistic

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[60] Cammie McGovern, "Autism's Parent Trap," *New York Times*, June 5, 2006.
[61] McGovern, "Autism's Parent Trap."
[62] Barry Neil Kaufman, "A Chance for Every Child," *New York Times*, June 12, 2006.
[63] Kaufman, "A Chance for Every Child."
[64] Herbert, Sharp, and Gaudiano, "Separating Fact from Fiction;" Bryna Siegel, *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders*, Revised ed. (New York Oxford: Oxford University Press, 1998), 330-331.

child, institutionalized at Bellevue Hospital, to fully recovered. Stehli discovered Dr. Bérard and AIT after moving from New York to Switzerland. In just ten days of treatment, eleven-year-old Georgiana was miraculously cured of her autism.[65] Josh Greenfeld, author of *A Child Called Noah*, reviewed the book for the *Los Angeles Times.* He found Georgiana's recovery to be proof not of the potential of AIT for autism—although he does not dispute her transformation—but of the meaningless category of autism:

> Never mind that the miracle described is at best what scientists usually dismiss as anecdotal evidence. I am not a scientist but I am a parent, and I disparage no fellow parent's experiences. In fact, in matters dealing with "autism," I find anecdotal evidence almost appropriate. For after an involuntary involvement with "autism" in its most devastating severity for about two dozen years, I have come to the conclusion that "autism" itself is an anecdotal affliction.[66]

For Greenfeld, who had catalogued his own family's struggles to find any kind of effective treatment or education for his son, autism had ceased to reflect anything more than a label given to a disparate set of anecdotal cases. The expansiveness of autism reflected the breadth of possible treatments, without any particular treatment offering him hope for his own son's case: "Any parental consumer can buy the diagnosis, any professional expert can sell the diagnosis, and so any alleged victim can be miraculously cured."

A number of scientific studies examined AIT's efficacy in the 1990s. Bernard Rimland—who wrote in the Afterword to *Sound of a Miracle* that "Georgie is by no means the only autistic person to have shown noteworthy improvement after Bérard's auditory training."[67]—conducted

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[65] Stehli, *Sound of a Miracle.*

[66] Josh Greenfeld, "Autism: A Mislabeled Malady?," *Los Angeles Times*, January 20, 1991.

[67] Rimland, "Afterword," in *Sound of a Miracle*, 225.

several studies at his Autism Research Institute.[68] Although some studies found possible benefits, the research consensus from the scientific establishment is that AIT does not have therapeutic benefits for autism.[69] In 1998, the American Academy of Pediatrics Committee on Children with Disabilities published a statement on AIT in *Pediatrics*, writing that "currently available information does not support the claims of proponents that these treatments are efficacious" and that "their use does not appear warranted at this time, except within research protocols."[70] That same year, Annabel Stehli founded the Georgiana Institute, a non-profit dedicated to promoting AIT to parents and professionals.[71]

In *Let Me Hear Your Voice: A Family's Triumph over Autism*, published in 1993, Catherine Maurice claimed her two children recovered from autism through applied behavioral analysis, an autism treatment developed by psychologist O. Ivar Lovaas at UCLA. Based on B. F. Skinner's work on behavior analysis and developed in the 1960s and 70s, Lovaas's technique involved intensive training of autistic children through positive and negative reinforcement, including electric shocks. Lovaas claimed that early intervention with applied behavior analysis

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[68] Bernard Rimland and Stephen M. Edelson, "Brief Report: A Pilot Study of Auditory Integration Training in Autism," *Journal of Autism and Developmental Disorders* 25, no. 1 (February 1995): 61–70; Bernard Rimland and Stephen M. Edelson, "The Effects of Auditory Integration Training on Autism," *American Journal of Speech-Language Pathology* 3, no. 2 (May 1, 1994): 16–24.

[69] Herbert, Sharp, and Gaudiano, "Separating Fact from Fiction;" "How Science and Evidence Won Out against Auditory Integration Therapies," Organization for Autism Research, February 7, 2011, https://researchautism.org/how-science-and-evidence-won-out-against-auditory-integration-therapies/.

[70] American Academy of Pediatrics, Committee on Children with Disabilities, "Auditory Integration Training and Facilitated Communication for Autism," *Pediatrics* 102, no. 2 Pt 1 (August 1998): 431–33.

[71] "Auditory Integration Training (AIT) Information · The Georgiana Institute," accessed September 6, 2019, https://www.georgianainstitute.org/.

could cure autistic children.[72] Lovaas's work was controversial among other autism practitioners and the public, particularly his use of aversives.[73] A 1965 photo essay in *Life* magazine showed children screaming, crying, receiving electric shocks, and being slapped by a therapist.[74] The practices of ABA vary widely—some practitioners use physical force, others do not.

Maurice's work waded into the controversy over whether Lovaas's treatments were effective in "curing" autism, and whether a child with autism could ever be determined to have become normal. Tracing her family's experience with a variety of experimental therapies for autism, Maurice claimed that the intensive ABA therapy conducted with her children using Lovaas's guidelines was effective and necessary for saving children from the tragedy of autism. Bernard Rimland wrote the foreword, endorsing Maurice's methods and results while offering his own belief in an alternative etiology for the condition: "For the past several decades I have devoted much effort to a search for natural substances—not drugs—which will help normalize brain function in autistic children and adults. Research, by myself and others (sixteen consecutive positive studies to date), has established that almost half of all autistic persons improve in numerous ways when given larger than normal amounts of vitamin B6 and magnesium."[75] Maurice and Rimland used *Let Me Be Your Voice* to support their understanding of autism, including the controversial belief that a child with autism could be recovered. Maurice used her children's experience as a beacon of hope for other parents: "We look at our children

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[72] O. Ivar Lovaas, "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children," *Journal of Consulting and Clinical Psychology* 55, no. 1 (1987): 3–9.

[73] Adam Feinstein, *A History of Autism: Conversations with the Pioneers* (Chichester; Malden, MA: Wiley-Blackwell, 2010), 129-134.

[74] "Screams, slaps, and love: A surprising, shocking treatment helps far-gone mental cripples," *Life* 7 May 1965.

[75] Bernard Rimland, "Foreword," in Maurice, *Let Me Hear Your Voice,* xvi.

today and we see that they are bright and happy. They are spontaneous, affectionate, sensitive to others' feelings, able to play cooperatively with each other and other children."[76] Maurice's testimony to her children's recovery existed outside a rigorous scientific study of ABA and offered parents the tools to follow in her family's footsteps. Individual experience became the ultimate arbiter of truths about autism. ABA remains highly popular among parents and professionals, and it continues to be one of the most common treatments for autism. Criticism of ABA has also continued since Lovaas's work began in the 1960s, and its use is debated in professional and activist circles.[77]

For parents interested in promoting their own understanding of autism's causes and their belief in a successful treatment, memoir was a valuable medium for reaching other like-minded parents. The ability to construct a narrative of recovery from autism aligned with the restitution narrative form that audiences expect from illness narratives, giving the reader a satisfying conclusion to the confusing diagnosis of autism. The arc of recovery, in which parents heroically save their children from the depths and terrors of autism, contributed to a broader cultural understanding of autism as a tragedy and a threat that necessitated drastic action from parents.[78] This framing of autism ultimately influenced the vaccine-autism debate, as the risk of autism became greater than the risk of the infectious diseases that childhood vaccines are designed to prevent.

A Siege upon Autism

Clara Claiborne Park used the metaphor of besieging the castle walls that trapped her daughter inside to explain her approach to treating and parenting Jessy. Park's extended

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[76] Maurice, *Let Me Hear Your Voice,* 288.
[77] Carey, Block, and Scotch, *Allies and Obstacles*, 94-95.
[78] Sousa, "From Refrigerator Mothers."

metaphor of laying siege to autism to access her daughter offered a vision of autism as obscuring the real child, who could be revealed even if the autistic traits would never disappear. Park wrote in 1967 about the then-eight-year-old Jessy, “Someone who saw her now for the first time and had no knowledge of her history would probably not think her autistic at all… The autistic isolation itself is very much attenuated.”[79] Park did not make claims of her daughter’s autism having been cured. She quoted another parent, Jacques May, who wrote, "Autism is only a symptom. As the child grows, if it is sympathetically handled, the autism recedes. But the child does not thereby become normal."[80] Jessy remained different to typically developing children, distinctions Park clearly described in *The Siege* and updated in later editions, but the improvements that had come from her daughter being “under siege” had allowed Park to reach Jessy and allow her to improve. This narrative recurs throughout the genre of parent memoirs about autism, varying according to changes in the diagnosis, treatment, and construction of autism at the time of writing.

The question of whether *The Siege* is a recovery narrative and whether the central metaphor was damaging to autistic people is controversial within scholarship on autism and parent memoirs. Disability scholar Chris Foss, in his analysis of autism memoirs, describes *The Siege* as “a script of disability as defectiveness… in Park's narratives, one again is confronted by two distinct worlds — the exclusively antagonistic world of disability out of which it is hoped the autistic individual will exit and the real world of normal ability into which it is hoped the autistic individual will emerge.”[81] He describes *The Siege* as the story of “A Mother’s Life with

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[79] Park, *The Siege*, 252.
[80] May, *A Physician Looks at Psychiatry*, 58, quoted in Park, *The Siege*, 261.
[81] Chris Foss, “Emerging from Emergence: Toward a Rethinking of the Recovery Story in Nine Contemporary Nonfiction Autism Narratives,” *Disability Studies Quarterly* 29, no. 2 (April 15, 2009), https://doi.org/10.18061/dsq.v29i2.924.

Autism." Foss's critique centers on the depiction of the autistic child's world as less human than the non-autistic world. Foss sees in Park's writing an understanding of autism that he argues directly comes out of the belief in autism as inherently tragic—through the parent's efforts, the autistic child has been able to access the superior, non-autistic, human world.

Not all scholars find Park's writing to be so problematic. English professor Debra Cumberland describes *The Siege* as a quest narrative, a distinct narrative type from the restitution narrative, in which the ending is unknown to the journeyer.[82] Marga Vicedo, in her biography of Clara Park, objects to critiques of "the siege to a citadel" metaphor and Park's work that identify it as inadequate and harmful. Vicedo does not cite any such critiques, but her defense seems directed, at least in part, at Foss: she argues that the metaphor was historically accurate to the understanding of autism at the time of Park's writing, and that Park does not present herself as Jessy's savior or Jessy as recovered at the end of the book.[83] Vicedo is correct that Park does not present Jessy as recovered from autism—her descriptions of Jessy in the penultimate chapter reflect continuing language, physical, and social differences. However, Park does describe Jessy as "improved and… improving. She has moved far beyond what she seemed likely to achieve in her early years, and a comparison of her case with other histories of children claimed as autistic could be used to support considerable optimism."[84] She concludes that, "It has been a long siege. And as a siege it has been successful, for we have reached [Jessy]."[85]

The promise of improvement that Park expresses through the siege metaphor and the necessity of such a siege reflect Foss's critiques—Park enacted the siege; her daughter's

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[82] Debra Cumberland, "Crossing Over: Writing the Autistic Memoir," in *Autism and Representation*, 183-196.
[83] Vicedo, *Intelligent Love*, 124-127.
[84] Park, *The Siege*, 271.
[85] Park, *The Siege, 272.*

improvement involves her ability to come into the non-autistic world; this improvement is due to Park's labor. Dismissing the idea that the success of *The Siege* was due, in some way, to its resemblance to the recovery narrative that people expected out of an illness narrative seems to avoid wrestling with the uncomfortable implications of such a narrative for Park's status as a pioneering, esteemed figure in autism parenthood. While there are clear differences between Park's work and, for example, the restitution narrative of *Dibs*, and Park is careful not to claim her daughter is cured, it is not a book that resolves with the acceptance of Jessy's autism as a facet of neurodiversity but with the belief that autism can be, and has been, attenuated. The media coverage of *The Siege* reflects this belief, as in Joan Beck's "You and Your Child" column of February 1968. Even while Beck describes Jessy's continued social disability and attendance at school with "the educable mentally retarded," she proclaims that Jessy has "improved and can no longer be described as autistic."[86] Park herself complicated the implications of the siege metaphor in her later memoir, *Exiting Nirvana*:

> It has not been about a miraculous recovery, through selective narration could give that illusion… It was like assaulting a walled city. I called my book *The Siege*, choosing the title two years before I'd ever heard of an empty fortress. The metaphor is that strong. Four years, five years, six years—we did get into that walled city. But of course when she began to look at us, to recognize us, to need us—even, in her way, to love us—this was no goal achieved but only a beginning. The siege metaphor became transmuted into a more ordinary one. Siege into journey.[87]

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[86] Joan Beck, "Their Elly Hid Behind Silent, Invisible Wall," *Chicago Tribune* February 13, 1968.

[87] Clara Park, *Exiting Nirvana: A Daughter's Life with Autism* (Boston: Little Brown and Company, 2001), 10.

Park reflects on the siege of her daughter's early years and how her approach towards Jessy became a journey with no fixed ending, which the siege metaphor demands. Yet Park's chosen metaphor for Jessy's autism in this later book—getting Jessy to come out of her autistic "nirvana" into the non-autistic world—supports Foss's conclusions about how Park understood autism.

The idea of a 'siege' as metaphor for a parent's treatment for an autistic child resonated with others who read Park's memoir. Like Park, many parents were given no reason for hope that their children would improve, to expect that their children would be best sent to an institution, and would never be able to speak, read, attend school, or manage their own bodily functions. Some parents found the metaphor of the siege to be problematic. Despite also recounting that she "fell in love with the book," Jane McDonnell said in 2019, "I was troubled by the central metaphor of that book, the castle that had to be assaulted." McDonnell titled her own memoir *News from the Border*, seeing her writing as a "trying to translate [her son] across that space between autism and non-autism, just to see autism as a different way of being in the world, but one with real validity."[88]

The interpretation of autism therapy and prognosis expressed by a siege infused the expectation of a narrative of improvement or recovery for autism memoirs. Although Park was careful to write that she and her husband had no expectation of a cure for autism, and to emphasize that the work they did with Jessy was ongoing, parents, including Catherine Maurice, found the narrative of improvement and dedication inspiring and became determined to besiege the walls around their own children. As Maurice wrote:

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[88] McDonnell, oral history, Oct. 17, 2019.

> From the beginning, my idea of a siege meant something more forceful and invasive than the kind of respectful, patient waiting portrayed in the scene [in which Park resolves to wait for her daughter's growth]. Nevertheless, it was in Mrs. Park’s book that I first found the germinal concept for my part in the battle. As I read on that night, two concepts fairly burst into my consciousness: the notion of Anne-Marie being ‘walled-in,’ and the idea of assaulting those ramparts. Besieging Anne-Marie, not so much in the sense of waiting and wooing, beguiling and beckoning, but in the far more violent sense of storming the walls.[89]

Upon reading Park's memoir, Maurice related to Park's metaphorical interpretation of autism and of autism treatment as a siege upon defensive walls. Park's work, she wrote, "enabled me, for the first time, to believe that I had some control, that I was not completely hopeless."[90] This measure of control and reason for hope inspired the dedicated therapeutic efforts Maurice made for her daughter, including ABA therapy and holding therapy, along with Maurice's own writing of a memoir about her daughter's, and, later, her son's, recovery from autism. Maurice, in turn, inspired other parents to commit to ABA, such as those profiled in the New York Times in 1995:

> Sergeant Pagoni said that while his job was stressful, nothing at work compared to coming home and seeing his young son out of control... The Pagonis say they don't feel helpless anymore. They gained hope after reading a book by another Connecticut woman, who wrote under the pseudonym Catherine Maurice, that chronicles what she describes as the recovery from autism of her two young daughters after treatment with an intensive behavioral method. The book, "Let Me Hear Your Voice" caused Ms. Pagoni to hire a

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[89] Maurice, *Let Me Hear Your Voice*, 80.
[90] Maurice, 79.

> team of therapists who began working with Billy last summer. Those therapists say Billy is making remarkable progress.[91]

Catherine Maurice's "siege" upon autism offered especial power because of her claim of full recovery, rather than mere improvement, for her children. For parents starved of hope, the potential of ABA therapy obscured the method's always uncertain results. Maurice's success was more visible, and more popular, than her admission of the fact that even in the most successful studies, only half of autistic children showed significant improvement through behavioral modification.

Other parents found the narrative of recovery that Maurice and others promoted to be unrealistic and problematic. Jane Taylor McDonnell expressed in 2019 that she was "very frustrated… very envious" with Maurice's book and similar promises of recovery, saying that "My experience wasn't like that. And I didn't know people whose experience was like that. All the parents that I knew and parent groups were continuing to struggle. In fact, [my son] Paul was considered the breakthrough child. And a lot of places he was considered the success, but I wouldn't claim that there was any one treatment that somehow saved him."[92] McDonnell's background as a literary scholar led her to believe she could write her own story, sharing the

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[91] Richard Weizel, "Escape From the Closed World of Autism," *New York Times*, January 29, 1995, sec. New York. Other parents in the 1990s cited Maurice's work as their inspiration for ABA therapy and expressed their belief, like Maurice's, that their children had recovered from autism. See Mary Amoroso, "Extra Help For Kids With Autism," *The Record*, October 12, 1997, Sec. Lifestyle; Sandra G. Boodman, "Intense Therapy Shows Signs Of Helping Autistic Children," *Washington Post*, January 24, 1995; Meg Breslin, "Parents On A Mission: With The Help Of Friends And Strangers, Sandy And Jim Sotzen Seek A Future For Their Autistic Toddler," *Chicago Tribune*, December 29, 1996, Sec. Southwest; Kate Stone Lombardi, "Parents Starting School For The Autistic," *New York Times*, April 30, 1995, Sec. New York; Mary Niederberger, "A Chance To Be Heard Controversial Method Of Learning Gives Autistic Children A Second Chance.," *Pittsburgh Post-Gazette*, January 6, 1998, Sooner Edition, Sec. Health.

[92] McDonnell, oral history, Oct. 17, 2019.

experience of raising an autistic child that was not a manual for recovery but a personal narrative of her life, including her experiences with her son. Her work garnered responses from "a huge number" of parents, as well as neurologists and writer Oliver Sacks, fellow parent memoirists Clara Park and Charlie Hart, and feminist authors including Kate Millet and Sara Ruddick.[93] McDonnell's central metaphor of autism as a borderland, directly informed by her grounding in literary scholarship, reflected her son's personality: his love of maps, of measuring, of conveying meaning through numbers that McDonnell would interpret into words. Unlike the restitution narrative of *Let Me Hear Your Voice* or the ambiguous recovery narrative of *The Siege*, *News from the Border* offers no claim that Paul was no longer autism or that autism could be separated from who Paul is.

Prenatal Diagnosis and Trisomy 21

The assertion of expertise occurred across the genre of parent memoirs, making experience with a child the greatest source of knowledge for autism and Down syndrome. As journalist Martha Moraghan Jablow wrote in her 1982 book about her daughter, Cara's life with Down syndrome, "At Cara's birth, we knew little about mental retardation and even less about Down's syndrome. In the past eight years, we have learned a great deal. Cara has been our greatest teacher."[94] Despite the shared sentiment, the history of Down syndrome lacks autism's productive unsettledness, allowing parents fewer ways to expand upon Down syndrome's meaning, as the cause of Down syndrome became fixed at the same time that the causes of autism became more unstable.

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[93] McDonnell, oral history, Oct. 17, 2019.

[94] Jablow, *Cara,* xi.

French physician Jerome Lejeune first identified Down syndrome's cause as a chromosomal anomaly, trisomy 21, in 1958. This led to the introduction of prenatal diagnosis of trisomy 21 via amniocentesis in the late 1960s. Observant Catholic Lejeune hoped that the discovery of trisomy 21 would lead to finding a cure for Down syndrome. Instead, this knowledge led to the ability to prevent the birth of babies with the chromosomal anomaly.[95] Prenatal diagnosis became increasingly available to pregnant women in the 1970s, simultaneously and non-coincidentally, as Ruth Schwartz Cowan has argued, with expanding access to abortion that resulted in the 1973 decision in Roe v. Wade that made abortion legal nationwide. Prenatal testing, and the possibility of terminating a pregnancy if a diagnosis were made, became central to contemporary genetic testing, as illuminated by Alexandra Minna Stern's work. [96]

The availability of prenatal diagnosis for Down syndrome has centered the cultural meaning of the disability on its legibility pre-birth and its construction *not* as an inevitable occurrence, but as the birth of a child with trisomy 21 as a deliberate, and avoidable, choice. This restructuring of responsibility, alongside the blame placed on advanced maternal age, has had significant effects on the positioning parents have done when writing the narratives of their memoirs. Selective abortion offered an answer to prenatal diagnosis. In her ethnographic research on amniocentesis and prenatal testing, anthropologist Rayna Rapp found that a prenatal diagnosis of Down syndrome led mothers to make a decision to terminate the pregnancy faster than for other, more serious conditions, such as trisomy 13 or 18. Rapp argues that the cultural

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[95] Ruth Schwartz Cowan, *Heredity and Hope: The Case for Genetic Screening* (Cambridge: Harvard University Press, 2009), 87.

[96] Alexandra Minna Stern, *Telling Genes: The Story of Genetic Counseling in America* (Baltimore: Johns Hopkins University Press, 2012).

familiarity of Down syndrome, along with the accepted purpose of amniocentesis specifically as a way to diagnose Down syndrome, allows parents to make a quick decision.[97] In her 1999 memoir, *Expecting Adam,* sociologist and parent Martha Beck recounted her husband expressing this opinion while they discussed the possible outcomes of an amnio: “I agree with you that birth defects are a tragedy any way you look at it, but abortion is a way to deal with the problem, you know? To limit it. That’s all I was saying.”[98] Amniocentesis and selective abortion allowed parents to avoid giving birth to a child with Down syndrome, to "deal with the problem," as Beck's husband described it. Such an understanding of the purpose of amniocentesis was widespread. A 1999 *Boston Globe* series profiling a couple with a child with Down syndrome included a moment in which the father reads an issue of *Newsweek* on prenatal screening. The article read, "Down syndrome in theory is completely preventable, in the sense that there is a reliable test for the extra chromosome known to be its cause, after which the pregnancy can be terminated."[99] The father was not surprised by this explanation of Down syndrome’s preventability. However, he was shocked to learn that ninety percent of women whose prenatal testing indicates Down syndrome choose to abort. By emphasizing the ubiquity of the decision to terminate a prenatally diagnosed pregnancy, such articles suggest that the end of Down syndrome is approaching and force parents of children with Down syndrome to defend and justify the lives of their children.

Earlier Down syndrome memoirists such as Dale Evans Rogers emphasized their children’s loving nature as a challenge to the idea that they should be institutionalized. Anti-

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[97] Rayna Rapp, *Testing Women, Testing the Fetus* (New York: Routledge, 1999), 263-303.
[98] Martha Beck, *Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic* (New York: Berkeley Books, 1999), 134.
[99] Mitchell Zuckoff, “Struggling to Grow,” *The Boston Globe*, December 8, 1999.

institutionalization was especially strong among parents of children with Down syndrome who had experienced the pressure to institutionalize their children from their diagnosis in infancy. Allison C. Carey has argued that parents of children with Down syndrome "were some of the first parents of children with intellectual disabilities to offer a strong and direct challenge to the medical community's role in childrearing, most likely because they were confronted with medical prejudice almost immediately at the birth of their child and still in the 1960s were most often advised to institutionalize their child early in his or her life."[100] The rejection of institutionalization created space where parents could assert their authority over their children's care and wellbeing.

Interpreting Down syndrome as a prenatal chromosomal defect forced parents to assert their child's right to have been born. Claire D. Canning described her daughter Martha as a gift in 1975, hoping to share with other families a positive side of raising a child with Down syndrome.[101] The Evangelical Christian overtones that characterized work like Dale Evans's took on new meaning when they circulated in a pro-life (anti-abortion) environment. As the editor of the compilation of parent narratives titled *Gifts* wrote in 2007, "there is one thing each of us holds in common. We [parents] know that the life of a child with Down syndrome is worth living. Whether we believe it is granted by the supernatural, or bestowed by Nature herself, we've come to understand that life—including life with an extra chromosome—is a gift. A good gift."[102] The subtext—that these are lives worth giving birth to, not terminating—is clear. The

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[100] Carey, "Parents and Professionals," 64.

[101] Claire D. Canning and Joseph P. Canning, Jr., *The Gift of Martha* (Boston: Children's Hospital Medical Center, 1975).

[102] Kathryn Lynard Soper, ed. *Gifts: Mothers Reflects on How Children with Down Syndrome Enrich Their Lives* (Woodbine House, 2007), xxvii.

metaphor of a gift shifts in a post-prenatal diagnosis world in which the receiver of said gift can choose to refuse it.

The opposition to terminations in the case of prenatal diagnoses of disability produces an uncomfortable political intersection between anti-abortion advocates and disability activists, who are typically not in alignment. The resistance to supporting broader anti-abortion goals has pushed disabilities scholars such as Adrienne Asch to insist upon an identity that was unilaterally pro-choice but opposed to prenatal diagnosis and selective abortion. Asch identified this position as the "any/particular" distinction. If one were to have an abortion for *any* reason, regardless of information known about the fetus, that would be ethically sound; to have an abortion because prenatal testing identified this particular fetus as disabled would be discriminatory.[103] Parent memoirists rarely expressed their beliefs in exactly Asch's terms, and their positions regarding abortion rights vary, but some measure of ambivalence about the decision to abort this particular fetus on the basis of its disability diagnosis, as Asch describes it, is common.

Academic and father Michael Bérubé spent a chapter of his 1996 work *Life as We Know It: A Father, a Family, and an Exceptional Child* examining the morality of the question of abortion. Bérubé wrestled with his belief in reproductive autonomy as a "strongly pro-choice" person before and after his son's diagnosis and his fears that misguided and ill-informed parents would choose a selective abortion due to their misunderstanding of the reality of a life with a child with Down syndrome, including the child's potential:

> What if we had been told, upon receiving the results of an amniocentesis, that our baby would never be able to live a 'normal' life? What if we had been told that he would never

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[103] Adrienne Asch, "Why I Haven't Changed My Mind about Prenatal Diagnosis," in *Prenatal Testing and Disability Rights*, eds. Erik Parens and Adrienne Asch (Georgetown: Georgetown University Press, 2000), 236.

> become a conscious being, never learn to talk, read, or recognize his parents? What, in other words, if we had been as seriously misinformed about Jamie's prospects in the spring of 1991 as were most previous generations of parents and providers?[104]

Parents are often careful not to suggest that their decision be seen as the correct choice, the choice others must make. Martha Beck, whose husband had considered Down syndrome to be a problem that could be limited by selective abortion, refrained from characterizing her decision not to terminate as an ethical or even rational choice, writing, "I want you to know that this was not a decision made out of ethical principles. I was going on sheer emotion."[105] Martha Jablow described getting an amniocentesis when pregnant with her second child, as her husband was adamant about not having another child with Down syndrome. Jablow, a lapsed Catholic, expresses her ambivalence about the decision, relieved when the test finds no chromosomal abnormality and she does not need to choose whether to terminate the pregnancy.[106] While parents including Bérubé and Beck refused to oversimplify the question of selective abortion to offer a clear ethical proscription, and therefore try to avoid judgment of other parents, the memoirs they wrote are offered as a corrective to the bad information that others might receive after the results of an amnio. Their memoirs exist to say, if such parents knew about my child, and my experiences, they might reconsider selective termination.

Parent memoirists write about how important the images they had of life with a child with Down syndrome were to feeling optimistic about their future after their child's diagnosis. Martha Jablow and her husband both had clear ideas of Down syndrome when they learned about their daughter's diagnosis in the early 1970s:

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[104] Bérubé, *Life as We Know It*, 46-47.
[105] Beck, *Expecting Adam,* 183.
[106] Jablow, *Cara.*

> On the phone with Paul, Dr. Chandler had used the word 'mongolism.' Now we both knew the name of the game. My mind flashed back fifteen years. My eight-grade teacher had a mongoloid son. We often saw him at church with his parents and two big Marine Corps brothers. In contrast to his brothers, Patrick was short, a bit chubby, and wore a dull gaze. Patrick had always seemed a part of his family: he went everywhere with them. His mother was one of the best teachers I had ever had and my respect and affectation for her had translated into sympathetic acceptance of him. For Paul, the term 'mongolism' triggered the story of Jimmy Erskine, the son of former Brooklyn Dodger pitcher Carl Erskine… From those two flashbacks our knowledge of Down's syndrome began to grow. They were positive images from which to begin because both Patrick and Jimmy lived with their families and gave them much joy.[107]

The visibility of Down syndrome, predicated on the shared dysmorphia that John Langdon Down had identified in 1866, increased as the successes of the disability rights movement brought people with Down syndrome into the community, but its power diminished as prenatal diagnosis allowed for the overidentification of the syndrome with trisomy 21 and subsumed its cultural meaning into a preventable concern of pregnancy.

Prenatal testing transformed the meaning of Down syndrome, shifting it from an inevitable occurrence to a preventable choice. This change pushed parent memoirs to wrestle with the ethics of selective abortion and write narratives of parenting that emphasized their children's lives as worthy of living. Earlier parents cast children with Down syndrome as little angels who deserved to live at home, attend public schools, and receive support from the state, writing memoirs that asserted their children's rights to greater inclusion into society. Stabilizing

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[107] Jablow, 9.

Down syndrome around trisomy 21 made it legible prenatally, but not visible in the wider culture, requiring parents to assert continually the value of Down syndrome lives and turn their narratives into a justification for the birth of their children. The prenatal detection of trisomy 21 made Down syndrome made giving birth to a child with the diagnosis a choice, offering little benefit to those living with Down syndrome.

Conclusion

Throughout the history of Down syndrome and autism from the mid-twentieth century to the present, the parents of children diagnosed have contributed greatly to the cultural understanding of each condition. Using the medium of memoir, parents shaped the narratives of life with a developmental disability, twisting the "Tiny Tim" figure of disability to fit their goals of anti-institutionalization, the rejection of mother-blaming, a changed diet, an antipathy toward vaccines, or the valuing of disabled lives. The ongoing fear that all parental memoirs respond to—the fear that anyone might have a child that resembles the author's, the fear of having a child with autism or Down syndrome—shapes the genre, as parents offer hope and comfort to those who share their biosocial ties and those who imagine they could, while simultaneously stoking those fears by continually invoking them in their narratives. Parents read other memoirs, reflecting on their shared experiences and emotions, seeking imagined community and reproducing it in their own memoirs, which frequently reference the works of other parents and recommend further works to their readers.

However, the opportunities offered to parents to shape the cultural prominence of autism and Down syndrome differed according to the fixity of each diagnosis's etiology. Prenatal testing transformed the meaning of Down syndrome, shifting it from an inevitable occurrence to a preventable choice. This change pushed parent memoirs to wrestle with the ethics of selective abortion and write narratives of parenting that emphasized their children's lives as worthy of living. Earlier parents cast children with Down syndrome as little angels who deserved to live at home, attend public schools, and receive support from the state, writing memoirs that asserted their children's rights to greater inclusion into society. Stabilizing Down syndrome around trisomy 21 made it legible prenatally, but not visible in the wider culture, requiring parents to assert continually the value of Down syndrome lives and turn their narratives into a justification for the birth of their children. The prenatal detection of trisomy 21 made giving birth to a child with the condition a choice, offering little benefit to those living with Down syndrome.

In contrast, autism's most stable etiology, the refrigerator mother theory, lost its coherence with the decline in psychoanalytical thought in the 1960s. Its effects linger, but the plasticity of autism, with many possible causes and the possibility of multiple autisms, allows parents to use memoir to examine and assert a variety of causes and meanings for the disorder and promote a variety of treatments, positioning autism to reflect the concerns of their time and capture the cultural zeitgeist.

CHAPTER THREE

Feelings as Important as Facts

In the introduction to her 1976 book *You Are Not Alone: Understanding and Dealing with Mental Illness, A Guide for Families, Doctors, and Other Professionals*, memoirist Clara Claiborne Park wrote about what she had gained from parenting her autistic daughter. In particular, she recalled the pain that she had experienced:

> Pain is a gift, if one can learn to use it. [Our daughter Jessy] gave us pain, as sharp, as aching as any that human beings can suffer, the pain of knowing that the child whose growth should carry with it so much joy and hope is growing inexplicably wrong. Through [Jessy], too, came other pain, though others than she bestowed it. This pain, like the first, turned out to be something one could make use of. That there were people who could convince themselves and almost a whole profession that who we were and what we had done as parents had had the power to distort and cripple our daughter's mind and spirit was a kind of pain that only those can understand who have lived it, an assault on the most fundamental of animal instincts, the desire to benefit the young creatures one had brought into the world. Out of the first pain came a longing for understanding; out of the second, anger; out of both, a slow discovery: we were not alone.[1]

Park drew upon the twin pains she describes as inspiration for writing a guidebook for other parents—the pain of seeing her daughter's development go "inexplicably wrong," in Park's view, and the pain of hearing from physicians, psychologists, and various experts that the cause

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[1] Clara Claiborne Park with Leon N. Shapiro, *You Are Not Alone: Understanding and Dealing with Mental Illness, A Guide for Families, Doctors, and Other Professionals,* (Boston: Little, Brown and Company, 1976), xii.

of their daughter's autism had been Park and her husband and the way that they parented. Park was referring to the refrigerator mother theory of autism etiology, which blamed parents for turning their children autistic through emotional froideur.[2] Through the pain she felt from parent blaming, Park found a source of comfort as other parents and families shared her experiences and struggles. The title of her work reflects her belief in that community: you, fellow parent, are not alone.

Clara Park's decision to begin her guidebook with the story of her daughter as inspiration is not unique to her work. Parents of children with Down syndrome and autism have similarly authored and edited various guidebooks for these conditions dating from the 1960s through the end of the twentieth century, Guidebooks authored by non-parent professionals often featured forewords written by parents testifying to the value of the work and highlighted parent perspectives throughout the text. The centrality of parent experiences as authoritative grew in this literature over time. Examining the role of parent voices in these works through the end of the twentieth century reveals narratives of grief, fear, anger, and concern at the initial diagnosis giving way to acceptance, joy, and hope for their children.

Over the mid-to-late twentieth century, disability rights activism and parent activism around deinstitutionalization and disability education led to the passage of federal legislation including the Education for All Handicapped Children Act of 1975 (since 1997, known as the Individuals with Disabilities Education Act) and the Americans with Disabilities Act of 1990, which transformed the rights of disabled children and adults and the services available to them.[3]

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[2] For more on the refrigerator mother theory and parental responses through memoir, see Chapter Two of this dissertation.

[3] For more on the disability rights movement, see Charlton, *Nothing About Us Without Us*; Davis, *Enabling Acts*; Fleischer and Zames, *The Disability Rights Movement: From Charity to*

As parents and professionals wrote, edited, and revised guidebooks over this time period, their advice reflected changing experiences and opportunities for children with Down syndrome and autism, reflecting their hope for continued legislative successes and ever-growing acceptance and improved treatment of their children.

While parents occupied a prominent place in constructing each of these disabilities throughout this period, and an increasingly prominent voice in guidebooks in particular, the differences in the narratives offered for autism and Down syndrome reveal significant points of divergence in these histories. The scientific shaping of Down syndrome as trisomy 21, a chromosomal anomaly that could, beginning in the 1970s, be diagnosed prenatally, created a settled etiology and subsequent meaning for the disability. Parents offered responses to this chromosomal knowledge but were unable to reframe the centrality of genetics and chromosomes to the meaning of Down syndrome or challenge the power of scientific authorities to create boundaries around the diagnosis. Parents became authorities on living with a child with Down syndrome, but without assuming the role of experts on trisomy 21.

In contrast, the unsettled nature of debates over autism's etiology—from psychogenic to organic explanations, parent-blaming to environmental causation, genetic factors to vaccines—along with the growing dominance of parent-focused treatments opened a space for the influence of expert parents not only to respond to controversies over autism but also to call into question the nature of autism spectrum disorders and the meaning of the diagnosis. Parents became not only authorities on living with a child with autism, but on autism itself.

Confrontation; Nielsen, *A Disability History of the United States*; Pelka, *What We Have Done;* and Shapiro, *No Pity.*

Imagined Community through Guidebooks

In 1991, the *New York Times* published an article about Barnes & Noble introducing a collection of books on childhood disabilities into their stores. The piece quoted Steve Riggio, an executive vice president at the company and the father of a daughter with Down syndrome: "When you have a child who is born with Down syndrome, after the initial shock, you want information… You want to know how to raise the child. You want books on Down syndrome."[4] Riggio's response to his daughter's diagnosis—turning to books on the subject—is not merely the involuntary action of a professional in the bookselling business, but also resonates with a belief in the value of reading books and gaining information about a diagnosis that runs throughout the genre of parent guides. In particular, guidebooks claim to offer their parent readership the authority, expertise, and experiences of the community of fellow parents who have been through the challenges and joys of raising a child with a developmental disability. Throughout the genre of parent guides for childhood disabilities, parents reference the value of reading guidebooks and memoirs that offer experiences of parenthood. The anecdotes, narratives, and images parents share through these works provide them with knowledge and hope, revealing the ways that parents develop imagined community and establish kinship biosociality, as described by anthropologists Rayna Rapp, Deborah Heath, and Karen-Sue Taussig.[5] Kinship biosociality refers to the production of intimate bonds through a shared diagnosis or genetic marker, the extension of Paul Rabinow's biosociality as identity-formation into the production of an imagined kindred on the basis of that biological marker.[6] Sociologist Daniel Navon has

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[4] Carol Lawson, "Reading Up on Childhood Disabilities," *New York Times*, August 8, 1991.
[5] Rapp, Heath, and Taussig, "Genealogical Dis-Ease," 384–412.
[6] Paul Rabinow, "Artificiality and Enlightenment: From Sociobiology to Biosociality," in *Essays on the Anthropology of Reason* (Princeton: Princeton University Press, 1996), 91-111.

explored the use of genomic information in identity formation, examining how genetic mutations such as the causes of Fragile X, NGLY1 mutation, and 22q11.2 Deletion syndromes create "support groups, foundations, specialist clinics and literatures, and a series of alliances spanning experts from a wide array of biomedical fields, caregivers, various stakeholders, advocates, and, last but not least, patients and their families."[7]

This use of advice books as a source of community is not unique to the disability parenting genre. In *Perfect Motherhood*, her work on the history of science and child raising, Rima Apple describes mothers in the late nineteenth century using advice columns and parenting articles to “creat[e] a virtual community of maternal support.”[8] This community became especially important for parents of disabled children, facing a diagnosis about which they often knew little or only understood in negative terms, and who lacked existing relationships with parents who could relate to their experiences.

Parents repeatedly recalled how reading about the diagnosis had helped them. After receiving the diagnosis of autism for her 18-month-old son, one mother wrote in a 1998 guidebook, “Through my tears I wondered how the most beautiful baby boy I had ever seen could possibly have this horrible disorder. I felt I was handed a life sentence. I wondered if he would ever play baseball, have friends, talk, and call me mommy. I wondered if I would ever dance at his wedding. Finally, I began to read and read and I haven’t stopped yet.”[9] Seeking out knowledge from trusted sources, including other parents, allowed parents not to feel alone in their struggles. In the introduction to *Babies with Down Syndrome: A New Parent’s Guide*,

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[7] Navon, *Mobilizing Mutations,* 307.

[8] Apple, *Perfect Motherhood,* 30.

[9] Sandra L. Harris and Mary Jane Weiss, *Right from the Start: Behavioral Intervention for Young Children with Autism, A Guide for Parents and Professionals* (Bethesda, MD: Woodbine House, 1998) 19.

published in 1986, editor Karen Stray-Gundersen wrote how her inspiration for compiling this guide came from the lack of good books she had found on Down syndrome following her son's diagnosis: "Our first image was a desperate one, primarily because we had literally no information or knowledge of what Down syndrome was. We expected the worst. We immediately tried to learn more about Down syndrome, but found little to read. What we did find was a collection of outdated and often insensitive material. But over time we learned a lot—mainly from doctors, teachers, Down syndrome organizations, other parents, and, of course, our son, with whom we fell madly in love."[10] After her reading options proved lacking, Stray-Gundersen found other sources of knowledge about Down syndrome, including spending time with her son, learning from other parents, and the support of Down syndrome organizations. Parents throughout the genre of guidebooks stressed the value of parent advocacy organizations and local parent groups as sources of comfort and knowledge, testifying to the importance of the expertise of fellow parents in understanding a diagnosis of autism or Down syndrome.

Amidst the discussions of possible medical problems, educational options, and legal concerns that formed the basis of the advice within guidebooks, the parent experiences recounted in guidebooks for Down syndrome and autism share some key features. Both sets of works reflect initial feelings of grief, bewilderment, anger, rejection, and fear as symptoms emerge or a diagnosis is made, alongside admissions of ignorance and prejudice towards the disabled that fueled these feelings. Typically, these negative emotions give way as the child grows and the parent learns about the disability, accepts their child, and loves their child. Anthropologist Rayna Rapp describes many narratives about parenting a disabled child as "narratives of enlightenment,

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[10] Karen Stray-Gundersen, "Introduction," in *Babies with Down Syndrome: A New Parents' Guide*, First edition, ed. Karen Stray-Gundersen (Bethesda: Woodbine House, 1986), v.

describing a journey from fear or even loathing toward a state of acceptance and appreciation."[11] One parent quoted in *Down's Syndrome: An Introduction for Parents* described the development of such acceptance and appreciation: "When we found out she was a Down's syndrome, I thought it would just be an endless burden… I didn't expect any joy or anything good. Of course we didn't know any better. We had no experience and the way we were told just made you think of all the problems… Over the years that changed… She did things and every little gain was such a joy."[12] Such statements of parental growth and acceptance alongside the child's growth often frame these works, either explicitly or implicitly. English child psychologist Cliff Cunningham attested to his belief in the importance of parents' feelings about their child in the guide's introduction, writing that "feelings about having a child with Down's syndrome are just as important as facts. And parents have made it quite clear to me that information about how other parents felt and coped with their feelings when the baby was born was of great help to them."[13] For Cunningham, writing as an expert on Down syndrome but *not* as the parent of a child with Down syndrome, a distinction he makes clear in his introduction, including the perspective of the parents whose children participated in his research studies allowed his guidebook to transcend medical knowledge to become a source for comfort and for community.

Parents Lillian and Joe Tommasone expressed the tragedy of a child's diagnosis in 1989's *Children with Autism: A Parents' Guide*, writing that "very few things indeed are worse than learning that your child has autism."[14] The Tommasones described a series of emotions that

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[11] Rapp, *Testing Women*, 264.

[12] Cliff Cunningham, *Down's Syndrome: An Introduction for Parents* (London: Souvenir Press, 1982), 20.

[13] Cunningham, *Down's Syndrome,* 16.

[14] Lillian Tommasone and Joe Tommasone, "Adjusting to Your Child's Diagnosis," in *Children with Autism: A Parents' Guide,* Michael D. Powers, ed. (Bethesda: Woodbine House, 1989), 33.

parents were likely to experience—shock, helplessness, guilt, anger, grief, resentment—while explaining their own emotional responses to their son's diagnosis. They saw clear value in sharing their experiences and reassuring other parents that their reactions were normal and common: "At the time [of the diagnosis], it just seemed as if no one else in the world understood what we were going through. You may feel the same way now, but believe me, it's not true. I understand your agony, and so do thousands of other parents of children with autism."[15] According to the Tommasones, only other parents could understand, making the sharing of the complex emotional responses that parents felt after their child's diagnosis vital to healing from the pain that parents felt. Other parents agreed, as one wrote in 1983: "We were advised, knowingly and wisely, that we would have many ups and downs—and we have, but I feel that talking with other parents of children with Down's syndrome has been more helpful than anything else in adjusting to these early months of Melinda's life."[16] Non-parent authors wrote about the importance of parent perspectives within their work, along with the gratitude that parents felt from being asked to contribute their experiences to guidebooks:

> Something we had not anticipated when we began our work was the astonishing number of parents who expressed their gratitude to us for undertaking the book. 'We should be thanking you for the opportunity to express our feelings and opinions,' the divorced mother of a child with Down syndrome wrote. 'If you are surprised at the volume of

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[15] Tommasone and Tommasone, "Adjusting to Your Child's Diagnosis," 36.

[16] George H. Durham II, "What If You Are the Doctor?", in *We Have Been There: Families Share the Joys and Struggles of Living with Mental Retardation,* eds. Terrell Dougan, Lyn Isbell, and Patricia Vyas (Nashville: Abingdon Press, 1983), 37-38.

> responses, possibility it is because many of us have not been treated as though our opinion had value. If you see pain in that statement, believe it![17]

Guidebook contributors stressed the importance of parent accounts for the professional audience of such works, too. Author and disability advocate Robert Perske described *We Have Been There: Families Share the Joys and Struggles of Living with Mental Retardation*, a guidebook comprising essays by parents and family members, many concerning Down syndrome, as "the first book you should read" if "you are preparing to be a volunteer or professional in the field of mental retardation."[18]

Guidebooks on autism have offered similar explanations for the orientation around parent knowledge as those on Down syndrome. Psychologist Kathleen M. Dillon referenced Oliver Sacks's work *Awakenings* in the preface to *Living with Autism: The Parents' Stories*, writing, "There were always two books, potentially, demanded by every clinical experience: one more purely medical or classical—an objective description of disorders, mechanisms, syndromes; the other more existential and personal—an empathetic entering into the patients' experiences and worlds."[19] For Dillon, the significant existential and personal experience of autism examined the parents' stories. She quotes Ivar Lovaas, the prominent researcher in autism and controversial advocate for applied behavioral therapy, who said, "I think sometimes… the parents hurt more than the kids."[20]

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[17] Irving R. Dickman with Sol Gordon, *One Miracle at a Time: How to Get Help for Your Disabled Child—From the Experience of Other Parents* (New York: Simon and Schuster, 1985), 13.

[18] Dougan, Isbell, and Vyas, eds., *We Have Been There*, 14.

[19] Kathleen M. Dillon, *Living with Autism: The Parents' Stories* (Boone, NC: Parkway Publishers, 1995), xi.

[20] Dillon, *Living with Autism*, xi.

The Refrigerator Mother Speaks Out

Alongside shared motivations over parental pain and imagined community, the looming specter of the refrigerator mother and parental blame for the causation of autism introduced a position of parental rejection of professional authority into the autism guidebook literature. Beginning with early guidebooks, such as Lorna Wing's 1964 pamphlet *Autistic Children,* published by the British National Association for Mental Health with the Society for Autistic Children, authors addressed the question of a psychogenic or biological etiology for autism. Wing and a group of fellow parents had founded the Society for Autistic Children in 1962, making an informational pamphlet an early endeavor of the society. In this early work, Wing briefly describes both psychogenic and physical theories of causation:

> The idea that parental attitudes cause the deviant development of autistic children has sprung primarily from the theories of the various schools of psychoanalysis, which suggest that much mental illness derives from disturbances in interpersonal relationships. This view was given substance and definition in a famous paper, in which the fathers of a group of autistic children were described as of high intelligence, many with academic careers, but cold and detached and unable to form warm relationships.[21]

Wing goes on to critique the validity of this theory, writing that "In several more recent studies, these findings have not been repeated, and the general view at the moment is that parents of autistic children are as diverse in their characters as any other group of human beings, and as likely to be as good or as bad parents as anyone else."[22] She describes possible sources of

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[21] This is likely Eisenberg—discussion of this paper, and the refrigerator mother/parent theory more broadly, is found in Chapter Two. Lorna Wing, *Autistic Children* (London: National Association for Mental Health with the Society for Autistic Children, 1964), 14.

[22] Wing, *Autistic Children* (1964), 14.

physical causes, but concludes that "Hormonal, biochemical, neurological, and perceptual abnormalities have all been suggested as the basic causes. The field is, for the very moment, completely open."[23] Wing emphasizes for her readers that their manner of parenting matters not for causation, but for how their child would be able to make progress: "Whatever the primary causes of the syndromes, there is little doubt that the way the handicapped child is handled has a considerable effect on his progress, for good or ill... In this sense, all experts will agree that parental handling is of immense importance."[24]

Following the publication of this brief pamphlet in 1964, Wing published a series of guidebooks for parents that expanded upon the causes of and care for autism over the next few decades. In her 1972 guide, *Autistic Children: A Guide for Parents*, Wing spent time examining both theories of psychogenic causation (or "emotional disturbance") and biological causation of autism, suggesting that parents consider both interpretations of etiology even as they may find it difficult: "Parents, quite naturally, are inclined to resent the emotional theories, because however carefully the explanations are worded, the parents feel they are being blamed. Indignation and a refusal to be browbeaten into guilt are healthy reactions, but it is also necessary to consider the evidence as carefully as possible and to understand the basis for these ideas."[25] Wing clearly believed in the biological theories and felt empathy for her fellow parents in facing the guilt and shame over being told they had caused their children to become autistic. However, the state of the field in the early 1970s necessitated that she address the psychogenic etiology as a valid theory.

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[23] Wing, 14.

[24] Wing, 14.

[25] Lorna Wing, *Autistic Children: A Guide for Parents* (New York: Brunner/Mazel, 1972), 32.

The prevalence of the etiology of parental causation and the blame it placed upon parents likely influenced Wing's positioning of her expertise. While the National Society for Autistic Children published her 1964 pamphlet, suggesting Wing's association with the organization, she did not identify herself as the mother of a child with autism as well as being a physician and autism researcher. Similarly, in her 1972 work, Wing wrote of herself as a professional who had relied on the expertise of parents, but did not identify herself as a parent: "I have drawn on the work of doctors, psychologists, and teachers with long experience in the field; but I could not have written the book at all without the help of the many parents who have, through patience and determination, found ways of coping with the never-ending series of problems presented by living with an autistic child."[26] The reasoning for this positioning likely reflects the continued circulation of parent blaming within the professional community around autism and the lack of credibility given to parents as sources of expertise in this period. As a parent, Wing was suspect in the eyes of some of her professional colleagues. As a professional, she could reach out to parents by writing a guidebook that did not promote parent blaming but shared useful information and means of finding support through the community of families with an autistic child while maintaining her scientifically objective perch as a psychiatrist.

Examining the differences between two books in the "Special Needs Collection" reveals a key difference in the construction of autism and Down syndrome and parents' roles in that work. The "Special Needs Collection" is a series of guidebooks published by Woodbine House since in the 1980s. Woodbine House is a press dedicated to publishing on topics of interest to families with children with disabilities, founded by the father of a daughter with Down syndrome

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[26] Wing, *Autistic Children* (1972), n.p.

in 1985.[27] In the following years, Woodbine published parents' guides on a variety of childhood developmental disabilities, including autism and Down syndrome, with nearly identical tables of contents: what is the diagnosis, medical concerns, daily life, educational options, etc. Some chapters were even duplicated from book to book, such as the discussion of legal concerns. These books featured parent statements at the end of each chapter, giving anonymous parent perspectives space to reply to the more formal content written by a professional.

Parent guidebooks reflect the experience of parents who did lots of things in response to their children's diagnosis: joined support groups and advocacy organizations, lobbied for better services for their child and all children at the local and state and national level, attended conferences with other families, sought out numerous experts—doctors, therapists, educators—for the best care of their children, wrote articles for newsletters and local media, they wrote memoirs— a variety of actions that resulted in their inclusion in guidebooks as parent experts and shaped the expectations for other parents.

Books such as the Special Needs Collection particularly espoused the view of parenting a disabled child as a set of responsibilities and obligations to your child and the community. As one parent expressed in a chapter on "Teaching Your Baby With Down Syndrome," "I feel very strongly that if you have a special-needs child you need to explore every option, even if it's an option that doesn't appeal to you at first. I checked out every program, and I talked to many therapists. My husband and I sat together and made lists of the advantages and disadvantages of each thing."[28] Parents could not trust their initial instincts or be allowed to make a decision based

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[27] Woodbine House, "About Us," https://www.woodbinehouse.com/about-us/.

[28] Linda Diamond, "Teaching Your Baby with Down syndrome: An Introduction to Early Intervention," in Karen Stray-Gundersen, ed. *Babies with Down Syndrome: A New Parents' Guide*, second edition, ed. Karen Stray-Gundersen (Bethesda: Woodbine House, 1995), 221.

on convenience. Being a good parent to a child with Down syndrome—or another disability—required significant research.

A review of the first edition of *Babies with Down Syndrome: A New Parents Guide* in the journal Health and Social Work expressed misgivings about the expectations for the parents expressed by the guide:

> One weakness of this book is that it may compound the guilt, fear, and feelings of being overwhelmed that many parents of Down's syndrome children feel. The authors expect parents to have a great deal of assertiveness, time, creativity, and energy in dealing with the needs of the child and with the community's care system. The authors set high standards and what may be at times unrealistic expectations for parents… Given the reality of two working-parent households, single-parent families, siblings, and inadequate community or personal resources, many parents may not have the ability, time, or energy to fulfill the expectations expressed in the book.[29]

The reviewer, Becky Williams of the Arkansas Department of Health, likely recognized the challenges that working-class, poor, or rural parents may face as they try to find adequate care for their child with Down syndrome. The high level of organizational skill and the entitlement to quality care that the guidebook expects parents to hold would be unattainable for many, limiting the value of the book to the well-educated, motivated parents who can follow every suggestion for optimizing their child's life.[30] Surveying histories of city and state parent organizations for

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[29] Becky Williams, "Review: *Babies with Down Syndrome: A New Parents Guide*, Edited by Karen Stray-Gundersen," *Health & Social Work* 13, no. 4 (October 1, 1988): 310.

[30] Landsman, *Reconstructing Motherhood.* For more on how class shapes the experience and expectations of parenthood, particularly the intensive parenting style common among middle-class white families in late-twentieth-century America, see Annette Lareau, *Unequal Childhoods: Class, Race, and Family Life* (Berkeley: University of California Press, 2003).

intellectual disabilities in the mid-to-late twentieth century, Allison C. Carey, Pamela Block, and Richard Scotch find that parent organizations were largely white and middle-class, even in diverse settings like New York City.[31] Neglecting to address questions of class and privilege is not unusual in parent narratives about raising a disabled child more broadly.[32]

The class-specific problems with guidebooks and the expectations they place on parents were rarely addressed. A more typical response to *Babies with Down Syndrome* was found in the Washington Post, which praised the book as "indispensable."[33] The expectations contained within parent guidebooks furthered a particular vision of disability parenthood: the parent who would do anything for their child, who committed to the disability family community, who had the education, resources, and energy to pursue the best care, research all options, and share their experiences with their fellow parents. Parents who did not fit this narrative—whether for reasons of class, education, time, or inclination—were excluded.

The introductions to the works on autism and Down syndrome framed each diagnosis in a distinct way. *Babies with Down Syndrome* began with the editor, Karen Stray-Gundersen, describing the moment of her son's diagnosis, sharing how much she has learned in the years since and reassuring readers that they have compiled a book with the most up-to-date information that will allow them to "understand Down syndrome so [they] can get on with loving their new baby."[34] Stray-Gundersen offered herself as an ambassador into the world of Down syndrome for parents new to the diagnosis, whose authority comes from her experience of care, who promises that Down syndrome can be understood. Stray-Gundersen took a parent's love for

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[31] Carey, Block, and Scotch, *Allies and Obstacles,* 43.
[32] Calton, "Obscuring of Class."
[33] Tania Demchuk, "Down Syndrome: A Book for Parents," *Washington Post*, February 9, 1988.
[34] Stray-Gundersen, "Introduction," in *Babies with Down Syndrome* (1995), iv.

their child with Down syndrome as a given—greater knowledge of the condition would be necessary for the parent, but that love is what the parent already has an expertise in. Stray-Gundersen's perspective is consistent with the broader maternal attitudes towards the expertise of the medical establishment in late-twentieth-century America—mothers as collaborators with experts, whose medical advice would shape maternal practices. This work reflects a different orientation of parents in the Down syndrome community in the late 1980s and 1990s than is found in earlier parent narratives. Allison Carey argues that parent memoirs from the 1950s to the 1980s reveal that parents with a child with Down syndrome specifically took on a position of skepticism towards the authority of the medical establishment following their experiences of pressure to institutionalize their children.[35] Stray-Gunderson's work suggests that parents in the 1990s should not expect such a negative experience with their physicians but would rather come to view professionals as part of the community that will support their child.

Children with Autism offered a very different introduction into the world of autism parenting. Alongside shared motivations over parental pain and imagined community, the looming specter of the refrigerator mother and parental blame for the causation of autism introduced a position of parental rejection of professional authority into the autism guidebook literature. Bernard Rimland, the author and parent activist described in Chapter Two, gave his personal history as an introduction. Rimland's message throughout was summed up in his advice for the parents reading this guide: "be cautious about accepting unquestioningly the diagnoses given to your child."[36] Rimland detailed his journey as the parent to an autistic son, beginning with his son's diagnosis and early childhood, which inspired his commitment to learning

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[35] Carey, "Parents and Professionals."
[36] Bernard Rimland, "Introduction," in *Children with Autism,* xvii.

everything he could about autism, determined to disprove the refrigerator mother theory of autism. His extensive research brought him to the conclusion that "it was nothing but bias, bigotry, and greed on [the medical professionals'] part that had led them to the psychogenic conclusion. This angered me greatly, because it was evident that many parents were feeling terrible guilt as a result of these unwarranted professional attitudes. Meanwhile, the professionals were growing richer, and the parents poorer, as the doctors probed, in session after expensive session, for the nonexistent psychic trauma."[37] Rimland used this research to write the book *Infantile Autism*, which collected evidence of a biological basis for autism and challenged the psychogenic theory. Based on its success, Rimland joined with other parents to form the National Society for Autistic Children in 1965 (later the Autism Society of America), organized around the belief that "without pressure from informed parents, nothing [about autism treatment and etiology] would change."[38] Rimland followed up this recounting of his accomplishments by describing the value he saw for scientific research based on the observations of parents, specifically citing the promise of multivitamin therapy involving high dosages of vitamin B6 and magnesium in autistic children.[39]

While the introduction to the guide for Down syndrome reassured parents of the value of the up-to-date knowledge and the sureness of parental love contained within, Rimland revealed through his personal narrative the complexity of the roles a parent of an autistic child would be expected to play. Parents could trust no one but themselves, and parents themselves had to become the experts in order to be able to help their children. The parent's expertise in knowing

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[37] Rimland, xii.

[38] Rimland, xv.

[39] For more on alternative therapies and Rimland's role in researching and promoting them, see Silverman, *Understanding Autism*, and Eyal et al, *Autism Matrix*.

their child translates into becoming the authority over their child's diagnosis, treatment, and prognosis.

In contrast to the importance of parents in the guides on autism and Down syndrome, another volume in “The Special Needs Collection” was 1993’s *Children with Mental Retardation: A Parents’ Guide*. Its editor, Romayne Smith, was a speech language pathologist with a private practice specializing in young children with multiple disabilities. While all the guidebooks in the series had a mixture of professional and parent perspectives within the text, *Children with Mental Retardation* lacked an introduction or foreword that offered a parent perspective to frame the guide. Smith opened the book with a short introduction that assured readers of her authority: “I work with many parents who are just learning about their child’s mental retardation. I have seen how much anguish, pain, and confusion they go through in the beginning, and how desperately they search for support, information, and guidance. And for many years, I have wanted to do something to help ease these parents’ entrance into the world of mental retardation. This book is my attempt to do just that.”[40] Anonymous parents’ comments were sprinkled throughout the chapters, as was the format of each book in “The Special Needs Collection,” but the effective positioning of the book cemented parents as the audience and professionals—physicians, therapists, researchers—as the experts. Compared to this, parents with Down syndrome were co-collaborators, and parents with autism were the authorities.

Rimland’s advice, while particularly strident, was not unique within the literature on autism. Parents regularly invoked the failures of the professional medical establishment to care for children with autism, although they did not always agree on whether parent-blaming and

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[40] Romayne Smith, “Introduction,” in *Children with Mental Retardation: A Parents’ Guide*, ed. Romayne Smith (Bethesda: Woodbine House, 1993), iii.

psychoanalytic treatment were a thing of the past. David Park, husband to Clara Claiborne Park, wrote the "Foreword for Parents" to Marian K. DeMyer's *Parents and Children in Autism*, a 1979 book aimed at a parent audience that provided a comprehensive overview of child psychiatrist DeMyer's study of autistic children and the medical literature on autism. Park advises readers that the book will guide them on what they should find in a professional who treats their child—someone knowledgeable, approachable, frank, who will not offer a cure but will discuss your child with you:

> Above all, you should expect to find a friend, not in the social sense, but someone totally free from any tendency to blame you for your child's autism. You will find in this book why no responsible and informed professional thinks that way anymore. If anyone tries to blame it on you, mention the data given here. If blame persists, walk out of the office—unless—but hope it is not true, that office contains "the only game in town." In that case you will have to make your accommodations, but never accept the guilt. You cannot expect that the mental health professionals you deal with will be instant experts in every rare condition that is brought before them but you can expect that they will take an interest in new findings. Many are reported here. Professor DeMyer has written her book with professional authority. This book will tell you much that you ought to know about how to live with an autistic child and what lies ahead.[41]

Park had experience with parent blaming, as his wife recounted in her memoir and her guidebook, but his message to parents encouraged them that such attitudes are—or, at least, should be—things of the past. His faith in a professional establishment that would support new

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[41] David Park, "Foreword for Parents," in Marian K. DeMyer, *Parents and Children in Autism* (Washington, D.C.: V. H. Winston and Sons, 1979), x.

parents of autistic children reflected his own close ties to autism research, as a member of the editorial board of the *Journal of Autism and Developmental Disabilities*, and his own scientific professional accomplishments as a physicist and professor at Williams College.

Other parents of autistic children wrote of experiences that would belie David Park's trust that parents would find valuable help from professionals. Mary S. Akerley, a former president of the National Society for Autistic Children and mother to a son with autism, wrote an essay about her experiences with mandatory parental psychoanalysis to gain access to therapy for her son in *Parents Speak Out: Views from the Other Side of the Two-Way Mirror*, a 1978 compilation of essays from parents of disabled children who were also engaged professionally in education, treatment, advocacy, or services for the disabled. Akerley's essay, "False Gods and Angry Prophets," attested to her rage at the ongoing failure of professionals to consider reasons for her son's condition that did not stem from her and her husband's parenting:

> So much has been written about the abuse of the parents of autistic children by traditional psychiatrists that even one more word seems superfluous, yet the abuse continues and thus so much the protests. We worked with two doctors at that school (sequentially—we weren't *that* bad!). Neither ever came right out and said, "You caused it," but everything they did say was based on that premise. Our involvement with a parent organization was viewed as a way of avoiding our emotions duty to our child; never mind that he was improving dramatically, in no small part because of what we had learned through that involvement. Our failure to need their kind of help was 'blocking;' our by-now angry fighting back, 'resistance.' The real mind-blower for Doctor Number One was my refusal to admit I hated and resented Eddie because I had had to turn down a graduate fellowship when full-time study would have kept him away from me too much. Doctor Number Two

> picked up on the theme and kept 'working with me' ('*on* me' is more like it) to admit my anger. Finally I blew: 'You bet I'm angry, Dr. B., and I know what I'm angry at—you![42]

Akerley expresses the frustration and fury that woman like herself—well-educated, white mothers—felt at the insistence or implication of psychiatrists and physicians that they had rejected their children and caused them to become autistic. Unlike David Park's calm reassurance that the establishment was improving and parents of the late 1970s and 80s would find a friend in their physician, Akerley cautions parents about the harm that professionals have caused her and countless other parents. Like Clara Park, who began her guidebook by writing about the pain she had experienced at the hands of professionals, Akerley sees sharing her experiences as essential to cultivating the possibility that other parents may discover better care and that professionals may cease in causing that pain:

> I… have not—cannot—forgive those who, instead of helping, added to our pain. I believe there can be no greater sin. True, we survived, and are stronger, richer people for the experience. But we, and all the contributors to this book, are exceptions. The average parent does not get a chance to speak out in books or on television. He had to sit still and take it. We cannot even always find him to offer help; the chances are 60-40 that he's already gone under. The people whose words you read here have survived in spite of the professionals, not because of them. There are many lessons for would-be helpers to learn from their stories: respect for parental competence, humility in the face of one's own

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[42] Mary S. Akerley, "False Gods and Angry Prophets," in *Parents Speak Out: Views from the Other Side of the Two-Way Mirror*, eds. Ann P. Turnbull and H. Rutherford Turnbull III (Columbus, OH: Charles E. Merrill Publishing Co., 1978), 42.

> ignorance, acceptance of the contributions of other professional disciplines; but they all stem from the eloquently simple tenet of the physician's code: Do no harm.[43]

David Park counseled parents who encountered a doctor who continued to believe in a psychogenic etiology for autism to share the professional research contained within DeMyer's book, to rely on the power of scientific findings to change attitudes and practices. For Akerley, as for Rimland, the time for faith in the professional workings of the medical establishment was over. Parents were the authorities to trust, in rage and righteousness, as they sought the care that their children needed.

Ackerly and other mothers' experiences of the rejection of professional authority developed in the 1960s and 1970s. Their growing belief in their own expertise rather than physicians' grew alongside the changing relationship of women to the medical establishment brought about by the women's movement. Feminists and women's health activists raised awareness about the risks of widely prescribed drugs, popularized the idea that the male-dominated medical profession mistreated women and withheld critical information, and encouraged women to take control of their own health. Historian Elena Conis has tied the rise in vaccine skepticism in the 1980s to the women's movement of the 1970s. The feminist argument that a woman is the ultimate authority over her own body contributed to the argument that a mother is the ultimate authority over her child's body.[44]

In another essay from *Parents Speak Out*, parent advocate Frank Warren, in a chapter titled, "A Society That Is Going to Kill Your Children," turned his rage to the subject of autistic children and adults who had died while institutionalized or otherwise due to state neglect. The

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[43] Akerley, "False Gods," 47-48.
[44] Conis, *Vaccine Nation*, 105-130.

father of a fifteen-year-old autistic son, Warren described cases in which parents fought for their children to be treated humanely, to be shown love, to be allowed to remain at home, and to have help to care for them, while the state and the medical establishment rejected their cries for help. In the case of a boy who repeatedly cuts himself and smears his own blood on the walls, Warren wrote, "What did the professionals offer this couple and their child? Talk. Jargon. Analysis. Tests. Play therapy. Institutionalization. Physical restraint. Nothing. Some children have been tied to their institutional beds, their hands and arms wrapped so tightly against their bodies, their feet and legs bound. Some have remained like that for years. More than a few have died."[45] The parents of this boy, according to Warren, were determined to find another way to care for their son: "They had to do it alone, without professional help, against professional advice."[46] After extensive research, the mother developed a form of aversive conditioning using a cattle prod to stop the boy from cutting himself. Her method, driven by a mother's love and performed against professional advice, resulted in the son ceasing to cut himself.

Warren's anger—at psychiatrists blaming parents for causing autism, at doctors for encouraging parents to send their children to institutions, at state institutions for failing to protect the autistic children in their care—reflects the life-and-death stakes he saw autistic people facing. Warren's advice for parents was rooted in the failings of the professional establishment, which he described as directly responsible for the deaths of autistic children. In this understanding of the landscape for autistic treatment, parents are the only people capable of changing the fate of their autistic sons and daughters.

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[45] Frank Warren, "A Society That Is Going to Kill Your Children," in *Parents Speak Out*, 193-194.

[46] Warren, "A Society," 194.

Parent Organizations: Vital Support or Endless Burden

A frequent suggestion within guidebooks for autism and Down syndrome is that parents should seek out their local parent organization for knowledge, community, and help in gaining services for their children. These suggestions came from professional as well as parent sources. Marian DeMyer's work was more technical than many in the genre aimed at parents—the suggestion by David Park to bring it to a professional reflects the more likely audience for the dense, academic style of the text. Within her synthesis of the research on autism, she includes a section co-written with Park on the accomplishments of parents in autism outcomes: "the major accomplishments can be traced to the development of parental self-help in the form of constructive participation as cotherapists and members of a dynamic supportive organization."[47] In less technical terms, DeMyer writes that the most significant accomplishments over the past decades of autism research have come from parents acting as cotherapists alongside professionals using behavior modification therapy with autistic children and parents organizing the National Society for Autistic Children creating the strongest system of support and information in the United States. DeMyer provides professional validation for the importance and usefulness of parent-led organizations, particularly the NSAC.

In the chapter on "The Role of Parents' Societies," in her 1972 guide, Lorna Wing writes favorably about the benefits of parents' groups, arguing that they "fill a great need by alleviating the isolation felt by families with an autistic child," keeping parents in touch and allowing them to find sources of advice and shared experiences.[48] She goes on to praise groups founded by parents themselves, writing that:

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[47] DeMyer, *Parents and Children in Autism*, 256.

[48] Wing, *Autistic Children* (1972), 147.

> A special quality of drive and determination is found in the groups in which parents have control of the organization. This is certainly true of societies for autistic children, at least up to the time of writing. Parents on the whole are sharply aware of the needs of their children and, compared with professional workers, are less likely to lose sight of the important concrete issues of because of attachment to a theoretical framework… Societies for autistic children are particularly well placed to solve the dilemma [of parents employed as professional administrators] because of the tendency of parents to be of above average intelligence and occupational level.[49]

Wing was a founder of the first parents' organization specifically for autism, in the United Kingdom, and her support of such groups reflects her own experiences, even as she did not disclose her own involvement in this work.

Wing's belief in parent groups and the importance of community for families with autism endured over the end of the twentieth century. In the foreword to *The Handbook of Autism: A Guide for Parents and Professionals*, a 1992 book authored by two speech and language therapists, Wing identified herself not as a physician with decades of experience in autism research, but as a mother to a daughter diagnosed with autism in the 1950s: "As an adult and a parent, I experienced the same sad transition from ignorance to painful knowledge when our daughter's difficulties were identified and named as autism. For a time it seemed that the whole world had become grey and empty but we slowly picked up the pieces and sought for constructive ways to help our child and, in doing so, also helped ourselves."[50] Wing went on to describe her involvement in founding the Society for Autistic Children in the UK in 1962 with

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[49] Wing, *Autistic Children* (1972), 148.
[50] Lorna Wing, "Foreword," in Maureen Aarons and Tessa Gittens, *The Handbook of Autism: A Guide for Parents and Professionals* (London and New York: Tavistock/Routledge, 1992), ix-x.

her fellow parents, although her account of their naïveté reveals sadness in the impossibility of their initial goals:

> We were full of determination and firmly believed that autistic children were not mentally retarded, and that their isolated, idiosyncratic abilities were the true indicators of their future potential. We did not believe the more guarded predications of the few professionals who had long experience in the field. We saw what some gifted teachers could achieve with some children. We did not recognize the difference between rote learning and true understanding, so we thought that appropriate education would cure all the problems and not just help to diminish them, as we know now. Because the concept of autism had been formulated only 20 years earlier, we did not know any parents of adults diagnosed as autistic who could tell us what the future might hold.[51]

Wing's belief in the power of parent organizations had changed. She and her fellow founders of NSAC in the 1960s had thought that by the 1990s, they would have made dramatic transformations in their children, that their abilities to educate autistic children would result in a cure for the condition and the revelation of the intact mind hidden within the autistic shell. Instead, the value of a parent group lay in the community, the kinship that it provided to parents and the experiences they would share: "Their book is for parents, the great majority… Their life will be different from how they had planned it but can be full of the satisfaction of difficulties overcome and the friendship, wherever they go in the world, of those who have lived through the same experience."[52]

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[51] Wing, "Foreword," in *The Handbook of Autism*, x.
[52] Wing, xi-xii.

For parents like Wing, parent organizations were a vital source of support, knowledge, and community. For others, the work that organizations demanded of their members piled additional burdens onto the already full plates of parents with a disabled child. In her 1978 essay analyzing the faults she sees with the "handicap-establishment," Janet M. Bennett, mother to a 15-year-old daughter with Down syndrome, reflected on her experiences with the New Jersey Association for Retarded Citizens (now the ARC). She describes the intention of parent organizations, as she saw it:

> The idea behind parent organizations is that in union there's strength. The many inadequacies of legislation, education, public opinion, could, it was thought, be overcome by the concerted efforts of a solid front of parents. Support gained along the way from the community and from professional people in the field of mental retardation, medicine, education, or public service (like the Kennedys or the Humphreys) would add to the parents' credibility and clout. As hoped-for programs were adopted by schools and government, the parent associations conceivable would be able to phase themselves out of existence.[53]

For Bennett, these promised gains—improved educational services, social services, community support, etc.—had been hopelessly diluted by the bureaucratic expansion of such organizations. While the organization and its promoters promise knowledge, community, shared experiences, and hope for the future, the actual benefits to parents are considerably more limited. Bennett considered the benefit of meetings to be in the presence of parents who could promise hope for the future—whether by modeling a life in which their child was not the sole, all-consuming concern or by showing "the unique kind of empathy, tact, wit, insight, and intelligence to

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[53] Janet M. Bennett, "Company, Halt!" in *Parents Speak Out*, 153.

perform for the other parents that miracle of healing that can come only through personal contact."[54] However, she found the information on Down syndrome to be useless—repetitive, limited, and disorganized. She writes that the real information gathering came from uniting with “a small group of equally novice mothers. Our own persistent reading, dogged research, and speculation began to piece together a fairly solid portrait of the problem. The rest of my learning came from my own volunteer activities with the unit as newsletter editor, column writer, program and publicity chairman, chiefly because in these capacities I had the leverage to command important people who knew things to talk to me and answer my question.”[55] Bennett found some value in the organization—in the one or two parents who inspired hope for a future not consumed exclusively by a diagnosis, in the research she and other parents shared with each other after meetings, in the ability to use organizational roles to access important people—but the promised benefits came alongside the heavy burden of getting involved in the organization. Her writing expresses her frustration with these obligations, as she laments that a child with an intellectual disability “is generally an immediate and continuing drain on body, mind, pocketbook, and time. Too many parents find their already overextended resources further taxed by this sense of obligation to the community.”[56] Bennett’s essay reflects a distinct form of rage at the expectations placed upon parents of disabled children, reflecting feelings that are rarely presented in parent guidebooks. Emotional responses to diagnosis, to treatment, to progress or a lack of progress, and to routine frustrations of parenting are repeatedly validated throughout this genre, but less often are parents given voice to disparage other parents for adopting the identity of “disabled child parent” or to bemoan the worthlessness and burdensome obligations that

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[54] Bennett, “Company, Halt!,” 154-55.
[55] Bennett, 154-55.
[56] Bennett, 157.

parent advocacy and support groups created. Bennett gave a voice to a different kind of frustration that resulted from having a disabled child, not due to the judgmental stares of strangers, but due to the expectations of disability organizations. As she said, mimicking the messaging that confronted her upon entering the world of the "handicap-establishment":

> *A retarded child initiates us into a cosmic fraternity—we're all one, we're all linked together like blood brothers, we're all responsible for everything that happens.* God, what a burden! Isn't one burden, dumped on us by fate, enough? Must we have the added load of organizational busy-work, presented as though each of us is a finger in the dike without which all the sad-eyed retarded children in the world will drown?[57]

Bennett is surely not alone in her rejection of this identity and the associated responsibility to the disability community that it entails. When asked whether he had joined any local organizations after his daughter was diagnosed with Down syndrome in the early 1970s, one father, the husband of a memoirist, said, "I just it didn't really occur to me. I'm not really an advocate type person. I'm really just not. I mean, did I think about joining the Down syndrome Congress? No, I guess I didn't."[58]

Bennett rejects the identity-formation that is central to the operation of both parent advocacy organizations and parent memoirists:

> In the process of belonging to and working for an association dedicated to retardation, parents join hands with fate. They cement their own identity as parents of retarded children; they wed themselves to the problem through a myriad of meetings and mailings; they immerse themselves in a society of people like themselves… Early on I decided that

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[57] Emphasis added. Bennett, "Company, Halt!," 156.

[58] Paul Jablow, oral history with the author, October 31, 2018.

> I would not be a parent to a retarded child. I would resist the tendency to alter my fundamental identity in recognition of the twist in the road that had come with retardation. The road might have twisted but it was still the same I who walked the road. Kathryn was not "a mongoloid" nor was she later on that equally invasive "child with Down's syndrome." She was a child, she was Kathryn, and she had mongolism, or whatever name; I didn't care what anyone cared to use to describe her condition. An ARC unit or any other kind of group could offer me services or information or moral support or advice, but it would not provide me—or Kathryn—with an identity.[59]

Bennett's stance against the identity-formation that many of her fellow parents find within advocacy or support groups—the biosocial kinship created by shared biological qualities—reflects a deep anger against the uselessness she found in her local ARC organization. She excoriates parents who adopt this identity, deriding them as pawns in the useless bureaucracy of the organization, their critical thinking diminished by the norm of appearing grateful and their attention diverted away from their own child toward to general cause, to their child's detriment.

The genre of parent guidebooks reflects the experiences and advice of highly involved parents. Bennett herself served on "various committees" of the New Jersey Association for Retarded Citizens—work she described as "newsletter editor, column writer, program and publicity chairman."[60] Such work reflects the rise in the active disability parent described by Allison Carey, who had to navigate the complex landscape of disability services, policies, advocacy work, and caregiving.[61] Scholars Amy C. Sousa and Linda Blum describe the development of such maternal models into the expectation that the mothers of children with

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[59] Bennett, "Company, Halt!," 158.
[60] Bennett, 155.
[61] Carey, "Parents and Professionals."

disabilities be “warrior-heroes” and “vigilantes” who fight unceasingly for their children.[62] The experiences of parents who rejected such roles, who went to one meeting of a parents’ group and never returned, who found their identity outside of parenthood, who were too busy or uninterested or unable to devote themselves to the cause of disability in this manner, are outside the pattern of disability parenthood shaped by and reflected in guidebooks. Bennett’s anger towards the “handicap-establishment” exposes a different type of parent—one who put in the work, but refused to become the work, who rejected "disability parent" as an identity.

Why Have Hope: Inclusion or a Cure

Guidebooks for Down syndrome repeatedly invoked the belief that every person with Down syndrome is unique, and no book can offer parents an accurate vision of what their child’s future or the future of their family will look like. As Cunningham wrote, “People, families and children are all so very different that it is impossible to say what effect the birth of the baby will have on you and your family.”[63] However, the decision to anonymize parent perspectives, common to this genre, and the nature of a guidebook as it brings the reader through the relevant needs of a person with Down syndrome means that a particular vision of what Down syndrome entails was inevitably generated, mediated though the parent perspective. The figure of a person with Down syndrome—and crucially, the experience of their parents—lacked the specificity of longer profiles on a few or many individuals with Down syndrome, and despite guides listing a variety of possible symptoms, intellectual capacities, and developmental variances, the parent’s feelings about the child offered a unified vision of Down’s syndrome. Each family may have been unique, but to read a guidebook for Down syndrome, the diagnosis seems to reflect a

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[62] Blum, “Mother-Blame in the Prozac Nation”; Sousa, “From Refrigerator Mothers.”
[63] Cunningham, *Down’s Syndrome: An Introduction for Parents*, Revised edition (Cambridge, Mass.: Brookline Books, 1987), 26.

consistent presentation of the condition: caused by some variety of trisomy in the 21st chromosome, creating a distinctive physical appearance, producing children with an intellectual disability but who do have a significant capacity to learn and who benefit from early and ongoing interventions for intellectual and physical development.

Parents asserted the value of their children with Down syndrome on the basis of what they offer to the parents. Children with Down syndrome taught their parents, as one said, how to "value the important things in life as opposed to achievement and financial success; we are less inclined to worry about silly things."[64] The overall image of Down syndrome produced is that children with Down syndrome will grow up to be "pleasant children" rather than with behavior difficulties—they are more likely to be nice, communicative, verbal, good-natured, and friendly, rather than "severely mentally handicapped with little speech, poor skills, and few interests."[65] The repeated invocation of the sweet, friendly, funny personalities of individuals with Down syndrome offered a compensatory side to the more difficult aspects of the disability, such as navigating the bureaucracy of the services each child was entitled to, while flattening out complexities that a more in-depth survey of individuals with Down syndrome could offer.

The hope that guides for Down syndrome offered parents relied on both the winning personalities of people with Down syndrome and improvements to services, education, and community support that would benefit families. Parents had fought for and made major legislative gains for disability services through ongoing advocacy on behalf of their children since the formation of local parent groups that became the National Association for Retarded Children in the 1940s, from the Education of Handicapped Children Act of 1975, which

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[64] Cunningham, *Down's Syndrome* (1987), 37.
[65] Cunningham, 21.

guaranteed public education, to the Americans with Disabilities Act of 1990, which prohibited discrimination against disabled people. These successes inspired hope for greater inclusion of children and adults with Down syndrome in the future, as Marlene Targ Brull, a speech therapist, wrote to parents in 1993:

> One bright spot is that you are seeking assistance at the best possible time in history. Years ago, parents of children with Down syndrome rarely received enough information about their child's condition. What they learned was riddled with misconceptions. Doctors gave little hope for their child's future. Usually, professionals encouraged parents to place their children in institutions. They assumed that all children with Down syndrome were too retarded to benefit society or lead fulfilling lives. Thankfully, times have changed. Medical scientists developed cures to common illnesses experienced by many children with Down syndrome, thereby extending life spans by decades. Federal and state laws created the vehicle for early stimulation programs to give babies with Down syndrome a head start on learning. Regulations emphasized learning in traditional public schools with non-disabled children. Researchers documented studies that most children with Down syndrome may be retarded, but they have a wide range of capabilities if given the chance. Once the condition was whispered about in secret. Now people with Down syndrome are on television shows and in commercials. Not every child will be a star, but neither will every non-disabled child. You need to discover what expectations are realistic for your child.[66]

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[66] Marlene Targ Brill, *Keys to Parenting a Child with Down Syndrome* (Hauppage, NY: Barron's Educational Series, 1993), v-vi.

Authors regularly referenced the improvements to society that they had seen in the recent past. The child with Down syndrome born in 1980 or 1990, they argued, would experience a society that was welcoming and inclusive, transforming the experiences of families. As Rosemary Dybwad and Gunnar Dybwad wrote in the second edition of *A Parent's Guide to Down Syndrome: Toward A Brighter Future*, published in 1990:

> In the short span of years since this book was first published in 1978, outstanding progress has been made to create better lift chances for persons with Down syndrome. Progress has been particularly impressive in terms of the public's improved perception of this chromosome disorder. The authors of this book have been at the cutting edge of these advances through their teaching, their contributions to the professional literature, and above all, their extensive clinical and personal contacts over many years with families having a member with Down syndrome.[67]

Siegfried Pueschel, the editor of *A Parent's Guide to Down Syndrome*, was both a physician and a parent of a child with Down syndrome, and his work expresses a strong belief in the benefit that more information on Down syndrome would have for families with a child with Down syndrome. In the book's introduction, Pueschel writes, "the book's primary purpose remains the same: to provide state-of-the-art information that should enhance the quality of all aspects of life for persons with Down syndrome."[68]

The belief that society's acceptance and inclusion of people with disabilities would continually increase following the legislative gains of the late twentieth century could be

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[67] Rosemary Dybwad and Gunnar Dybwad, "Foreword," in Siegfried M. Pueschel, *A Parent's Guide to Down Syndrome: Toward A Brighter Future* (Baltimore: Paul H. Brookes Publishing Co., 1990), xiii.

[68] Pueschel, *A Parent's Guide to Down Syndrome*, xvii.

challenged by the availability of prenatal diagnosis and selection termination of trisomy 21. Parent guides typically address the possibility of prenatal diagnosis but are either more obviously opposed to selective abortion than similar discussions in parent memoirs or uninclined to wrestle with such questions.[69] The short discussion of prenatal diagnosis in *Keys to Parenting a Child with Down Syndrome* simply states, "Many parents who discover their unborn child has Down syndrome grapple with the painful decision about whether to seek an abortion."[70] The chapter on prenatal diagnosis in *A Parent's Guide to Down Syndrome*, written by Pueschel and new for the second edition, briefly covers options for testing, including amniocentesis, chorionic villus sampling, ultrasonography, and alpha-fetoprotein screening. Pueschel then explores what he considers the ethical considerations of such testing, in which his perspective—that selective terminations following the prenatal diagnosis of trisomy 21—are wrong:

> Although proponents of prenatal diagnosis and of termination of pregnancy if an affected fetus has been identified emphasize that each child should have the right to be born healthy, some professionals as well as parents of children with handicaps do not agree with the notion that every chromosomal defective fetus categorically should be aborted. Of course, prenatal diagnosis has many potential beneficial uses, particularly in cases where therapy of the affected fetus is available or if parents can be counseled in regard to future reproductive risks. These justifiable uses, however, should not be overshadowed by allowing prenatal diagnostic techniques to become strictly an exercise in selective abortion.[71]

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[69] For discussion of parent memoirs on prenatal testing, see Chapter Two.
[70] Brill, *Keys to Parenting,* 46-47.
[71] Pueschel, *A Parent's Guide to Down Syndrome*, 60-61.

He quotes an anonymous parent of a child with Down syndrome as saying, “why assume a child with a handicap will be a negative experience? For all the joy and richness they have brought into our lives, I am grateful to have all our children with all their weaknesses and strengths.[72] Pueschel presents these “ethical considerations” as merely the opinion of some, unnamed authors, despite the fact that he does not offer alternative perspectives, such as from a parent who chose to terminate following a prenatal diagnosis or a genetic counselor who sees patients who have made the choice to terminate. He rejects the justification for a termination following prenatal diagnosis on the basis of intellectual disability, describing IQ testing as "a demeaning measure of human potential" and not a valid basis for an abortion.[73]

Pueschel implicitly ties his rejection of selective terminations to religious objections. On the opposite page from this condemnation of selective abortion is a photo of a young girl with Down syndrome walking down the aisle of a church, carrying a floral bouquet and wearing what looks like either a flower girl’s dress or First Communion dress, signifying both the integration of this child with Down syndrome into her family and community and a signal to the well-known anti-abortion beliefs of the Catholic Church.[74] Pueschel goes on to suggest that parents choose to give their child up for adoption, rather than choose abortion, a common anti-abortion argument:

> Some parents who for whatever reason may be unable to rear and care of a child with Down syndrome and who may be appalled by the thought of aborting an affected fetus may want to choose this alternative. Thus, these parents would not have to deal with the

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[72] Pueschel, 61.
[73] Pueschel, 61.
[74] I do not think Pueschel himself was Catholic. His funeral service was held at an Evangelical Christian church. In post on a memorial Facebook page created following his death, a short autobiography by Pueschel references being a Protestant who grew up in a Catholic community. https://www.facebook.com/In-Memory-of-Dr-Siegfried-M-Pueschel-365451906891366/

> trauma and guilt often associated with abortion. Since improved medical services and progressive educational opportunities have resulted in an enhanced quality of life for persons with Down syndrome, and since the majority of them have delightful personalities, these children are generally easy to place for adoption. Actually, there are long lists of families waiting to adopt children with Down syndrome.[75]

Chapters like this on prenatal diagnosis raise the question of audience for these guides. Would parents who had just received a prenatal diagnosis of Down syndrome read a parent's guide? The presumption of audience found in the standard presentation of a parent guide assumes that the reader has a newborn child with the condition, not that one is questioning whether to continue a prenatally diagnosed pregnancy.

Pueschel's presentation of prenatal diagnosis and selective termination is clearly anti-abortion. He offered no suggestion that he is sympathetic to parents who chose to terminate, nor does he clearly express an ethical rationale for such decisions. His framing is fundamentally opposed to abortion, and yet he did not explicitly state that he is writing from the perspective of a parent to a son with Down syndrome. He did not position himself as one voice on the subject sharing his position—he could have begun the chapter with a statement that he is opposed to such abortions or, perhaps, all abortions, and thus will be writing about prenatal diagnosis without an openness to selective termination. Instead, he continued to write from his authoritative position as the objective expert on Down syndrome.

Pueschel's writing marks a departure from the complex treatment of prenatal testing and abortion found in parent memoirs. Memoirists labored over their conflicted feelings about reproductive rights, disability rights, their individual experiences, and the political maneuvering

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[75] Pueschel, *A Parent's Guide to Down Syndrome*, 63-64.

that could result from their writing. They emphasized their lack of judgment and the complexity of the decision to parent a child with Down syndrome, in its joys and its challenges, even as they expressed no regrets about their own decisions. Pueschel presents rejecting selective abortion as a simple decision, even as he acknowledges that there are reasons parents may be unable or unwilling to care for a child with Down syndrome. In this way, even as a guidebook incorporates and reflects parent experiences—and as it attempts to support the thesis that all children with a particular condition are unique and distinct—it collapses the experience of parenting a child with Down syndrome into a simplistic message of love, joy, and the lessons that people with Down syndrome teach their parents. The guidebook's authorial positioning as an authority on why abortion following prenatal diagnosis is morally wrong prevents the possibility of exploring this question deeply and of exploring parenting as anything other than a positive decision. The overwhelming narrative of a guide to parenting a child with Down syndrome becomes, yes, we know you may have found the diagnosis of trisomy 21 a tragedy—one that you may see causes people to consider terminating a pregnancy after the diagnosis of this condition—but the hope for a better future lies in your acceptance of your child.

Guidebooks on autism can also offer a generalized vision of autism through the particular narrative of life with autism depicted in the works. In contrast to the narrative of Down syndrome, in which a parent learns to love their child because of the unique advantages of the child's disability, parents of children with autism offer love in spite of the challenges. The potential for improvement—improvements in treatment, improvements in condition, improvements in the child—acted as a source of hope, albeit one that depended heavily on the willingness of parents to invest heavily on time spent teaching and caring for their children. As one parent said, “You have to be Superman personified.”[76]

Guidebooks for autism often focus on specific treatment options, supporting particular interpretations of the diagnosis and narratives of recovery. Over the decades of parent guides, authors propose and critique varying treatment options based on the popular methods of the time—applied behavioral therapy, speech therapy, holding therapy, multivitamin therapy, medications, facilitated communication. Often, individual stories of triumph are presented, suggesting to parents the hope for a cure for autism and encouraging them to attempt many treatments in their pursuit of their children’s recovery. Parents whose children were older often encouraged new readers to think that the future was bright, and breakthroughs were coming soon. As Beverly Sills Greenough, a professional opera singer and mother to an adult son with autism wrote in 1989, "I would not change my son for anyone. His triumphs are ours. But those gains only are possible because of the wealth of information now known about autism and how to deal with it. But we can't stop there. The next step is discovering why the many forms of autism occur, and then ways of prevention. I am confident that we shall live to see that!"[77]

In his 1993 work, memoirist and writer Charles A. Hart was more measured than many parent-guides about the contemporary options for autism as well as the possibilities of the future. While encouraging parents to be diligent in pursuing treatment and services for their children and surveying a variety of therapeutic options for autistic children in his guide—from medication to experimental diets to auditory training—he does not invoke a tragic or desperate tone when discussing autism. His writing feels matter-of-fact: “Autism is not hopeless, nor necessarily

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[76] Powers, *Children with Autism,* 135.

[77] Beverly Sills Greenough, "Foreword," in *Children with Autism*, vii.

tragic. People with this condition can become less dependent and lead happier lives than we once believed."[78] Hart's encouragement towards his fellow parents—of course, you want a cure, but things aren't so bad where we are right now—reflects his background as not only the father to an autistic son, but the younger brother to an autistic man. The radically different experiences of his son and his brother informed his optimism:

> Twenty years ago we wanted a miracle that would make our son's life better than his uncle's had been. The miracle didn't come in a flash of light, or a quick response to treatment, so we didn't notice, until looking through our family album. Then we saw the miracle. School, pictures, including graduation and the senior prom, showed how rich our son's life had become. How rich it could have been for my brother, if he'd been born in 1970, instead of 1920![79]

In comments like these, Hart's message about progress is similar to that of books about Down syndrome—things have gotten and are getting better, even if progress can feel slow. But Hart also addressed the complex therapeutic landscape for autism that had developed by the 1990s. While he regularly referenced the expertise of physicians and researchers and cites scientific journals including the *Journal of Autism and Developmental Disabilities* as sources for parents to seek research on treatments for their autistic children, he also described a number of individual experiences of parents developing effective, near-miraculous breakthrough therapies for their children.

A chapter on the technique of facilitated communication—in which a facilitator holds the hand of a non-speaking client over a keyboard, supposedly providing support for sending

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[78] Charles A. Hart, *A Parent's Guide to Autism* (New York: Simon and Schuster, 1993), 90.
[79] Hart, *A Parent's Guide*, 2-3.

messages—presents a positive vision of the technology and its potential for giving voice to non-speaking autistic people. Facilitated communication began in the 1970s in Australia, coming to the United States in the late 1980s through the efforts of Douglas Biklen, a Syracuse University professor of education.[80] By the 1990s, facilitated communication was gaining popularity, inviting scrutiny, and fomenting controversy, as the media covered cases involving sexual abuse supposedly revealed through facilitated communication.[81] These cases repeatedly resulted in findings that no abuse had occurred and that facilitated communication was directed by the facilitator, not the client, casting doubt on the medium of facilitated communication.[82] Hart discusses one such case, concluding that "this court verdict [that allegations of abuse were false] doesn't show that facilitated communication is a fraud, or that people with autism can't express themselves through this system. It merely points out the hazards of zealous facilitators, jumping to conclusions based on their own social attitudes or assumptions."[83]

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[80] Douglas Biklen, "Communication Unbound: Autism and Praxis," *Harvard Educational Review* 60, no. 3 (September 1, 1990): 291–315. For a parent memoir that is favorable towards facilitated communication, see Ralph Savarese, *Reasonable People: A Memoir of Autism & Adoption: On the Meaning of Family and the Politics of Neurological Difference* (New York: Other Press, 2007).

[81] Janyce Boynton, "Facilitated Communication—What Harm It Can Do: Confessions of a Former Facilitator," *Evidence-Based Communication Assessment and Intervention* 6, no. 1 (March 1, 2012): 3–13.

[82] Bryna Siegel, "Brief Report: Assessing Allegations of Sexual Molestation Made through Facilitated Communication," *Journal of Autism and Developmental Disorders* 25, no. 3 (June 1, 1995): 319–26.

[83] Hart, *A Parent's Guide*, 177. Hart does not name the case but identifies it as an Australian case made public in February 1992. This is likely the Carla case, in which a 28-year-old intellectually disabled woman alleged through facilitated communication that her family had sexually abused her. The Australian High Court determined that Carla's allegations were the result of her facilitators directing her messages and concluded that the allegations were entirely fictional. Paul Heinrichs, "Suffering at the Hands of the Protectors," *The Sydney Morning Herald*, February 16, 1992, https://www.smh.com.au/national/suffering-at-the-hands-of-the-protectors-20090821-esuq.html.

The case of facilitated communication offers a complex site for interpreting the role of guidebooks in encouraging specific, controversial therapies for autism. While Hart did not ignore the controversies surrounding facilitated communication, the chapter begins with individual cases of autistic adults whose lives were transformed via the technique. For parents seeking miraculous methods of reaching the child trapped within the autistic shell, facilitated communication seemed like the answer to their prayers. The power of the recovery narrative type shaped the presentation of such controversial therapies, resulting in Hart's optimistic interpretation of a complex therapeutic story.

This narrative focused on hope, with endless possibilities for future improvements but no settled pathway forward, reflects that autism guidebooks did not offer parents a clear vision for the future, as Down syndrome guides did. The uncertainties of autism existed within all possible registers of the diagnosis. Unlike the prediction that most children with Down syndrome would grow up to be pleasant, autism offered a range of social, behavioral, intellectual, and communication symptoms and possibilities. The shared narrative produced through parent perspectives did not offer the reader a unified vision of autism, but instead of the resilience, significance, and value of the parents, whose expertise gained prominence in the literature over the course of the late 20th century.

On Whose Authority: Parents Challenge Professional Expertise

The position of parent as expert has developed over the course of autism's history. A number of prominent researchers in autism came to the work through their position as parents of a child with autism—psychiatrist Lorna Wing, for example, was a pioneer in the field. She developed the concept of an autism spectrum, introduced the triad of impairments in the areas of social interaction, social communication and social imagination that have become definitional for autism (and are now known as Wing's triad), and brought Hans Asperger's work to the English-speaking world. She also had a daughter who was diagnosed with autism at age three in 1959, inspiring Wing's life's work. And yet, Wing made no reference to her position as a mother of an autistic child in her early guides to autism, published as a short pamphlet in 1964 and a revised monograph in 1972. In her discussion of objectivity and the creation of authority in the autism community, historian of science Marga Vicedo describes how Bernard Rimland made no acknowledgement of his position as a father in his 1964 book *Infantile Autism*, emphasizing his scientific credentials rather than his parental bona fides. That early appeal to objectivity is absent in his many essays used as introductory materials for the writings of other parents dating from the 1980s onward. The letters he received from parents who were grateful that he had shown them empathy and rejected parent-blaming theories convinced him to shift his authoritative position so that his status as a parent was foremost. Vicedo writes that Rimland found his status as a parent invaluable in his ability to connect with other parents: "the very bit of information that he had not mentioned in his book was the one thing that brought him closer to all the parents who had felt alone for so many years."[84] The outpouring of parental letters that Rimland received following *Infantile Autism*'s publication led him to found the National Society for Autistic Children in 1965, and, like Wing did later in her career, he increasingly made his own experiences central to his appeals to parents.

Parents have occupied distinct positions and identities within the community surrounding autism. Parents act as consumers of literature on autism and Down syndrome, as sources for others to write such works, as experts shaped through professional development, and as experts on the basis of parenthood and giving loving care to a child with this diagnosis. Historian Chloe

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[84] Vicedo, *Intelligent Love*, 115.

Silverman has described the process by which parents engaging in applied behavior analysis became expert amateurs in autism treatment, arguing for the centrality of the term "amateur" to how these parents created an authoritative place for themselves: "[Amateur] serves at once as a demure renunciation of expertise and a claim about commitment and particularity of knowledge."[85] The position of parents as expert amateurs occupies a different place in autism from Down syndrome. Autism's unsettledness—in etiology, in treatment, in understanding—gave parents room to generate authority through their experimental approaches to caring for their children and their knowledge of their individual children. Parents of children with autism generated authority through the lived care of their children, their testimony to their children's progress, and their dedication to their children, communicated through memoirs such as Clara Park's *The Siege,* Charles Hart's *Without Reason: A Family Copes with Two Generations of Autism*, and Catherine Maurice's *Let Me Hear Your Voice: A Family's Triumph Over Autism*. This translated to parents writing guidebooks on the basis of this authority. Charles Hart declared his 1993 guide as "The Essential Handbook for Understanding All of Your Child's Needs," using his position as a father and brother of an autistic son and sibling as his credentials.

The decades between Hart's work and Lorna Wing's reveal significant changes in the opportunities for parents to position themselves as experts, and for parenthood to be an important aspect for the framing of a guide written for parents to read. Wing's writing in the 1960s and 1970s relied upon her expertise as psychiatrist and autism researcher—she wrote about parents and to parents from her professional perch, not from her perspective as a parent, establishing her scientific objectivity rather than her subjective position as a parent. In contrast, Charles Hart wrote as a parent to his peers, relying upon their trust of his experience in navigating the

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[85] Silverman, *Understanding Autism,* 96.

complex world of autism diagnosis, etiology, treatment, and education to confer authority over his work. Hart offered a synthesis of the scientific literature on autism and the perspectives of parents and individuals with autism, drawing upon parent memoirs and interviews. His position as a parent conferred authority upon the information he imparts, leading one reviewer to exclaim, “My first thought as I read *A Parent's Guide to Autism* was "Wow, I wish this book had been available when I was looking for accurate information about autism!"[86]

In the intervening years between Wing’s first guides and Hart’s writing in the 1990s, even professionals acknowledged the particular expertise and authority parents of autistic children held, along with the damage caused to the parent-professional relationship by the popularity of psychogenic etiological explanations for autism. Maria J. Paluszny, child psychiatrist working at the University of Michigan, wrote in her guide for parents and professionals in 1980:

> The professional’s major need is to be better informed and generally to communicate more effectively with parents. This is true in all disturbances of childhood but perhaps especially so in autism for several reasons. First, historically, because of the earlier suspicion that parents were instrumental in etiology, there has been a rift between parents and professionals, and professionals need to work hard to repair this rift. Second, progress in recent years has been rapid, and professionals who rarely see autistic children may not be up to date in this area. On the other hand, parents of autistic children as a group are remarkably well informed. Thirdly, as has been pointed out previously, the

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[86] Jill A. Whelan, “A Parent’s Guide to Autism,” *New Beginnings* 11(4) (1994): 123.

> most effective program for an autistic child is one in which professionals and parents work closely together.[87]

Charles Hart was not the first or only memoirist to author a guidebook. As mentioned, Clara Park, the most influential parent memoirist for autism, published *You Are Not Alone: Understanding and Dealing with Mental Illness, A Guide for Families, Doctors, and Other Professionals* with Leon Shapiro in 1976. Park wrote that her experience as a mother inspired this work: "It is because of [my daughter Jessy] that I wanted to write this book. But more important, it is because of [Jessy], and the understanding that she has given our family, that I have been able to write it. For sixteen years ago I knew nothing of what I was going to need to learn."[88] Although Park frames her work around her parenthood, she also chose to collaborate with a professional, psychoanalyst Leon Shapiro, and the voices of parents are not a primary aspect of the text. The adoption of the parent as trusted authority for interpreting autism had not become widespread by 1976.

The decades between Lorna Wing and Clara Park's guidebooks and Charles Hart's reveal significant changes in the opportunities for parents to position themselves as experts, and for parenthood to be an important aspect for the framing of a guide to autism. Wing's writing in the 1960s and 1970s relied upon her expertise as psychiatrist and autism researcher—she wrote about parents and to parents from her professional perch, not from her perspective as a parent. In contrast, Charles Hart wrote as a parent to his peers, relying upon their trust of his experience in navigating the complex world of autism diagnosis, etiology, treatment, and education to confer authority over his work. Hart offered a synthesis of the scientific literature on autism and the

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[87] Maria J. Paluszny, *Autism: A Practical Guide for Parents and Professionals* (Syracuse: Syracuse University Press, 1980), 152.

[88] Park and Shapiro, *You Are Not Alone*, xii.

perspectives of parents and individuals with autism, drawing upon parent memoirs and interviews. His position as a parent conferred authority upon the information he imparts. By 2001, when Lorna Wing published a revised version of her earlier book, she described her daughter's diagnosis in the introduction, citing her life as a valuable source of experience for her research.[89]

In contrast to autism, the role of parent expertise within Down syndrome lacked the ultimate authority conferred to autism parents. Whereas autism's etiology and best treatment were disputed and the relationship between professionals and parents had a history of contention and conflict resulting in rejection of professional authority, Down syndrome had a clear etiology—trisomy 21. The relationship between parents and professionals had not always been smooth—parents of children with Down syndrome often spoke of their frustration with physicians who did not have sufficient knowledge of the condition. Historically, parents' organizations had formed in the 1940s to fight the professional recommendation that they institutionalize children with Down syndrome, and the experience of pressure to institutionalize had made parents wary of the authority of the medical establishment.[90] By the 1980s, parents had been largely successful in deinstitutionalization, and the memories of doctors who dismissed their ability and insistence on caring for their children at home had not resulted in a turn away from medical authority over the legitimacy of trisomy 21. Even as parents rejected doctors who did not recognize the potential that their children had for educational, emotional, and social

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[89] Lorna Wing, *The Autistic Spectrum: A Parents' Guide to Understanding and Helping Your Child* (Berkeley, Calif.: Ulysses Press, 2001).

[90] Allison C. Carey, "Citizenship and the Family: Parents of Children with Disabilities, the Pursuit of Rights, and Paternalism," in *Civil Disabilities: Citizenship, Membership, and Belonging*, eds. Nancy J. Hirschmann and Beth Linker (Philadelphia: University of Pennsylvania Press, 2015), 165-87; Carey, "Parents and Professionals;" Castles, "Nice, Average Americans," 351-70.

growth, their guidebooks continued to urge others to seek out the good physicians. The belief that not all the medical establishment is bad pervades the genre of guidebooks for Down syndrome, and there is a durable recognition of the authority of physicians. Parents find reassurance that the system can work if they are willing to try—good information exists, good doctors exist, and if the parent seeks out the good, she and her child will be rewarded with a better quality of life. There is a fundamental optimism to parent guidebooks for autism and Down syndrome, but that optimism lies in distinct directions—the improvement of the child, or the improvement of society.

Conclusion

The typical framing for a parent guidebook centered around the parents, rather than the child with autism or Down syndrome. As psychologist Michael D. Powers wrote in the first chapter of *Children with Autism: A Parents' Guide*, "Autism is a very puzzling and painful disorder *for parents* to understand and deal with. You have a beautiful child who seems totally withdrawn—you reach out with love in your heart and get no response. You are bewildered and hurt. You feel helpless. Autism, however, is not an impenetrable wall; there are things you can do to reach your child and to try to help her."[91] For parents to turn to such a guidebook, Powers suggests, they must have found their child to be an alien, strangely unloving thing. Parents must experience their autistic child's interactions and feel hurt and helpless. Parents are loving and autistic children are cold, according to this construction of the autistic child-parent relationship, and that is what is normal. Parents' negative feelings are validated, while also their ability to change this relationship is promised. This framing of autism—as a tragedy for the parents, who nonetheless hold the power to change their children's ability to relate to them, along with the

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[91] Emphasis added. Michael D. Powers, "What is Autism?" in *Children with Autism*, 1.

ability to enact a miraculous change in their child's condition—centers the parents within the autistic family.

Parent guidebooks for Down syndrome share a centering of parent experiences, parent emotions, and parent responsibilities, but the power that parents hold over their children's future is less concrete, less expansive. Claire D. Canning, who had authored a memoir about her daughter in the 1970s, wrote in the first chapter to *A Parent's Guide to Down Syndrome: Toward a Brighter Future*:

> Of all the joys and sorrows of a lifetime, no event was ever more traumatic for my husband and me than the birth of Martha, our daughter who has Down syndrome. We were shocked, shattered, and bewildered. No woman ever really expects to give birth to a child with disabilities. Prior to Martha's birth, mental retardation had been simply a statistic to us—something that happens to someone else; yet no child has ever taught us so much or brought us so much love.[92]

Echoing the messaging of parent memoirs, Canning emphasized the love brought into her life by her daughter. The hope promised to parents lay not in the potential that a child with Down syndrome had for recovery from the condition, as with autism, but in teaching her parents about the true meaning of life. The potential for a "brighter future" promised by the subtitle of this guidebook lay in the improvement of services for children and adults with Down syndrome, their greater integration into society, and parents' ability to continue supporting these efforts at greater rights for the disabled. Hope lay in society, not in the individual.

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[92] Claire D. Canning, "Parent to Parent," in *A Parents' Guide to Down Syndrome: Toward a Brighter Future*, ed. Siegfried M. Pueschel, revised ed. (Baltimore: Paul H. Brookes, 2001), 1.

Down syndrome lacks the model of parent authority that autism has. Although there are parent-professionals and parents who wrote about the disability for other parents, the settledness of Trisomy 21 in its various forms as the cause of Down syndrome did not permit parents to challenge its etiology or the scientific authority that stemmed from that chromosomal legibility. Parents could, and did, assert their authority on the best forms of care for their children, on the rights of their children, and on the value of their children as independent individuals but they could not challenge what Down syndrome was. Parents of children with autism could challenge the psychogenic etiology of autism, could challenge the value of psychoanalytical therapy, and could assert themselves as more expert than any researcher, because autism lacked the stable scientific basis of Down syndrome.

Cliff Cunningham's claim that "feelings about Down syndrome were as important as facts" offers an accurate representation of the two bodies of content of most parent guidebooks on childhood developmental disability: feelings about the disability, and facts about the disability. For Down syndrome, those two categories could be neatly bounded and separated, as feelings came from parents, and facts came from the medical establishment. No amount of feelings would transform the facts of Down syndrome and its legibility as trisomy 21, and no amount of parent intervention could create a cure. In contrast, autism blurred the lines between feelings and facts from its inception. The popularity of a psychogenic etiology that blamed the refrigerator mother reflected broad cultural fears about changing parental roles in post-war America. Parents' responses to being blamed for their children's disability created a space in which their rejection of blame and of the medical establishment that blamed them unsettled what autism was and where it came from. The ongoing controversies over the causes of autism were echoed in a lack of consensus over how to treat the condition and changing diagnostic criteria, in which parents could assert that their ability to treat their children offered clear improvements, even a cure. In this environment, parenthood as the ultimate generator of feelings about autism became an essential part of asserting authority over the meaning of autism. Feelings about autism—about its causes, about its therapies, about its future—directed its facts.

CHAPTER FOUR

“I Must Let Him Tell His Own Story”

“It gives me great pleasure to write this, my very first book. I hope it will do well in America and in England.”[1]

In 1967, Nigel Hunt published his autobiography, *The World of Nigel Hunt: The Diary of a Mongoloid Youth*. Twenty-year-old Nigel’s writing was notable because Nigel had Down syndrome, and his father, experts on Down syndrome, and the media hailed his writing as the first book authored by someone with this condition. As Nigel’s father, Douglas Hunt, wrote in the preface to the book, “This book is unique, using the word strictly in its most literal sense. It was written by a mongol—my son. No mongol has ever written a book before.”[2]

Nigel’s book also featured a foreword by Professor Lionel Penrose, an expert on Down syndrome at the Kennedy-Galton Centre for Mental Retardation Research and Diagnosis, who personally knew Nigel, and a lengthy preface written by Nigel’s father. Penrose and Douglas Hunt both attested to the veracity of Nigel’s authorship, anticipating naysayers who would deny the ability of someone with Down syndrome to read or write sufficiently to complete a book. Such declarations of the book’s authorship recall, according to Michael Bérubé’s analysis of disability life narratives, the authentication of slave narratives in the antebellum period. Bérubé argues that:

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[1] Nigel Hunt, *The World of Nigel Hunt*, 45.

[2] Douglas Hunt, “Preface,” in Nigel Hunt, *The World of Nigel Hunt*, 15.

> For [writers with a cognitive or developmental disability], the act of self-authorship performs the same performative function it did for Frederick Douglass and Harriet Jacobs and Mary Prince and William Wells Brown: it establishes the life writer as, at bare minimum, someone capable of self-reflection and self-representation, someone capable of life writing. And for populations considered constitutionally incapable of self-reflection and self-representation, that "bare minimum" is actually the crux of the matter, a meta-claim from which all other claims follow.[3]

Nigel’s act of writing is the necessary evidence of intellectual capability for people with Down syndrome, which attests to their ability to self-reflect and self-represent, as Bérubé describes such work. Douglas’s preface offered the reader a frame for understanding Nigel’s work:

> When the skeptics have all had their say, there will be some who object that the book was not worth writing anyway. I would like to persuade them that although the literary value of the book may be small they will find quite a lot of entertainment in it, that it is an epoch-making book because it may encourage other parents or teachers who have children like Nigel to deal with, and that it may show them that the “experts” are often wrong and that almost all defective children are capable of being taught a great deal more than people admit.[4]

Douglas made clear that the value of Nigel’s work lies in its ability to persuade parents and teachers that children with Down syndrome or other cognitive disabilities are educable and worth educating, whatever the expert authorities may advise.

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[3] Michael Bérubé, “Autobiography as Performative Utterance,” *American Quarterly* 52, no. 2 (2000): 341.

[4] Douglas Hunt, “Preface,” 21-22.

Psychiatrist and influential Down syndrome researcher Lionel Penrose's foreword offered a different significance to Nigel's writing than the argument made by Douglas Hunt. Describing the book as "remarkable," Penrose argued for the importance of the work in several ways:

> The essay, with its paternal introduction, is a poignant human document. It is also of considerable scientific interest. In consequence of a natural talent for verbal expression, which has been fostered by the devoted encouragement of his parents, Nigel has been able to give an account of the world as he sees it. He is thus, as it were, able to speak on behalf of thousands of similarly affected people who are either less gifted or have had less opportunity than he.[5]

For Penrose, Hunt's work stepped into the void created by the lack of communication from people with Down syndrome or other cognitive disabilities. This void, according to Penrose, stems from lack of ability or lack of opportunity. Douglas Hunt's argument in favor of education would seem to address both aspects—improving ability and offering opportunities for children with intellectual disabilities to be included in mainstream society.

The publication of Hunt's autobiography and Penrose's recognition of Hunt's work as an important representation of the disability community coincides with the activism of the disability rights movement. Beginning with the independent living movement of the 1960s, disabled activists fought for their full inclusion into American society. As evidenced by the slogan "Nothing About Us, Without Us," disability rights advocates insisted upon speaking for themselves rather than relying on parents or professionals to lobby on their behalf. Disabled

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[5] Lionel Penrose, "Foreword," in Nigel Hunt, *The World of Nigel Hunt*, 9-10. For more on Penrose, his role in discrediting the racial and eugenic theories of Down syndrome etiology through genetics research is discussed in Wright, *Downs.*

activists rejected the paternalism of earlier parental activism and considered cross-disability alliances—in which disability operated as a source of identity formation and a culture that transcended the specific qualities of different conditions—to be an organizing principle. Rather than look to a disabled child's parent for understanding of autism or Down syndrome, disability rights activists said to look to disabled adults.[6]

Amidst the background of a growing list of successful campaigns for increased disability rights—from the 504 Sit-In of 1977 to the Americans with Disabilities Act of 1990—the memoirs of disabled adults were positioned to challenge the supremacy of the parent voice within American culture. However, the genre of parent memoir continued to grow throughout the late twentieth century, while publication of works such as *The World of Nigel Hunt* remained relatively rare. In a 1979 article in the journal *Mental Retardation*, "Speaking for Themselves: A Bibliography of Writings by Mentally Handicapped Individuals," psychology professor Keith E. Stanovich and special education teacher Paula J. Stanovich compiled an annotated bibliography of the writings of developmentally disabled people:

> It is not uncommon to hear parents, professionals, and advocates say, "We speak for the retarded because they cannot speak for themselves." Unfortunately, like most cliches, this assertion encourages stereotyped thinking. Taken in the extreme, the statement is manifestly untrue. Most retarded people can speak for themselves. The problem is that until the recent development of increased concern for the rights of mentally handicapped people, no one seemed to be listening. Hopefully, in the future, when a history of the

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[6] For more on the conflicts between parents and self-advocates, see Carey, Bloch, and Scotch, *Allies and Obstacles.*

> treatment of mentally retarded people is written, our era will be viewed as a time when society began to open its ears to these individuals.[7]

The Stanoviches insisted upon the importance of listening directly to disabled people and recognizing them as equal humans, identifying a problem in the framing of disability as "specialness," however well-meaning such efforts may be. This critique of "specialness" aligns with the analysis of disability scholars Paul Longmore and Allison Carey on the "Tiny Tim" trope and the eternal child rhetoric of disability.[8] The Stanoviches's argument about the need for inclusion, rather than exceptionalization, reflects the demands of the Disability Rights Movement for the full participation of disabled citizens in American life, rather than the siloing of disabled children and adults away from mainstream education, employment, and housing:

> Community acceptance will never come as long as we in the profession inculcate society with the belief that retarded individuals differ qualitatively from nonretarded human beings. The sense of "specialness" is emphasized by the fact that retarded individuals are always placed in a subordinate position in every social exchange in which they participate.[9]

They point out the large body of work by parents about their disabled children, but the relative paucity of works by intellectually disabled authors written with parents, professionals, and advocates as their audience. The works by intellectually and developmentally disabled writers that they describe included autobiographies, short stories, disability conference reports, transcripts of discussions and interviews with disabled people living in institutions, and speeches

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[7] Keith E. Stanovich and Paula J. Stanovich, "Speaking for Themselves: A Bibliography of Writings by Mentally Handicapped Individuals," *Mental Retardation* 17, no. 2 (April 1979): 83.
[8] Carey, *On the Margins;* Longmore, *Telethons*. See Chapter One of this thesis for more on this framing of disability.
[9] Stanovich and Stanovich, "Speaking for Themselves," 83.

to the Presidential Committee on Mental Retardation. The Stanoviches concluded that there is much work to be done both in publishing more from disabled people, and in the analysis of such works, particularly in examining the different ways that disabled people speak about themselves and what their parents, professionals, and the public say.

Nigel Hunt's diary offers an early look into memoirs, diaries, and essays authored by people with developmental disabilities, a genre which would not expand significantly until the late 1980s and early 1990s.[10] In the meantime, the scope of disability rights, particularly the right to an education for all disabled children and the right to live in the community rather than in institutions, would transform the general expectations for the life and intellectual potential of people with Down syndrome. The message that Douglas Hunt sent through his framing of Nigel's writings—that people with Down syndrome were educable and worth educating—became legally inscribed through such laws as the 1975 Education for All Handicapped Children Act, leaving later works to grapple with complex questions about the meaning of inclusion, social acceptance, and the value of disabled people to society.

The messages that came from authors with Down syndrome differed significantly from the messages from autistic authors. The most prominent autistic memoirist and writer of the late 20th century was Temple Grandin, whose 1986 memoir *Emergence: Labelled Autistic* marked one of the earliest monographs from an autistic author writing about their experiences growing up autistic and their understanding of the world.[11] Grandin received wide public recognition

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[10] For a discussion of writings as of 1979, see Stanovich and Stanovich, "Speaking for Themselves."

[11] *Emergence* is often referred to as the earliest memoir on autism by an autistic author. David Medzianik's *My Autobiography* (Nottingham: University of Nottingham, 1986), was published in the UK in the same year, although it did not receive a US publication until the Autism Society of America published it in 1993. Grandin's work has received much greater attention, in the United States and internationally.

when profiled by neurologist Oliver Sacks in the *New Yorker* in 1993; that profile provided the title essay for Sacks' 1995 collection *An Anthropologist on Mars*. Her 1996 memoir *Thinking in Pictures: Other Reports from My Life with Autism* offered Grandin's deeply considered reflections on autism, combining her own experiences with wide-ranging research into scientific and popular representations of the diagnosis. While Grandin's first autobiography and works from other autistic authors in the early 1990s conformed to expectations of a recovery narrative, in which an autistic person overcomes their autism to find success, *Thinking in Pictures* disrupted that expectation, showing Grandin to be an autistic adult who has adapted to her autism but will not recover from it.

The life narratives from writers with Down syndrome and from autistic writers reflect differing positions regarding the relationship of disability to society. Authors with Down syndrome tend to emphasize their assimilability into mainstream culture, building narratives that show their successful integration into societal institutions. The reader is encouraged to relate to the author over their shared humanity and abandon stigmas against people with intellectual disabilities. In contrast, by the late 1990s, autistic autobiographies, including *Thinking With Pictures*, emphasized difference. She does not claim to want the same things as neurotypical people—on the contrary, she finds understanding what other people want to be profoundly difficult. Grandin recognizes that autism offers her strengths as well as weaknesses as she lives an independent and highly successful life as an animal behavior expert, academic, and designer of cattle technologies. Grandin's memoir allows the reader to gain access to her mind in its uniqueness—the reader marvels at her strangeness, her resilience, her ability to communicate difference. Throughout, she cultivates the reader's sense of respect for the particularities of autistic people, those like and unlike herself, encouraging recognition of the abilities and value that autistic people have within society without relying on simple shared feelings. For Grandin, she and other autistic children and adults are worthy of society's respect not for the universality of aspects of their condition, but because of their uniqueness.

Seeking a Helen Keller for Down Syndrome: Early Writings

Published by the UCLA psychologist and education professor May V. Seagoe in 1964, a psychologist and professor of education at the University of California, Los Angeles, *Yesterday Was Tuesday, All Day and All Night* tells the life story of Paul Scott, a pseudonymous man with Down syndrome. Born to a wealthy family in 1917 and raised by his devoted father, Paul received an unusually complex education from Helen Bass Keller at the UCLA training school. He learned to read and write. For most of his life, he wrote daily diary entries covering his activities. Following his death, Seagoe received Paul's diary in 1961 and recognized it as unusual and important evidence of the abilities of people with Down syndrome when educated and supported.[12]

Yesterday Was Tuesday featured Paul's diary entries and letters, interspersed with May Seagoe's narration of Paul's life and explanation of each passage from Paul. The stated intent of the book—to prove that someone with Down syndrome could learn, could grow, could live a full and fulfilled life—shaped the framing of Paul's life. After the first chapter, which covered his education and the methods that his teachers found successful, the majority of the book focused on Paul's extensive travel with his father, using his travel diaries and scrapbooks to document their excursions across the globe and Paul's growth and maturation from adolescence into

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[12] Christopher Kliewer, Douglas Biklen, and Christi Kasa-Hendrickson, "Who May Be Literate? Disability and Resistance to the Cultural Denial of Competence," *American Educational Research Journal* 43, no. 2 (Summer 2006): 178-179.

adulthood. After his father's death, Paul's family decided to send him to an institution, where he died at age forty-seven.

Seagoe's introduction for the book presented its potential to make Paul Scott into an icon for intellectual disabilities, comparing him to Helen Keller and Clifford Beers. She argued that the publication of his diaries will address the question of the potential for intellectually disabled children and adults, as Paul's own writing will give the best evidence of what a man with Down syndrome can achieve when he is supported:

> Still the mentally retarded child himself is faceless, a category. He has had no one to speak for him. There is no life-long record to give color and motion to him as a person. Thus the reason for publishing and explaining the diary of Paul Scott. Given the best opportunities, can a severely retarded child learn to read and write in the usual sense? Can he develop a way of life that is satisfying? Can he care for himself and become self-directing? Can he live a normal life? These are the questions this book attempts to answer.[13]

To answer the question of whether a child with Down syndrome or another intellectual disability could "live a normal life," Seagoe presented the material from Paul's travel diaries beginning in 1929, when he was 12. She interspersed excerpts from his writing with commentary that highlights the evidence of complex emotions and intellect in Paul's writings: "The first sign of a more complex style was Paul's discovery of feelings, and of adjectives to express them… *June 17. Continental Divide. It was a wonderful sight. I saw snow, deep valleys and waterfalls, threw stones.*"[14] Paul's observations become a demonstration of the potential that he and other

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[13] May V. Seagoe, *Yesterday Was Tuesday, All Day and All Night* (Boston and Toronto: Little, Brown, and Company, 1964), vii.
[14] Seagoe, *Yesterday Was Tuesday,* 37.

intellectually disabled children have to develop complex thoughts: "*The Wind Caves. South Dakota. They were not as pretty as the Jenolan Caves in Australia*. The mentally retarded can detect similarities and make comparisons between experiences."[15] Paul's writings offered a window into his experiences, but without the structure or self-referential qualities of a memoir. As travel diaries, they traced his likes and dislikes about various places and people while cataloging what he saw and did. Seagoe emphasized the literary quality of his writing and the intellectual development that Paul displayed over time. As a testament to the fullness of Paul's life and an argument in support of educating children with intellectual disabilities, the diaries are effective. In addition to her emphasizing the intellectual achievements of Paul's writing, Seagoe framed the diaries as evidence of Paul's good nature, his capacity for joy and friendship, and his lack of pretense or prejudice.

Paul's diaries take a sad turn when, following his father's death and the inability of his long term caretaker to support him adequately, Paul's elder sister and guardian sent him to live in an institution for the intellectually disabled. Having spent over forty years traveling extensively with his father and, later, his caregiver, Paul hated his life in the institution. He wrote to his sister of his agony at living there.[16] Paul's pleas to leave the school and return to his sister are heartbreaking, but do not seem to have been included in the book as evidence that institutions were bad or that this institution was not the proper place for Paul. Instead, Seagoe described how Paul's upbringing as a pampered, wealthy child, encouraged in intellectual pursuits and travel rather than manual or practical tasks that the school required, made him a difficult resident of the school.

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[15] Seagoe, 37.
[16] Seagoe, 206.

In the book’s epilogue, Seagoe addressed what she identified as “question[s] arising from the poignancy of Paul’s dilemma, and from the way in which it was met. Exactly what is mongolism? Can’t something be done to increase the ultimate ability of the mongoloid, or to ease the ultimate tragedy? Should a mongoloid be taught to read? Or placed in a residential school from the start? Or ever placed in a school at all?” [17] Seagoe wrote about promising research on the education of developmentally disabled children, giving readers hope but cautioning them to manage expectations. She did not definitively argue for the potential of people with intellectual disabilities, cautioning readers that “the limits of improvement are narrow. He will always remain dependent. The best of environments cannot make him normal.[18]”

On the question of whether children with Down syndrome should be taught to read and write, Seagoe again did not offer a definitive answer. Seagoe wrote that, though learning to read and write took time, Paul found the process and its rewards to be a source of pleasure. His diaries were a source of joy and pride for Paul, his father, and his tutors. Seagoe did not suggest that Paul was indicative of every person with Down syndrome or conclude that all children with Down syndrome should be taught to read and write.[19] Seagoe described the different ability levels of different people with Down syndrome, including the significance of life in residential institutions for limiting the ability of its residents to retain their education.[20]

Seagoe accepted that residential institutional placements would continue to be a common setting for children and adults with Down syndrome. She recommended that parents consider their child’s future: “The answer to ‘What shall we do with this child?’ then, may need to

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[17] Seagoe, 219.
[18] Seagoe, 221.
[19] Seagoe, 223.
[20] Seagoe, 224.

precede 'Shall we teach him to read?' If it is likely he will remain in his home, with adults of intellectual interests most of his life, yes. If it is likely he will be placed in a residential school early, no."[21] Seagoe advised parents to determine whether they wish to keep their child at home for babyhood and childhood, writing of Paul as a meaningful member of his family: "Paul was a giver of pleasure as well as a receiver of help in his intimate family circle."[22] However, she also concluded that all developmentally disabled adults will eventually need to be institutionalized:

> *Should a mentally retarded child who has been kept at home into adulthood ever be placed in a residential school?* Isn't it too hard on him? Shouldn't he be kept at home for the rest of his life? Inevitably, after four or five, or forty or fifty years, the severely retarded person must be placed in a residential school or a foster home, public or private. Parents are by definition older than their children, and grown 'children' can never be totally self-directing. Someone must assume supervision when parents die. It is unfair to ask brothers or sisters or nieces or nephews to shape their lives around the needs of a grownup mentally retarded child.[23]

Seagoe's advice to parents remains firmly placed in a mindset in which institutionalization is normalized and parent and family needs are prioritized over the best benefit to the disabled family member.

Seagoe did not reflect on the fact that Paul's family's immense wealth shaped his life as surely as his disability did—the endless, luxurious traveling; the private tutoring; the lack of work obligations for his father. As an example of a life with Down syndrome, Paul's experiences would hardly reflect a universal set of experiences or opportunities. While Dale Evans' daughter

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[21] Seagoe, 225.
[22] Seagoe, 227.
[23] Seagoe, 228.

Robin, immortalized in *Angel Unaware*, was similarly born into an unusual life of wealth as the daughter of celebrities, Evans' writing highlighted universal aspects of parenting and childhood—family togetherness, love, community, religion—rather than the exceptional aspects of a life lived in the public eye or with great wealth.

The media coverage of *Yesterday Was Tuesday* highlighted the exceptional commitment Paul's father showed in pursuing his son's education. In an article in the *Chicago Tribune*, Norma Lee Browning described *Yesterday Was Tuesday* as "one of the most poignant stories to reach print in a long time."[24] Browning presented the book as evidence of Paul's father's devotion to his care but remained ambivalent about the lessons the book purportedly teaches about the value of educating people with Down syndrome:

> The diaries are a dramatic and suspenseful revelation of Paul's own learning progress; they also reveal the terrible loss and sorrow he suffered at his father's death. There is no question but that the years Paul and his father shared together enriched both their lives, but there are many questions which arise from Paul's eventual placement in a residential school, after his father's death, and his gradual deterioration… Paul Scott's diaries show that a Mongoloid may have capabilities far beyond what is commonly believed. The painful question is whether and how far they should be developed.[25]

The message of *Yesterday Was Tuesday* and the model of Paul as an intellectually and emotionally complex person with Down syndrome existed uncomfortably alongside the conclusions about Paul's unhappiness at institutionalization and Seagoe's acceptance of its inevitability. Other media coverage of the work often ignored this ambiguity, describing the

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[24] Norma Lee Browning, "This Brain Business: Was Paul Only One of a Kind, Or...?," *Chicago Tribune*, February 7, 1965.

[25] Browning, "This Brain Business."

book as evidence for the value of the education of people with intellectual disabilities without reflecting Seagoe's reservations.[26]

Paul's life offered a remarkable testament to the potential for intellectual development of persons with Down syndrome. Paul's achievements are particularly notable when considering that his education having started in 1923, at a time when experts in education considered literacy for children or adults with Down syndrome to be unattainable.[27] Despite their success with Paul, his teacher, Helen Bass Keller of the UCLA training school, and her colleague, UCLA Professor Grace Fernald, never publicized their work with him or used his achievements as evidence of the success of their method with children with Down syndrome.[28] Burton Blatt, disability education scholar, reviewed Paul's diary and found its veracity difficult to believe given the complexity of the ideas within Paul's writing and the fluidity of his prose. In his posthumously published 1987 textbook, *The Conquest of Mental Retardation*, Blatt writes, "Why was it that someone like me—someone engaged in the study of educability, someone who hypothesized that capability is educable—would find it difficult to believe that such a work could elicit anything but serious reservations if not outright disbelief? The answer to that question perhaps lies in the deeply embedded hopelessness associated with virtually everything associated with mental retardation."[29] Blatt writes that Seagoe had difficulty finding a publisher because the book did

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[26] "Latent Intelligence," *New York Times*, September 18, 1964; "The Big Books: Book of the Year," *Chicago Tribune*, December 6, 1964, sec. 9.

[27] Christopher Kliewer, "Citizenship in the Literate Community: An Ethnography of Children with Down Syndrome and the Written Word," *Exceptional Children* 64, no. 2 (January 1998): 167–80.

[28] Fernald and Keller mentioned Paul only once in their published work and did not identify him by name or as someone with Down syndrome. They used an excerpt of his journal to show evidence that children with low IQ scores may learn to read for enjoyment. Kliewer, Biklen, and Kasa-Hendrickson, "Who May Be Literate?," 178-79.

[29] Burton Blatt, *The Conquest of Mental Retardation* (Austin, TX: Pro Ed, 1987), 102.

not align with the commonly held belief that Down syndrome was a static condition without possibility of growth. He noted that the narrative of Helen Keller and her teacher, Anne Sullivan, had been plausible because “the intelligent layman’s idea about deaf, blind, or deaf-blind persons is that an education treatment can help the child overcome or circumvent the handicap. The same person’s conception of ‘Mongolism’ is that it is permanent, a condition immutable and forever destructive. Thus, how could Paul—or any ‘Mongoloid’—not only read at grade level, not only write at grade level, but think at grade level, and beyond?”[30] Blatt interprets the limited public attention to the book as a response to Paul’s unimaginable success: “The results [of Paul’s education] were so astonishing that they were hard for anyone to believe, and thus publishers were reluctant to publish them; and even after publication of the book, not much attention was paid to it. It was almost as if the story were so powerful it defied acceptance as valid.”[31] Blatt concludes that Paul’s achievements made the book implausible and, ultimately, nearly irrelevant—without a cultural framework that recognized that people with Down syndrome could learn to read and write at a high level, individual testaments to educability like Paul’s diary languished.[32]

Yesterday Was Tuesday and *The Diary of Nigel Hunt*, published three years apart, offer similar messages about the educability of children with Down syndrome. However, *Nigel Hunt* presents the value of Nigel’s education without the specter of institutional unhappiness. At the time of publication, Nigel and his father, Douglas, were living at Campbell Village Trust in

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[30] Blatt, *Conquest*, 103.

[31] Blatt, 103.

[32] Christopher Kliewer, Douglas Biklen, and Christi Kasa-Hendrickson place the lack of recognition that Paul’s diary received within a broader culture of denial of literate citizenship for disabled students and adults. Kliewer, Biklen, and Kasa-Hendrickson, “Who May Be Literate?,” 163–92.

Hertfordshire, one site of a number of communities for adults with intellectual and learning disabilities in the United Kingdom.[33] Douglas and Nigel's adjustment to Camphill was positive, and Douglas wrote of Nigel and the other Camphill residents' pride in their disabilities.[34] In the introduction to *The World of Nigel Hunt*, Douglas Hunt presented answers to similar questions as May Seagoe on the education of people with Down syndrome. His answers do not share her ambiguity over possible downsides to being overly educated for an institutional setting or the inevitability of life without family in an institutional setting for all disabled adults.

Douglas Hunt firmly positioned his advice to readers as supportive and enthusiastic about the experience of parenting a child with Down syndrome: "I must let [Nigel] tell his own story. However, I feel that we, his parents, owe a few more words of encouragement to those who face the same problem we have had… 'Problem' is the word, not 'tragedy.' Nigel has brought us untold joy. He has been loving, considerate, generous, and immensely rewarding."[35] Douglas tried not to romanticize Nigel, but relied upon the trope of the devoted parent to explain Nigel's imperfections:

> Nigel is not perfect nor is he a genius, though he may be a genius manqué. He used to have a vile temper, but his mother cured him of this completely and with the minimum of physical correction. He still finds money a considerable difficulty, and, most normally, finds it hard to keep in his pocket. But he is learning. This, above all, is the message we,

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[33] The Camphill Movement also operates in the United States and elsewhere. Historian Katherine Sorrels has an article forthcoming, "Complicating the Medical Model of Disability: The Camphill Movement and the Legacy of Viennese Curative Education."

[34] Douglas Hunt, "Preface," 40-41.

[35] Douglas Hunt, 30-31.

> his parents, would like to give to our readers. MONGOLOIDS CAN LEARN AND GO ON LEARNING IF THEY ARE GIVEN THE ENCOURAGEMENT.[36]

Through the strength of his mother's teaching, Nigel overcame his temper, and through his parents' constant encouragement, he has grown and learned and continues to learn, in his father's telling. Douglas further referred to Nigel in religious terms, evoking the "angel unaware" of Dale Evans Rogers' bestselling book and describing Nigel as "a gift from God… He is an individual soul, as precious as any other, and we deemed it a great privilege that we were entrusted with this precious soul in a somewhat handicapped body, who needed especial care and understanding. We would not exchange him for the most brilliant child in the world and we have been richly and abundantly rewarded for all that we have tried to do for him."[37] Douglas encouraged parents to trust that their children will show the same love, affection, and joy that Nigel brought to his and his wife's lives, so long as they are willing to work for it.[38]

Following Douglas's introduction, Nigel's text covered his family, his travels to Germany and Austria, reflections on day trips to Windsor Castle and Hampton Court, his opinions of pop music and television shows, and his thoughts on his school. His writing is funny and charming, showing Nigel to have an ease with words and a good-natured personality. His father regularly interjected into the text, adding short explanations or commentary, often enhancing or highlight the humor in the text: "My mother used to read to me and she would read all the way through and the title of the book was 'Alaplied' which I said every time my mother came up. [*This was actually 'he replied.' It was not the title of the book.*]"[39] At other points,

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[36] Douglas Hunt, 32-33.
[37] Douglas Hunt, 33.
[38] Douglas Hunt, 34.
[39] Nigel Hunt, *The World of Nigel Hunt*, 98.

Douglas Hunt's commentary emphasized Nigel's accomplishments, reinforcing his abilities in the reader's estimation. Following Nigel's description of how he travels via bus to visit his aunts' house, Douglas added, "*This is a long and fairly complicated journey, which Nigel easily makes on his own.*"[40] The book's writing supports Douglas Hunt's argument—Nigel's abilities, personality, and intellect are evident within the text, marking the value of the education he received.

The book finishes with Nigel's message of gratitude to his publisher and his readers, and a final interjection from Nigel's father: "To all good people who read my books and take my sincere wishes, TATTYBYE [*It went sorely against the grain to leave this horrible word at the end of the book, but after all it is his book and only with the absolute minimum of editing can it give a picture of the lad himself.*][41]" Douglas Hunt did not allow the book to end with the "horrible word" of TATTYBYE, instead adding one final anecdote about Nigel and the treatment he had faced by those ignorant to his potential. Writing that he wishes to give parents one last piece of encouragement and "to illustrate the fallibility of the experts," Hunt describes a meeting with a government official "concerned with mental affairs," who saw Nigel and said, "*Oh, yes, a little mongoloid. Quite ineducable. Do you want him put away?*"[42] Nigel's parents were not impressed, and Douglas advised other parents reading this anecdote to share in their rejection of such expertise.

The reception of *Nigel Hunt* was largely positive and sometimes effusive in its praise. Although unimpressed with the quality of Nigel's prose, Ridgely Hunt wrote in the *Chicago Tribune* "Other Books Briefly" column that "the merit of this book lies in the fact that it was

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[40] Nigel Hunt, 116.
[41] Nigel Hunt, 125.
[42] Nigel Hunt, 125-126.

written at all."[43] Remarking on the belief that people with Down syndrome cannot be taught to read or write above a rudimentary level, Hunt described *The World of Nigel Hunt* as proof of the fallacy of that idea: "here stands the printed work of a mongoloid, a British youth who has traveled at home and on the continent and who records his experiences with the directness and good humor that characterize the mongoloid personality."[44] *The Times Educational Supplement* included *The World of Nigel Hunt* in its "New Books" column, describing Nigel's diary as "not only astonishing, but also readable and amusing."[45] Throughout the 1970s, *The Exceptional Parent* magazine included *The World of Nigel Hunt* in the advertisements for "*The Exceptional Parent* Bookstore," a collection of books sold via mail order in the magazine's pages. The advertisement divided between "books of interest to readers concerned with the life of children with disabilities" and "books which provide practical guidance about children for parents and professionals—but are not specifically focused on children with disabilities." *The World of Nigel Hunt* was the former, described as "A heartwarming autobiography by a young man with Down's syndrome. Nigel Hunt's parents were told, 'Your son cannot be educated. He is mentally handicapped and you will never be able to do anything with him.' Encouraging for parents; challenging for professionals and students."[46] Presumably, Nigel Hunt's autobiography challenged professionals who refused to support the education of children with Down syndrome, as his writing proved the potential achievements that lay within everyone with Down syndrome

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[43] Hunt's comments recall the "bare minimum" described by Bérubé in "Autobiography as Performative Utterance." Ridgely Hunt, "Other Books Briefly," *Chicago Tribune*, April 2, 1967.
[44] Ridgely Hunt, "Other Books Briefly."
[45] "The World of Nigel Hunt: The Diary of a Mongoloid Youth," *The Times Educational Supplement*, no. 2,742 (December 8, 1967): 1336.
[46] "*The Exceptional Parent* Bookstore," *The Exceptional Parent*, January/February 1975, n.p. Other books on offer included *A Child Called Noah* and *Caring for Your Disabled Child.*

when given the opportunities that Nigel had and empowered parents in their demands for the right for their children's education.[47]

Other parents agreed with *Exceptional Parent*'s endorsement of *Nigel Hunt*. In a 1978 profile of new parents with a child with Down syndrome for *The Humanist*, a magazine from the American Humanist Association, Marilyn C. Trainer—herself the mother of a child with the diagnosis, a member of the Arc, and the future author of a parental guidebook-memoir, *Differences in Common: Straight Talk on Mental Retardation, Down Syndrome, and Life,* published in 1991—identified *The World of Nigel Hunt* as the book that "lifted [the parents'] spirits tremendously. The book… was written by a young man with Down's Syndrome. This beguiling youth's moving testimony attests to the value of raising such a child at home rather than consigning him at birth to an institution. The Carrs bought copies for both sets of grandparents and lent their own copy to various friends and neighbors."[48] This glowing review of *Nigel Hunt* contrasted with the general response to literature on Down syndrome, based on the advice of "experienced" parents in the article: "The second thing the experienced parent will tell the new parent is to stay away from the library! Steven could vouch that this was excellent advice after a trip he had made to the library. Until recently most literature on Down's Syndrome is so disheartening that the new parent risks real emotional depression by reading it. Forget what the books say."[49] Unlike those other, depressing works, Nigel's autobiography—and the message from his father—reassured parents that the future of their children with Down syndrome was

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[47] Castles, "Nice, Average Americans," 351-370.

[48] Marilyn C. Trainer, "Don't Take 'That' Baby Home," *The Humanist* 38, no. 4 (July/August 1978): 33.

[49] Trainer, "Don't Take 'That' Baby Home," 33.

hopeful, and that their decisions to keep their children at home, rather than institutionalize them at birth or at a young age, was the correct choice.

The significance of Nigel's parents to his accomplishments—and by extension, the parent readers to their children's accomplishments—echoed in professional evaluations of *The World of Nigel Hunt*. In her 1995 guidebook *Teaching Reading to Children with Down Syndrome*, Patricia Logan Oelwein, then the coordinator of Down Syndrome Programs at the Child Development and Mental Retardation Center of the University of Washington, described the book as "the glimmer of hope" amidst a dearth of documentation of literacy among people with Down syndrome. However, Oelwein singled out Nigel's parents, rather than Nigel, as the exceptional figure in his story: "I respect and admire Mr. Hunt for his accomplishments and feel very grateful to him for his great contribution… However, I must confess, I do not believe Nigel Hunt was the exceptional one: his parents were the exception. They gave him the opportunity to read and write."[50] Oelwein's crediting of Nigel's literacy to his parents' commitment to his education both accepts the educability of people with Down syndrome as entirely typical and reorders Nigel's achievements so that his literacy is his parents' success story. Any child with Down syndrome could accomplish as much, Oelwein suggests, if only their parents would make the necessary commitment.

Even within work that calls for greater attention to the voices of disabled adults, Nigel's parents receive special mention. In their 1979 bibliography of writings from intellectually disabled people, Keith and Paula Stanovich identified seven works by developmentally disabled authors as "the most important works."[51] These included autobiographies such as Nigel Hunt's

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[50] Patricia Logan Oelwein, *Teaching Reading to Children with Down Syndrome: A Guide for Parents and Teachers* (Bethesda, MD: Woodbine House, 1995), 1.
[51] Stanovich and Stanovich, "Speaking for Themselves," 84.

diary and J.J. Deacon's memoir, *Joey*, about his life with cerebral palsy; a short story about two people with cerebral palsy falling in love, coauthored by J. J. Deacon; and transcripts of conversations with intellectually disabled adults, in and out of institutional settings. Of *The World of Nigel Hunt*, they write, "Nigel's parents worked from the very beginning to develop his educational abilities… Nigel's book, which is entirely the product of his own efforts, is a fitting monument to his and his parents' determination."[52]

Yesterday Was Tuesday and *The World of Nigel Hunt* offer an early look at the writings of people with Down syndrome, framed by the messages from parents and teachers that children with Down syndrome can be and should be educated. Published at a time when the educability of children with Down syndrome was contested, *Nigel Hunt*, especially, echoes and furthers arguments from parents that their children should not be institutionalized but should be raised at home and parents should be dedicated to their children's education and development. *Yesterday Was Tuesday* is a more ambiguous book—its origins as Paul's private travel diary make its contents less obviously digestible than Nigel's writings, and May Seagoe as its non-disabled interlocutor resisted adopting the firmly anti-institutionalization stance that Douglas Hunt professed.[53]

A Fulfilment of All Our Dreams: Down Syndrome on Television and in Writing

In 1974, Emily Perl Kingsley gave birth to a son, Jason. Soon after his birth, Jason was diagnosed with Down syndrome.[54] Emily, a writer for *Sesame Street*, called her boss, Joan

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[52] Stanovich and Stanovich, "Speaking for Themselves," 84.

[53] *Yesterday Was Tuesday* received less media attention and academic attention than *Nigel Hunt*, based on my review of the literature. Stanovich and Stanovich and Oelwein both mention it, but do not offer it the extended discussion that they show *Nigel Hunt*.

[54] Within the disability parenting world, Emily Perl Kingsley is also well known for her poem, "Welcome to Holland," which is extremely popular.

Cooney, at the Children's Television Workshop, upset that the doctors had predicted Jason would be uneducable and should be institutionalized. As Cooney recalled decades later, "Emily and Charles were planning to bring Jason home and would try to bring him up themselves. Remembering Dale Evans, I said something that probably sounded facile to Emily but with which I'm sure she would agree—something like, 'It will be a very intense parenting experience.'"[55] Cooney recounts that the *Sesame Street* team was already working on how to include disabled children on the show, consistent with their mission to include and appeal to as many children as possible. "Thanks in part to Jason and Emily, 'Sesame Street' soon began to include children with Down syndrome: when Jason was only fifteen months old, he made his television debut sitting on Buffy Sainte-Marie's lap. When he was six, we showed him counting in Spanish. Jason and Mitchell Levitz, who was three years older and also had Down syndrome, both appeared many times as two of the regular kids on the Street."[56]

Jason Kingsley and Mitchell Levitz's appearances on *Sesame Street* in the 1970s and 80s marked early television depictions of Down syndrome. Jason's work on "Sesame Street" led to further acting opportunities—he appeared on *All My Children* in 1981, *The Fall Guy* in 1984, and *Touched by an Angel* in 1997, as well as tv-movie "This Is My Son," written by his mother and based on his life. He also inspired Chris Burke, who became the most prominent actor with Down syndrome in Hollywood with his starring role on the family drama *Life Goes On*, which premiered on ABC in 1989. According to Burke's biography, which he co-wrote with Jo Beth McDonald, Jason's appearance on *The Fall Guy*—in which he attended public school, spoke

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[55] Joan Ganz Cooney, "Foreword," in Jason Kingsley and Mitchell Levitz, *Count Us In: Growing Up with Down Syndrome* (New York: Harcourt Brace & Company, 1994), xii.
[56] Cooney, "Foreword," xii.

several languages, and played a pivotal role in the episode's plot—inspired Burke.[57] After watching Kingsley on the show, Burke wrote a letter to Jason's mother, and they became pen pals. Emily Perl Kingsley looked at Burke as a role model for what she hoped her son would grow up to become: "We didn't have many people to look to for a really clear view of what the future was going to be for our kids. When we looked at adults with Down syndrome, we were, generally speaking, looking at people who didn't have the advantages of early programs, or heavy-duty academic educations."[58] Burke represented a generational shift in the potential for adult life with Down syndrome: someone who had strong parental and community support throughout his life, whose parents had fought for his right to a quality education, and who successfully attended school and worked. As Emily described him, "When I saw Chris, I saw that a young adult with Down syndrome could be this attractive, this capable, this smart, with such a sense of humor. He was the fulfillment of all our dreams. He was a real inspiration."[59] Parent memoirist Martha Jablow described Chris Burke and *Life Goes On* as "one of the best things to give public exposure and acceptance" for Down syndrome, saying that her daughter Cara loved the show.[60]

Chris Burke's biography exists to further that inspirational image. Although the book's subtitle is *Chris Burke's Own Story*, it is not a memoir or autobiography written from Chris's perspective. Co-author Jo Beth McDaniel, a former correspondent for *Life* magazine, wrote the majority of the book, focusing the narrative on the story of the Burke family and how Chris grew into his acting career. McDaniel recounts Burke's life and his family history in sometimes

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[57] Chris Burke and Jo Beth McDaniel, *A Special Kind of Hero: Chris Burke's Own Story* (New York: Doubleday, 1991), 103-104.
[58] Burke and McDaniel, *A Special Kind of Hero*, 106.
[59] Burke and McDaniel, 106.
[60] Martha Moraghan Jablow, oral history with the author, November 8, 2018.

exhausting detail, offering endless perspectives on Burke from people who have known him but only occasional insights from Burke himself.

The narrative of *A Special Kind of Hero* foregrounds Burke's family life. Burke was born in 1965 as the youngest of four children in a Catholic family. His parents, Marian and Frank Burke, were a stay-at-home mother and a Second World War veteran-turned-New York City cop. Burke's birth does not occur until the end of the second chapter, as Frank's time as a prisoner of war and their pre-Christopher married life take up the first two chapters. While Chris's diagnosis shocked his parents, McDaniel emphasizes his much-older siblings' endless devotion to him and his parents' continual striving for the best possible education for Chris, including sending Chris to private boarding schools his parents felt mainstreaming in New York City public schools was not the right environment.[61] McDaniel extensively details Chris's academic and social development, with Chris's ambition to be an actor growing until he finds success, in part through his relationship with Emily Perl Kingsley, who recommended him to the creator of *Life Goes On*.

Scattered throughout the narrative are four short interludes directly from Chris, which reiterate the inspirational messaging of the book. These passages feature Chris's perspective on himself, his life, and Down syndrome. Burke insists upon his own abilities: "I hate the word 'can't.' 'Can't' is like a disease that keeps you from doing things. I have an extra chromosome, but I can do lots of things. I'm happy for myself. I've had my dreams come true, and that's what's important."[62] Chris encourages his readers to treat all people with Down syndrome with respect and show others the opportunities he had: "Everyone needs to know that we are people,

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[61] Burke and McDaniel, 72.
[62] Burke and McDaniel, 245.

too. We have hopes and dreams and ambitions. We laugh and have fun, and we can be serious and do a good job. We can do lots of things if people give us a chance. And the show has opened doors for lots of families who have a son or daughter with Down syndrome or other disabilities. It gives them hope in their private lives, and lets them know that life goes on."[63] Burke and McDaniel's emphasis on Chris's abilities, achievements, and exceptional success draw upon the longstanding cultural image of the inspirational disabled figure, described by activists in the disability rights movement as the "supercrip." Journalist Joseph P. Shapiro describes the supercrip as "the flip side of the pitiable poster child… it implies that a disabled person is presumed deserving of pity—instead of respect—until he or she proves capable of overcoming a physical or mental limitation through extraordinary feats. Today, these "supercrips" remain among our most glorified disabled role models, lavishly lauded in the press and on television."[64]

The supercrip is a richly studied topic within disability studies. Disability scholar Sami Schalk has called for a more complex use of the supercrip idea in disability studies, arguing that "calling a representation a supercrip narrative, it seems, is a clear and unquestioned critique, the ultimate scholarly insult that dismisses the possibility of finding recuperative, liberators, or positive aspects of a representation."[65] *A Special Kind of Hero* reflects certain aspects of the supercrip narrative. The emphasis on Chris Burke as an exceptional individual whose success results from his and his family's hard work produces the depoliticization that Alison Kafer describes in *Feminist, Queer, Crip*, as she writes that "that rhetorics of disability acceptance and

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[63] Burke and McDaniel, 248.
[64] Shapiro, *No Pity*, 16.
[65] Sami Schalk, "Reevaluating the Supercrip," *Journal of Literary & Cultural Disability Studies* 10, no. 1 (March 1, 2016): 71.

inclusion can be used to decidedly un-crip ends."[66] Schalk builds upon Kafer's analysis, writing that "the focus on individuality is often simultaneously in tension with appeals—typically in the language of inspiration—to sentimental universal humanity that is supposedly highlighted by supercrip representations."[67] This ambiguity—Burke as both inspirational and universal—runs throughout *A Special Kind of Hero*.

Despite these critiques, when viewed through the lens of an audience with Down syndrome, Burke's narrative takes on different meaning. Rhetoric professor Wendy Chrisman has called for a reconsideration of the value of inspiration in disability studies, noting the significance of inspirational people and events for intra-group development.[68] Chrisman's appeals for the validity of inspiration resonate with the welcome reception that Burke received within the Down syndrome community for his work on *Life Goes On*. Media coverage of advocacy groups for Down syndrome reported their glowing praise for Burke's work.[69] Nancy Hall, executive director of the Down Syndrome Association of Los Angeles, wrote in the *Los*

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[66] "Un-crip" in this parlance refers to actions that are against the political aims of disability activists who have reclaimed the word "crip." Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: Indiana University Press, 2013), 97.
[67] Schalk, "Reevaluating the Supercrip," 77.
[68] Wendy Chrisman, "A Reflection on Inspiration: A Recuperative Call for Emotion in Disability Studies," *Journal of Literary & Cultural Disability Studies* 5, no. 2 (January 1, 2011): 173–85.
[69] Joy Horowitz, "'Life Goes On' Stretches Reality, Within Reason," *New York Times*, 1989, sec. Arts & Leisure; Marc Gunther, "A TV Breakthrough: Down's Syndrome Victim to Star in 'Life Goes On,'" *Chicago Tribune*, July 26, 1989; Rick Kogan, "Down's Syndrome Goes Mainstream with Dignity in TV's 'Life Goes On': Season Premiere," *Chicago Tribune*, September 12, 1989; Mark Dawidziak, "Pressure of Rave Reviews and Endorsements Saves 'Life Goes On,'" *Chicago Tribune*, June 16, 1990, sec. Weekend Chicago; Nancy Randle, "'Our Ticket to Acceptance': Actor with Down's Syndrome on 'Life Goes On' Has Become a Role Model," *Los Angeles Times*, December 15, 1990, sec. Calendar; Nancy Randle, "'Life' Helps Others Go on: The Historic Program Has Inspired Those with Down's Syndrome," *Chicago Tribune*, January 25, 1991, sec. Tempo; Howard Rosenberg, "ABC Series a 'Life' Line for Viewers," *Los Angeles Times*, April 18, 1992, sec. Orange County; Howard Rosenberg, "There's More to 'Life' Than Ratings: 'Life Goes On, 'ABC's Endangered Series about a Family with a Down's Syndrome Teen-Ager, Is an Inspiration," *Los Angeles Times*, April 20, 1992, sec. Washington.

Angeles Times that the show "probably has done more to help people with Down syndrome than anything else in the last 20 years."[70]

Coming nearly three decades after *Yesterday Was Tuesday* and *The World of Nigel Hunt*, *A Special Kind of Hero* reflects real changes in the acceptance of people with developmental disabilities and the legal rights afforded to them. McDaniel quotes many people who hold Chris as exceptional, but he is exceptional for his professional accomplishments—no one doubts that Chris is capable of reading or writing, even as his acting talent is sometimes found astonishing. In comparison to the need for May Seagoe and Douglas Hunt to validate Paul Scott and Nigel Hunt's literacy, Burke's is taken for granted—he does not need to write a memoir to prove his abilities. He exists as inspiration, rather than argument.

Jason Kingsley, Chris's inspiration as an actor with Down syndrome, authored his own book about his life with Down syndrome. Kingsley and his friend and former *Sesame Street* co-star Mitchell Levitz published *Count Us In: Growing Up with Down Syndrome* in 1994. *Count Us In* is structured as a series of conversations on topics like friendship, school, sex, Down syndrome, politics, and their lives and futures. Over three years, Emily Perl Kingsley and Barbara Levitz transcribed conversations between their sons, themselves, and some other family and friends to form the basis of the book, along with some individual written contributions from Jason and Mitchell. In their co-written introduction to the book, they address their son's maturation into adolescence, which led them to conclude that a book of their conversations would be valuable:

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[70] Nancy F. Hall, "For Some, 'Life Goes On' Has Been a Lifeline," *Los Angeles Times*, May 22, 1993.

> [Jason and Mitchell's adolescent growth] involved much exploration of self-esteem issues and grew into a deep analysis of their own disability. Their increasing self-awareness itself was contrary to the earlier beliefs: that young people like Jason and Mitchell would never be bright enough to conceptualize the fact that why had a disability. But they *were* able to conceptualize it, and they had their own need to discuss it and begin to work through it… Mitchell and Jason had *a lot* to talk about, and it seemed deeply important for them to do so. We felt it might also be valuable for them to share some of their insights with other young people with and without Down syndrome.[71]

As chapters were compiled from material over the course of the three-year book project, the ideas and opinions expressed by Jason and Mitchell change and develop over time. A chapter on finding independence features a running discussion over when, if ever, either one will get a driver's license. After insisting in earlier conversations that he would soon be mature enough to be trusted with a license, Mitchell comes to accept that he may never drive:

> I do want to drive, but it's difficult for me to have the skills to drive. My father doesn't see me driving until a certain age. Dad, he sees me driving at twenty-three, which is next year, but I think that's not going to happen. I don't think I'm going to have the skills by twenty-three or twenty-four. Or at all.
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> There will be other methods of transportation. I don't think I will ever get those skills. It's difficult for me to face, but I'm learning to accept the fact that I may not be able to do some things that my sisters are doing. Which is a main fact which I will understand.[72]

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[71] Emily Perl Kingsley and Barbara Gibbs Levitz, "Introduction," in Kingsley and Levitz, *Count Us In*, 7.

[72] Kingsley and Levitz, *Count Us In*, 160.

Michael Bérubé describes Mitchell's acceptance that he will never drive as a testament to "an emotional maturity greater than that of any hundred nondisabled adults I know."[73] Mitchell's reflection on driving becomes a meditation on the ways that his disability shapes his life. His acceptance of his disability changes over the chronology of the book—three years before the conversation about driving, in 1990, he said, "I'd rather think of myself as normal than as a disability."[74] *Count Us In* highlights Jason and Mitchell's complex feelings about Down syndrome, along with their opinions and ideas about a variety of other topics, like the 1992 Presidential election (Mitchell supported Bush; Jason supported Clinton).

Count Us In featured a foreword by Joan Ganz Cooney, cofounder of the Children's Television Workshop and co-creator of *Sesame Street*. Cooney described working on the publicity for a Roy Rogers-Dale Evans television special in the 1950s. Among the pair's publicity materials was a copy of *Angel Unaware*. For Cooney, "Dale's book was an epiphany… Her description of her family's delight in that adorable and affectionate child moved me to tears. So did her account of their sense of less and bereavement when their little girl died. Later Dale told me that one of her greatest satisfactions in the years after her book came out was seeing, at last, children with Down syndrome in the audiences that came to watch her and Roy perform."[75] Cooney writes that she never forgot about *Angel Unaware* and about her commitment to including disabled children on *Sesame Street:*

> Today, we can be proud of how much the world has changed since Dale Evans told me that children with Down syndrome were nearly always hidden from public view. Times have changed, thanks to parents like the Kingsleys and the Levitzes and young people

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[73] Bérubé, *Life as We Know It*, 262.
[74] Kingsley and Levitz, *Count Us In*, 48.
[75] Cooney, "Foreword," in Kingsley and Levitz, *Count Us In*, xi.

> like Jason and Mitchell. Parents of other children with Down syndrome have told me how much it meant to them and to their own kids to see Jason and Mitchell on "Sesame Street." And now we have events like the Special Olympics, television programs like "Life Goes On," and most important, new basic civil rights legislation.[76]

Cooney went on to briefly discuss the 1990 Americans with Disabilities Act, describing it as "the most sweeping nondiscrimination legislation since the Civil Rights Act of 1964."[77] Cooney's appeal to readers for better treatment of the disabled in America argues for the economic benefits that investing in disability education can reap, producing "responsible tax-paying citizens who contribute to their communities in many ways… We cannot relearn too often the great lesson of "Sesame Street": if you work with any child who is disadvantaged—physically, intellectually, or socioeconomically—he or she will do better, sometimes amazingly better."[78] Cooney twice highlights the potential and ability of disabled adults to be taxpayers, rather than, presumably, tax burdens who live on disability benefits afforded them by the state. The construction of disability presented in this short introduction is oriented around achievements—education, work, home ownership—that align with historical understandings of disability and work, with conventional middle-class American values, and with the particular demonization of welfare in the 1980s and 1990s. Disability, in this understanding, does not foreclose the disabled from becoming worthwhile members of society. However, any American for whom disability does make paid labor impossible or inadvisable will fail to attain the status of American citizenship.[79]

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[76] Cooney, "Foreword," xiii.

[77] Cooney, xiii.

[78] Cooney, xiv.

[79] For more on disability, work, and dependency, see Sarah F. Rose, *No Right to Be Idle: The Invention of Disability, 1840s–1930s* (Chapel Hill: UNC Press, 2017); and Hirschmann and Linker, *Civil Disabilities*.

Jason and Mitchell’s mothers, Emily Perl Kingsley and Barbara Gibbs Levitz, co-wrote the introduction to *Count Us In*, framing the book around arguments and tropes familiar from the genres of parent memoirs. Barbara Gibbs Levitz, Mitchell’s mother, opens the introduction by echoing a familiar refrain from parent accounts: “Absolutely nothing prepares you for being told that your newborn child is ‘less than perfect.’”[80] Barbara and Emily both recall being told by their doctors, in 1971 and 1974 respectively, that they should choose to institutionalize their sons, and refusing to do so. They describe the lengths they have gone in demanding their children’s rights and respect at school, at camp, and in their communities, concluding that “these boys have succeeded because they were given opportunities and allowed to take risks, and because we refused to let anyone write them off.”[81] At the time of the book’s publication, Mitchell and Jason were 23 and 19, respectively—but to their mothers, they remained “boys.” Barbara and Emily shared about their involvement with parent advocacy and their continued work to fight for Mitchell and Jason’s rights to a mainstream public education. Perhaps anticipating that the readers of *Count Me In* were likely to be non-disabled, they argued for the benefits of inclusive disability education to parents and the classmates of disabled children, not solely to the disabled children themselves.[82]

Compared to Chris Burke’s book, in which Chris’s voice is a secondary presence and Jo Beth McDaniel’s prose takes center stage, the presence of non-disabled family members and friends in *Count Us In* is minor—the book focuses on what Jason and Mitchell say and write throughout, many of the conversations are solely between the two of them, and their voices feel genuine. Given the continued lack of works written by people with Down syndrome, *Count Us*

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[80] Emily Perl Kingsley and Barbara Gibbs Levitz, “Introduction,” 1.
[81] Emily Perl Kingsley and Barbara Gibbs Levitz, 4-5.
[82] Emily Perl Kingsley and Barbara Gibbs Levitz, 7.

In holds a significant place in the disability life-writing library and is highly important to the Down syndrome community. In 2018, parent memoirist Martha Jablow described *Count Me In* as "an influential book," although she was unsure if Emily or Jason had written it.[83] However, the framing of books by people with Down syndrome by their parents that is done here via the introduction, as in *The World of Nigel Hunt*, aligns these works thematically with parent memoirs. The existence of the book is still due to the parents—Emily Kingsley and Barbara Levitz were the ones with the idea for the book, they transcribed the conversations, they compiled the book's material, and they make sure the reader is immediately aware of their involvement from the book's start. Within the context of the literature on Down syndrome, parent voices are loud and the voices of individuals with Down syndrome are relatively absent.[84] *Count Us In* remains steeped within the culture of parent-oriented disability discourse, existing in an ambiguous space of disability writing mediated by parent voices.

Just as *The World of Nigel Hunt* and *Yesterday Was Tuesday, All Day and All Night* reflected the political struggles of the 1960s as they argued against institutionalization and in favor of the education and educability of people with Down syndrome, *Count Us In* and *A Special Kind of Hero* reflected the disability politics of the 1990s. By the 1990s, parents no longer faced pressure to send their infants to institutions. The right to an education was generally accepted and legally protected, albeit requiring constant vigilance from parents to ensure the system was providing their children their rights. Instead, the introduction of amniocentesis and prenatal diagnosis of Down syndrome made these works a response to the question of whether parents should proceed with a prenatally diagnosed pregnancy. The direct question of prenatal

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[83] Martha Moraghan Jablow, oral history with the author, November 8, 2018.

[84] Other than some self-published works, I am not aware of any more recent books than *Count Us In* and an updated edition of *Count Us In*, published in 2007.

testing does not come up in either work, although Mitchell Levitz briefly discusses abortion. His statement suggests some consideration of the idea that more knowledge about life with Down syndrome would cause fewer women to terminate pregnancies diagnosed prenatally: "I think a woman should decide whether to have a child or not. Because it is not an issue of the Supreme Court or any of our government leaders to decide. But what we can do to help them is to give them the information that they need, regarding to help them to make a decision."[85] The lack of engagement with the specific topic of prenatal testing perhaps suggests an ambivalence towards abortion restrictions of any kind, similar to what Michael Bérubé described in his memoir *Life as We Know It*.[86]

In a conversation with their fathers, Jason and Mitchell ask about how their parents responded to learning their babies had Down syndrome. Both fathers say they cried, but Charles Kingsley adds:

> I think the reason I cried was I didn't know anything about Down syndrome. I didn't even know the words *Down syndrome* at that time. I'd heard them, but I didn't know what they meant. When you were born, people that had Down syndrome didn't have a lot going for them. But you guys were two of the first kids in this country that started to let people know that people with Down syndrome could learn, could be bright, could be funny, sweet, could be charming, could be terrific kids.[87]

Jason shares that he is familiar with himself and his life being an inspiration for other parents of children with Down syndrome as they make a decision about whether to bring their babies home:

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[85] Kingsley and Levitz, *Count Us In*, 134.

[86] Bérubé's discussion of prenatal testing and abortion is analyzed in Chapter Two.

[87] Kingsley and Levitz, *Count Us In*, 37.

> I guess some parents took their child to our house to talk about how… good… I am. To talk about Down syndrome and their baby. And how do you expect that child's future. And then they see me, how tall I am, how smart I am; and now nice I am and how friendly I am… and after a while, a couple of days, for all the things that I have done,… their decision for their baby to come to their house and have their parents. They feel happy about their baby because of me. That makes me feel proud that I helped them a lot.[88]

For Jason, being an inspirational figure to parents with children with Down syndrome was a positive aspect of his life. Since his and Mitchell's early appearances on *Sesame Street*, they had been involved in advocacy and public awareness work. They routinely appeared in local and national media for their advocacy work with their parents, for Jason and his mother's television work, for the publication of *Count Us In,* and for accomplishments like Mitchell's bar mitzvah.[89]

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[88] Kingsley and Levitz, *Count Us In*, 36.

[89] Lynne Ames, "Westchester Journal," *New York Times*, 1987, Sec. Westchester Weekly; Lynne Ames, "Star Is Born," *New York Times*, 1984, Sec. Westchester Weekly; Eleanor Berman, "'Sesame Street' Boy: Helps The Disabled," *New York Times*, 1981, Sec. Westchester Weekly; Georgia Dullea, "Opening The World To A Generation: Down's Syndrome Children Face Fewer Limitations," *New York Times*, 1989, Sec. Home; Charlotte Evans, "Plan To Shut Retardation Unit Draws Fire: Proposal To Close Mental Retardation Unit Sparks Opposition," *New York Times*, 1980, Sec. Westchester Weekly; Martin Gansberg, "A Father's Dream," *New York Times*, 1984, Sec. Westchester Weekly; Donna Greene, "Mr. Levitz Goes To Washington: Explaining Down Syndrome 'From Our Perspective.,'" *New York Times*, 1992, Sec. Westchester Weekly; Fred M. Hechinger, "About Education: Puppets Teach Sensitivity," *New York Times*, 1978, Sec. Science Times; Roberta Hershens, "Parents Obtaining Early Help With Down Syndrome: 'We Help Them Do The Best They Can.,'" *New York Times*, 1991, Sec. Westchester Weekly; Jodie Jacobs, "Touring Down's Syndrome Authors Make Deerfield A Special Stop," *Chicago Tribune*, March 6, 1994, Sec. Lake; Rita D. Jacobs, "A Son's Disability, Through His Mother's Eyes," *New York Times*, 1987, Sec. Arts & Leisure; Emily Perl Kingsley, "With Maturity Comes Compassion," *New York Times*, 1991, Sec. Westchester Weekly; Luisa Kreisberg, "Down's Syndrome In A Loving Family: Down's Syndrome In A Loving Family," *New York Times*, 1977, Sec. Westchester Weekly; Kate Stone Lombardi, "Walking The Road Of Life In The Face Of A Disability: Living In The Face Of A Disability," *New York Times*, 1994, Sec. Westchester Weekly; Tessa Melvin, "Aid For Parents Of Disabled," *New York Times*, 1982, Sec. Westchester

Charles Kingsley's belief that his son and Mitchell Levitz had shown Americans how great people with Down syndrome could be reflected this commitment from their parents, not only to dedicating themselves to advocacy on behalf of their children, but on including their children as inspirational figures who proved the importance of that advocacy. Given the history of parental activism for intellectual disabilities, including Down syndrome, dating back to the 1940s, Charles Kingsley seems unaware of the antecedents to himself, his wife, and his son. Mitchell Levitz and Jason Kingsley and their parents were certainly active in ending stigma against Down syndrome and in improving services and support for families with a child with Down syndrome. Both families were involved in activism for Down syndrome starting soon after their sons' diagnoses, and Emily Perl Kingsley's position at Sesame Workshop had given her a platform for advocating for disability rights on Sesame Street and elsewhere. Yet *Count Us In* presents a narrative in which their actions are singular and individually exceptional, rather than part of a broader movement of parent activism or disability activism.

A Special Kind of Hero features several discussions of prenatal testing. The show creators, crew, and cast discuss Burke's performance as Corky at length in the text, paying particular attention to the ways that Burke is inspirational specifically to the Down syndrome community and to the broader American public. At one point, a crew member shared that a

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Weekly; John J. O'Connor, "Tv: 'Sesame Street' Takes Some New Directions: Bicentennial Themes And Visits Are Used Special Segments Set For The Retarded," *New York Times*, 1975; John J. O'Connor, "Tv: 'Kids Like These,' About Down's Syndrome," *New York Times*, 1987, Sec. Television; Howard Rosenberg, "'Fall Guy' Casts Real-Life Winner In 'The Winner,'" *Los Angeles Times*, December 19, 1984, Sec. Part Vi; Jacques Steinberg, "Opening A Window Despite A Disability: Writing About A Lifelong Battle," *New York Times*, 1994, Sec. Metro Report; Ellen Tomson, "Rising Above Disability," *Chicago Tribune*, March 23, 1994, Sec. Evening; Cynthia Wetzler, "Meeting The Challenge Of Down Syndrome: An Actor's Habit Of Attaining Milestones. Down Syndrome Challenge," *New York Times*, 1997, Sec. Westchester.

friend had decided after watching the show to keep a baby diagnosed with Down syndrome via amniocentesis.[90]

McDaniel shares the filming of a storyline from *Life Goes On*, in which Patti Lupone's character Libby, Corky's mother, gets pregnant. McDaniel writes about how this spurred a discussion on the show of whether Libby's baby would have Down syndrome, like Corky, which upsets Corky. Libby asks if Corky would want the baby to have Down syndrome, and he has no response. McDaniel does not offer Burke's perspective on this scene, but quotes Lupone: "Nobody's giving him a break; nobody's soft-soaping anything… He just delivered his lines and understood the full effect."[91] A later scene featured Corky crying over the family's joyful response to an amniocentesis that showed the baby did not have Down syndrome. Shooting the film was difficult, according to the episode's writer, because Burke was laughing throughout each take. He suggests that Burke's laughter was due to embarrassment at the emotional nature of the scene.[92] Burke's thoughts on this storyline or how filming went are absent from the text, leaving the meaning of his laughter up to the suppositions of the writer who witnessed it. Patti Lupone's judgment that Burke understood the effect of the storyline stands without input from Burke himself.

The final chapter of *A Special Kind of Hero* looked at Chris's future from his own and his family's perspectives, addressed ongoing issues for people with Down syndrome, including independent living, marriage, parenthood, and employment, and raised the ethical questions of prenatal testing and selective terminations. After McDaniel reports that the majority of pregnancies diagnosed prenatally are aborted, Chris's mother Marian offers her perspective:

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[90] Burke and McDaniel, *A Special Kind of Hero*, 188.
[91] Burke and McDaniel, 202.
[92] Burke and McDaniel, 202.

> Amnio was not yet available when Marian was pregnant with Chris, and she says she is glad she never had to face such a decision. 'No matter when you hear the diagnosis, it is devastating. There is no easy answer for people facing this issue. I wouldn't dare tell someone what they have to do, except that if they have this child, to give them every opportunity to develop. I can say, it's not all that bad. They do bring you a lot of joy. And with all the education and treatment available now, it's not going to be as hard for these kids, or for their parents, as it has been in the past. I was never thrilled that Chris had Down syndrome. I always wanted only the best for my children. I always wished he was normal. We just made the best of it. I cannot imagine not having been given the challenge of Chris, and now being able to feel the pride that I do. I can't imagine life without Chris. He has added so much to our lives; I have a much, much richer life because of him. It is sad to think that because people have a choice, they may not make the right decision.'[93]

Marian's response to the question of prenatal testing is ambiguous. She offers an initial response which refuses to castigate abortion and acknowledges the difficulty of the decision to keep a baby with Down syndrome. She describes having a child with Down syndrome positively, but in a measured way—she admits that she always wished Chris were normal. Yet she concludes that Chris improved her life immensely, and she implies that the decision to terminate a prenatally diagnosed pregnancy is the wrong decision. Chris's perspective on prenatal testing remains absent.

A Special Kind of Hero and *Count Us In* offer a shared argument for the potential that children with Down syndrome have, as reflected through the accomplishments of Chris Burke in acting and Jason Kingsley and Mitchell Levitz in the publication of their book. For parents

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[93] Burke and McDaniel, 243.

seeking a vision of their children's future, these works shed light on the young adult perspective of someone with Down syndrome and assure them of the intellectual and emotional development in their children's future, if they support their children like the Burkes, Kingsleys, and Levitzes have done.

Autism Writes: Extraordinary, Unprecedented, Unthinkable

In 1986, Temple Grandin published her first memoir, *Emergence: Labeled Autistic*. *Emergence* was the first self-authored autism autobiography, disproving a long-held belief that no one with autism would be able to conceptualize such a work and would have sufficient language skills to compose their life story. Co-written with Margaret M. Scariano, *Emergence* traces Grandin's life from her early childhood through her school days to college and her professional career, recounting her changing behavior and growth over time, including the development of her squeeze box. *Emergence* features extended excerpts from letters between Grandin's mother, her psychiatrist, other family members, and her school administrators to illuminate periods of Grandin's life. Grandin's personal experiences are well-analyzed, and she emphasizes her successful career against the prospects that doctors had given her in childhood. As she writes in the introduction:

> Today I am in my late thirties. I am a successful livestock handling equipment designer, one of very few in the world. I am called upon by firms throughout the world to advise and consult and to design special equipment for them. I contribute regularly to the professional journals in my field and speak at professional conferences across the

> country. Presently, I am completing my Ph.D. in Animal Science. My life is normal and totally independent with no financial worries.[94]

Grandin's adult life, in which she appears to have overcome many of the particular challenges of autism, offers the culmination of a narrative of recovery from autism.

In comparison to Down syndrome autobiographies, the field of autism autobiographies—known as "autie-biographies"—is a much larger body of work.[95] Scholars in disability studies, medical humanities, and related fields have analyzed autie-biographies to a much greater extent than the relatively limited attention that works from authors with Down syndrome have received.[96] Scholars have examined works from authors including Temple Grandin, Donna Williams, Dawn Prince-Hughes, and Liane Holliday Willey, analyzing questions of autism and gender, autistic representation, and autism narratives produced through these texts.[97] Although

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[94] Temple Grandin and Margaret M. Scariano, *Emergence: Labeled Autistic* (Novato, Calif.: Arena Press, 1986), 13.

[95] Sidonie Smith and Julia Watson, *Reading Autobiography: A Guide for Interpreting Life Narratives,* Second Edition (Minneapolis: University of Minnesota Press, 2010), 256.

[96] As a rule, much more scholarly attention is paid to autism than to Down syndrome.

[97] For example, Jenny Bergenmar, Hanna Bertilsdotter Rosqvist, and Ann-Sofie Lönngren, "Autism and the Question of the Human," *Literature and Medicine* 33, no. 1 (2015): 202–21; Chris Foss, "Emerging from Emergence: Toward a Rethinking of the Recovery Story in Nine Contemporary Nonfiction Autism Narratives," *Disability Studies Quarterly* 29, no. 2 (April 15, 2009), https://doi.org/10.18061/dsq.v29i2.924; Ian Hacking, "Autistic Autobiography," *Philosophical Transactions of the Royal Society B: Biological Sciences* 364, no. 1522 (May 27, 2009): 1467–73; Ian Hacking, "How We Have Been Learning to Talk About Autism: A Role for Stories," in *Cognitive Disability and Its Challenge to Moral Philosophy* (John Wiley & Sons, Ltd, 2010), 260–78; Jack, *Autism and Gender*; Victoria McGeer, "The Thought and Talk of Individuals with Autism: Reflections on Ian Hacking," in *Cognitive Disability and Its Challenge to Moral Philosophy* (John Wiley & Sons, Ltd, 2010), 279–92; Monica Orlando, "Double Voicing and Personhood in Collaborative Life Writing about Autism: The Transformative Narrative of Carly's Voice," *Journal of Medical Humanities* 39, no. 2 (June 1, 2018): 217–31; Osteen, *Autism and Representation*; Irene Rose, "Autistic Autobiography or Autistic Life Narrative?," *Journal of Literary & Cultural Disability Studies* 2, no. 1 (May 1, 2008): 44–55; Sidonie Smith, "Taking It to the Limit One More Time: Autobiography and Autism," in *Getting a Life: Everyday Uses of Autobiography*, ed. Sidonie Smith and Julia Watson (Minneapolis: University of Minnesota Press, 1996); Natalie Collins Trice, "Reading Autistic Experience"

there are a wealth of autism memoirs, even only from the late 1980s and 1990s, within this chapter, I focus on only three autistic autobiographers—Temple Grandin, Donna Williams, and Sean Barron, each of which received popular attention in the United States. Building upon the scholarship about autie-biographies, I use their writings to find both continuity with autism parent memoirs and the rupture of the recovery paradigm that parents and early autistic autobiographers had cultivated.

Throughout *Emergence*, Grandin provides clear imagery that allows the reader to envisage her thought processes over her life. Doors are an extended motif, literally and figuratively. When in high school, Grandin hears a minister quote John 10:9 — "I am the door: by me if any man enter in, he shall be saved."[98] Temple's internalization of the minister's message led her to pursue a literal door to heaven, which Temple interprets as an adult writing her autobiography as a figurative representation of how she approached changes in her life. Temple scrutinizes every door she encounters looking for *the* door, until she finds a newly constructed door to an addition to her dorm which leads to an observation room at the top of her dorm. When inside the room, she feels immense relief: "For the first time in months I felt safe in the present and hope in the future. A feeling of love and joy enveloped me. I'd found it! The door to my Heaven… A visual symbol. All I had to do was walk through that door. Of course, I didn't realize at the time that I was a visual thinker and need concrete symbols for abstract concepts."[99] The door becomes a literal interpretation of Grandin's religious faith, as well as a

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(Ph.D. diss, Georgia State University, 2008); Mitzi Waltz, "Reading Case Studies of People with Autistic Spectrum Disorders: A Cultural Studies Approach to Issues of Disability Representation," *Disability & Society* 20, no. 4 (June 1, 2005): 421–35.

[98] Grandin and Scariano, *Emergence,* 80.

[99] Grandin and Scariano*,* 80-81.

representation of the uncertainty she was feeling over her future after high school.[100] Doors recur for Grandin at points of transition and growth:

> Actually stepping through a doorway was my means of acting out a decision—like graduating from high school and planning for college. Going through a physical door made abstract decisions real. Symbolically, my door fixation marked the passages in the corridors of time. Because my learning strength was visual, this acting out was a logical extension of that ability.[101]

Grandin's visual thinking, which she consistently identifies as something particular to her autism, is translated for a non-visual reader through these discussions. The seemingly enigmatic elements of autism—such as an obsession with doors—become meaningful and relatable.

As the first book about autism written by an autistic person, *Emergence* was a landmark publication, but it lacked the greater reach of later publications from Grandin and other autistic authors in the 1990s. Arena Press, a division of Academic Therapy Publications, a disability-focused publisher of work for educators, researchers, and parents, published the first edition of *Emergence*. It received little press attention—a brief review in the *Los Angeles Times*, but no other coverage in major newspapers. The quotes on the book jacket come from parents and professionals in the autism community and suggest that these groups are the primary audience for the book, not a wider public. Within this context, Grandin's work in *Emergence* gives greater insight into autism for people who were already familiar with the condition, whether professionally or parentally.

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[100] Grandin and Scariano*,* 85.

[101] Grandin and Scariano*,* 107.

The premise of *Emergence*, according to its introductory framing, dust jacket quotes, and even its title—as Temple has emerged from the label of autism—present the narrative that Grandin's story is a narrative of recovery from autism. The back cover includes references to Temple as "a woman who has overcome a serious disability to lead a normal life" and laud her "triumph over autism."[102] In the foreword to *Emergence*, Bernard Rimland described the book as "the first book written by a recovered autistic individual… Temple's ability to convey to the reader her innermost feelings and fears, coupled with her capacity for explaining her mental processes, will give the reader an insight into autism that very few have been able to achieve."[103] The choice of Rimland, as a prominent parent advocate, to write the book's foreword further supports an understanding of the book's audience as primarily for parents and professionals in autism—Rimland would be well known to anyone involved in the autism in the 1980s. The preface to the book came from William Carlock, one of Grandin's former teachers, bringing insight into her growth from adolescence. Carlock's framing of the significance of the book offered reassurance to parent readers about the potential in similar growth for their children: "Temple has demonstrated, without question, that there is hope for the autistic child—that deep, constant caring, understanding, acceptance, appropriately high expectations, and support and encouragement for what is best in him will provide a base, from which he can grow to his own potential."[104] The promise within *Emergence*—that autistic children can grow up to be productive, independent, successful adults—animates much of the literature on autism from parent authors and holds similarities to the promises of Down syndrome literature.

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[102] William Christopher, quoted in Grandin and Scariano, *Emergence*, back cover; William Carlock, "Preface," in Grandin and Scariano, *Emergence*.
[103] Bernard Rimland, "Foreword," in Grandin and Scariano, *Emergence*, 7.
[104] William Carlock, "Preface," in Grandin and Scariano, *Emergence*, 5.

A distinction between autism and Down syndrome narratives lies in the premise of recovery. Down syndrome narratives emphasize the potential for and rewards of assimilation of Down syndrome within American culture and institutions. The successes of Jason Kingsley, Mitchell Levitz, and, to an extent, Chris Burke are that they are capably living as adults with Down syndrome—working, paying taxes, living independently, in mainstream education, etc. Their diagnosis has not changed and is never in question. In contrast, Rimland and others position Temple Grandin's adult life as proof that autism can be overcome, even though her writing does not suggest that Grandin is no longer autistic. Narratives of recovery are commonly found in parent memoirs and align with the practices of "normalization" that have been popular in autism treatment for decades.[105] As described by autistic writer Penni Winter, normalization "springs out of the belief that Autism is an inferior or 'wrong' state. Thus 'becoming normal' is seen by many parents and therapists as the ultimate goal, the only one worth pursuing."[106] The recovery from autism is the ultimate achievement of normalization. The use of the term recovered suggests that autism was a set of behaviors and managing them successfully, as Grandin was able to do in adulthood, was enough to negate the need for an autism diagnosis. In contrast, while Grandin does describe herself as ceasing certain behaviors, she does not insist that she is no longer autistic. Near the end of *Emergence*, Grandin writes that "as an adult, I have overcome some autistic tendencies—I no longer hit people or 'peep,' but I still have deficit

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[105] Catherine D. Tan, "'I'm a Normal Autistic Person, Not an Abnormal Neurotypical': Autism Spectrum Disorder Diagnosis as Biographical Illumination," *Social Science & Medicine* 197 (January 2018): 161–67; Iris Schneid and Aviad E. Raz, "The Mask of Autism: Social Camouflaging and Impression Management as Coping/Normalization from the Perspectives of Autistic Adults," *Social Science & Medicine* 248 (March 2020): 112826.
[106] Penni Winter, "Loud Hands & Loud Voices," in *Loud Hands: Autistic People, Speaking,* ed. Julia Bascom (Washington, DC: Autistic Self Advocacy Network, 2012), 115.

areas," going on to describe a particular time of difficulty at a conference in Vienna.[107] Grandin offers her life as evidence that "the characteristics of autism can be modified and controlled."[108] Disability scholar Chris Foss argues that Grandin presents her narrative as a clear recovery tale. He cites her introduction to the work, which he describes as "meant to challenge the notion of 'once autistic, always autistic' (8)."[109] However, Foss acknowledges a complexity to Grandin's presentation of the role of her teacher, William Carlock, in whether she recovered or he accepted her: "Significantly, the connection between Carlock and Grandin did not require the latter to emerge from her world into his real world; instead, it is the former who journeys into the world of his friend."[110] *Emergence* can thus be read as a recovery narrative or a narrative of autism acceptance. English professor Mark Osteen has argued that the recovery narrative for early autistic writers reflects a particular dilemma that parent authors share: "how to represent their lives as both uniquely autistic and akin to those of other humans. Perhaps that is why these early autist autobiographers present their accounts as recovery stories—why, for example, Bernard Rimland and William Carlock's prefatory materials emphasize Temple Grandin's 'rescue' from autism."[111] The ambiguity regarding recovery that Grandin's own writing reflects would later become more clearly delineated in her following work.

Along with Grandin's work in the late 80s and 90s, Donna Williams' autobiographies, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic Girl* (1992), *Somebody Somewhere: Breaking Free from the World of Autism* (1994), and *Like Color to the Blind: Soul Searching and Soul Finding* (1996) made her a recognizable figure in the world of autism

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[107] Grandin and Scariano, *Emergence*, 134.
[108] Grandin and Scariano, 13.
[109] Foss, "Emerging from Emergence."
[110] Foss, "Emerging from Emergence."
[111] Mark Osteen, "Introduction," in Osteen, *Autism and Representation*, 26.

literature. Williams was an Australian woman in her late twenties at the time of the publication of *Nobody, Nowhere* who had received a diagnosis of autism at age 26. In her first memoir, she detailed her life before her diagnosis, recounting her memories back to age three and the difficulties she had found with interacting with the world due to her autism. *Nobody, Nowhere* became popular in the United States, and the book was a *New York Times* bestseller for fifteen weeks in 1993.[112]

Like Grandin's work, Williams offers access into the meaning behind her childhood behavior through her writing. Williams writes, "I developed a language of my own. Everything I did, from holding two fingers together to scrunching up my toes, had a meaning, usually to do with reassuring myself that I was in control and no one could reach me, wherever the hell I was."[113] She describes her difficult childhood, including emotional abuse and physical violence from her mother and within her parents' relationship. Williams' response to the violence of her family life was to mimic it. After her mother broke a china dish that Williams had cherished, Williams used a broken piece to cut her own face and express her anger, horrifying her parents. She writes, "Inside my head, what I was doing was completely sane. I didn't know how to cry out for understanding. I was lost and trapped, and I was making a statement."[114] While Temple Grandin's life story included supportive parents, private education, and an early diagnosis of autism, Williams' life story lacks these reassuring aspects. Her coping mechanisms included developing multiple personalities to mimic what she understood to be appropriate behavior in different settings, and Williams writes about all of her personalities in third person. Her writing

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[112] "BEST SELLERS: May 9, 1993," *New York Times*, May 9, 1993, sec. Books.
[113] Donna Williams, *Nobody Nowhere: The Extraordinary Autobiography of an Autistic* (New York: Times Books, 1992), 29.
[114] Williams, *Nobody Nowhere*, 40.

is non-linear and often fragmented, creating a voice that Mark Osteen describes as “blunt, headlong, self-obsessed but curiously unreflective— [Williams’ writing] bespeaks an *autistic* consciousness that rarely generalizes or condenses, shows little comprehension of or interest in how others think, and possesses a weak grasp of narrative connection.”[115]

A common thread in the reception of Grandin's and Williams's work is the idea that they represented a window into the world of autism. The *New York Times* review of *Nobody Nowhere* compared the work to narratives of mental illness, stating, "Accounts such as these illuminate the perplexing and disturbing inner landscape of the mentally ill, revealing to outsides that what may seem bizarre and unpredictable follows its own internal logic, however strange. As one such Baedeker of the troubled mind, Ms. Williams maps a territory that has seemed the most impenetrable of all: the closed world of the autistic."[116] By translating their own behavior into something understandable for the non-autistic reader, Grandin and Williams support the longstanding belief that an intact mind exists within children diagnosed with autism, waiting to be accessed. While many parent memoirists have recounted the successful treatments and therapies that allowed them to "besiege" their children's minds, these autistic autobiographers reveal the inner workings of their autistic behavior from their vantage points as "recovered" adults. Philosopher Ian Hacking, in his examination of four autistic autobiographers, identifies the tendency to describe their work as getting "inside the mind" of an autist as a dangerous concept: "It is the idea of ‘a unique insight into the autistic mind’: as if ‘the autistic mind’ were a species of mind."[117]

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[115] Osteen, *Autism and Representation*, 27.
[116] Daniel Goleman, “A World of Her Own,” *New York Times*, 1993, sec. Book Review.
[117] Ian Hacking, “Autistic Autobiography,” *Philosophical Transactions of the Royal Society B: Biological Sciences* 364, no. 1522 (May 27, 2009): 1467–73.

Williams's work featured similar introductions as Grandin's—Bernard Rimland again wrote a foreword, and Australian psychology and special education professor Lawrence Bartak wrote the introduction. As he did for *Emergence*, Rimland emphasizes Williams' narrative of recovery: "Very few have made the almost superhuman transition from autism to near-normalcy."[118] Bartak's description of Williams is more measured, as he writes that she "has autism and yet has managed to develop into a perceptive and thoughtful adult… Life is still an enormous struggle for [Donna], and she continues to be handicapped in many ways."[119] Bartak emphasizes that bad parenting or familial disruption does not cause autism, highlighting that Donna's memoir "provides a clear account of a disabled child living with a disturbed family without the two sets of unfortunate circumstances being necessarily connected. Donna is clear about this, far more so than many professionals in the field, much to their discredit and the misfortune of their clients."[120] Whether Williams contributed to the refrigerator parenting discourse remains debatable—English professor Mark Osteen cites *Nobody Nowhere* as an example of the trope in the introduction and conclusion to the edited volume *Autism and Representation*.[121] Williams herself is ambiguous on the question—she writes that "people were saying that she had caused me to be so withdrawn by her coldness and her violence. She probably believed this, and I let her. Had I ever wanted to reach out as myself to the intrusive outside world, I am sure she would have inhibited me."[122]

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[118] Bernard Rimland, "Foreword," in Williams, *Nobody Nowhere*, ix.
[119] Lawrence Bartak, "Introduction" in Williams, *Nobody Nowhere*, ix.
[120] Bartak, "Introduction," xviii.
[121] Mark Osteen, *Autism and Representation,* 27; 298.
[122] Williams, *Nobody Nowhere*, 12.

Williams received broad media attention, not only in the United States, but throughout the English-speaking world.[123] Along with reviews in the *New York Times* and other national media, she was profiled in the CBS nighttime news program *Eye to Eye with Connie Chung* and featured as the Person of the Week on *ABC World News Tonight* with Peter Jennings.[124] These TV news features portrayed Williams as a hero to families with autistic children. Media coverage hailed Williams for her ability to act as an interpreter of autism. Jennings described Williams' significance, saying, "Many autistic children can't talk at all, which is unspeakably frustrating to their parents, which is why so many of them will be moved by Ms. Williams' eloquence. As one father of a grown autistic child said, 'I only wish I had been able to read it 25 years ago.'"[125] In the longer *Eye to Eye* segment, Williams's interview was juxtaposed with footage of children footage of autistic children at the Eden Institute in New Jersey. Williams offered her interpretation of the children's behavior, suggesting to the reporter that "some children who appear to have no language have language on their own and disguised in their own way." At the end of the *Eye to Eye* segment, Chung asked Edie Magnus, the reporter, "Edie, Donna's story is just so incredible. Could other autistic children 'come out of it' to the extent that she did?" Magnus replied, "It's really not clear. Certainly not all autistic children are as, quote-unquote, "high-functioning" as Donna. However, she says there may be a lot more going on in the minds of some of these autistic youngsters than anybody realizes. And if you can learn how to approach

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[123] A particular point of contention became questions over whether Williams was truly autistic, which played out in the Australian press following the publication of her second autobiography, *Somebody Somewhere*. Pitt, Helen. "Experts Raise Doubts over Author's Autism." *Sydney Morning Herald*. July 30, 1996.

[124] "A World Apart; Donna Williams' Struggles with Autism Aids Researchers in Understanding Others," CBS News Transcripts, *Eye to Eye with Connie Chung* (CBS, March 10, 1994; "Person of the Week: Donna Williams," ABC News Transcripts, *ABC World News Tonight with Peter Jennings*, December 4, 1992.

[125] "Person of the Week: Donna Williams."

them, how to speak their language, you may be able to reach them, and they may be able to reach back."[126]

Another notable autism autobiography of the 1990s was *There's a Boy in Here*, a collaboration between Sean Barron, a 30-year-old autistic man, and his mother, Judy Barron. Alternating between their voices, the book integrates the parent memoir with the autistic autobiography. Like *Nobody Nowhere* and *Emergence*, *There's a Boy in Here* constructs a narrative of recovery from autism that echoes and furthers the arc of *The Siege*, as a mother's love and determination rescues her child from the mystery and tragedy of autism. As Judy writes in the book's preface, "No matter what the statistic said, despite the horror of the prognosis, we caught rare and fleeting glimpses of a helpless child trapped inside the bizarre behavior of Sean's autism, and we were determined to get him out. Eventually we turned away from the professionals and followed our own instincts and common sense."[127] Judy's writing is consistent with the tropes established in the parent memoir literature—parents are the key to their children's improvement—while Sean provides the kind of explanatory insight into his behavior that Temple Grandin and Donna Williams also offer in their first works.

While they carefully avoided describing Sean as cured, Judy and Sean Barron emphasized the narrative of recovery in the press coverage of their book. While Sean stated, "I know quite well that my autism will always be part of me, that it isn't something I can expect to be 'cured,'" the message of recovery aligned with the conversion narratives of prominent parent memoirs, including *Son-Rise* and *Let Me Hear Your Voice*.[128] A feature on the power of parental

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[126] "A World Apart."

[127] Barron and Barron, *There's a Boy in Here*, viii.

[128] Barron and Barron, 254. For more on conversion narratives, see Fisher, "No Search No Subject?"; also discussed in Chapter Two of this dissertation.

strength in the face of adversity in *Good Housekeeping* encouraged other parents to have hope, despite the caution of experts: “Experts say fewer than one percent of autistic people recover as fully as Sean—but he refuses to accept statistics. ‘You can't put limits on the human spirit,’ Sean tells listeners in speeches across the country. ‘It's capable of things we never would have imagined.’”[129] *People* magazine profiled Sean and Judy, writing that "Some remnants of Sean’s autism do linger,” but describing his recovery from autism as “near miraculous.”[130] Reviews of the book referred to Sean as having overcome his autism, using metaphors including that he escaped autism’s prison and climbed out of his own private hell.[131]

The promise of recovery that shaped Grandin’s, Williams’s, and Barron’s works in the late 80s and early 1990s was absent in Grandin’s follow-up, *Thinking in Pictures and Other Reports from My Life with Autism*. Grandin begins *Thinking in Pictures* with a distinct declaration of difference. Beginning with the title, Grandin emphasizes that, unlike many non-autistic people who may be reading, she thinks visually, not verbally. She notes that this distinction makes her subject to “one of the most profound mysteries of autism… the remarkable ability of most autistic people to excel at visual spatial skills while performing so poorly at verbal skills.”[132] Grandin explains her professional success as a direct result of her ability to visualize ideas: “Visual thinking has enabled me to build entire systems in my imagination.

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[129] Marianne Jacobbi, “The Courage to Carry On,” *Good Housekeeping*, March 1993, 136.

[130] K. Hubbard, “Winning the War Within,” *People*, March 23, 1992.

[131] Karen Stabiner, “Non Fiction,” *Los Angeles Times*, April 5, 1992, sec. Book Review; Book Review Desk; “There’s a Boy in Here,” *Publishers Weekly* 239, no. 3 (January 13, 1992): 42–43; Barbara Hoffert, “There’s a Boy in Here: A Mother and Her Son Tell the Story of His Emergence from Autism (Book),” *Library Journal* 116, no. 19 (November 15, 1991): 69–69; David C. Taylor, “Bookshelf,” *Lancet* 339, no. 8809 (June 27, 1992): 1593,; Dorothy Addison, “Book Reviews: Adult Books for Young Adults,” *School Library Journal* 38, no. 7 (July 1992): 98; Nina Darnton, “Tales from Another World,” *Newsweek* 119, no. 20 (May 18, 1992): 70.

[132] Temple Grandin, *Thinking in Pictures and Other Reports from My Life with Autism*, 1st edition (New York: Doubleday, 1995), 19-20.

During my career I have designed all kinds of equipment, ranging from corrals for handling cattle on ranches to systems for handling cattle and hogs during veterinary procedures and slaughter. I have worked for many major livestock companies. In fact, one third of the cattle and hogs in the United States are handled in equipment I have designed."[133] Her memoir thus begins with a clear demonstration of the value that Grandin's autism has to her professionally, along with an extended insight into how Grandin thinks, how she learned words, and how she understands written materials.

Throughout *Thinking in Pictures*, Grandin explores different aspects of autism, from varying diagnostic criteria to sensory problems to possible treatments to relationships, using her own experiences along with scientific research and popular accounts of the condition to illustrate the complexity of the diagnosis. Grandin uses her work to allow a non-autistic reader to understand her and other autistic persons' behaviors. She describes the frustration of being a non-verbal three year old, writing, "I could understand what people said to me, but I could not get my words out. It was like a big stutter, and starting words was difficult… I can remember logically thinking to myself that I would have to scream because I had no other way to communicate."[134] Grandin references parent memoirists and their accounts of their children to add her own insights into their descriptions, as in a description of Ted Hart from his father's book, *Without Reason*. Grandin explains that Ted "has almost no ability to generalize and no flexibility in his behavior."[135] He learned to do laundry by rote, without understanding the logic of the steps. Once, when the dryer broke, he simply moved the wet clothes to his chest of drawers. Grandin speculates that "such rigid behavior and lack of ability to generalize may be

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[133] Grandin, *Thinking in Pictures*, 19.
[134] Grandin, 44.
[135] Grandin, 37-38.

partly due to having little or no ability to change or modify visual memories.[136]" Grandin becomes an ambassador for the world of autism through these insights. She uses her own autism to open up the possibilities of the autistic mind and autistic reaction and behaviors to her non-autistic audience, challenging expectations that autistic people had no inner lives.

Grandin offers greater insight into the symbolic meanings of her visual thoughts in *Thinking in Pictures*, building upon the motif of doors that ran throughout *Emergence*. Saying that she no longer used physical doors to symbolize transitions, Grandin writes, "When I reread years of diary entries while writing this book, a clear pattern emerged. Each door or gate enabled me to move on to the next level. My life was a series of incremental steps. I am often asked what the single breakthrough was that enabled me to adapt to autism. There was no single breakthrough. It was a series of incremental improvements."[137] Grandin recognizes that the symbolism that she, like other autistic people, had used throughout her life to make sense of the world is unusual, but she asks the reader to recognize its value: "Many people are totally baffled by autistic symbols, but to an autistic person they may provide the only tangible reality or understanding of the world. For example, 'French toast' may mean happy if the child was happy when eating it. When the child visualizes a piece of French toast, he becomes happy. A visual image or word becomes associated with an experience."[138] Through these explanations, Grandin invites the reader to grapple with a way of thinking—and a way of being—that has meaning where previously autistic thoughts and associations have been considered nonsensical.

Unlike her earlier writing with Margaret Scariano, Grandin wrote *Thinking in Pictures* without a co-writer, allowing her unadorned prose to reach the reader without the mediation of a

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[136] Grandin, 37-38.
[137] Grandin, 35.
[138] Grandin, 37.

non-autistic writer. Osteen marks the stylistic differences between the flowery language of *Emergence* and the straightforward style of *Thinking in Pictures*, attributing the former to Grandin's co-author, Margaret Scariano.[139] Reviewing *Thinking in Pictures* for *The Village Voice,* Stacey D'Erasmo described the difference between the two work. While *Emergence* has a narrative drive that the essays of *Thinking in Pictures* lacks, "it is as if, in the second book, Grandin has replaced the teleology of autobiography with something much closer to her heart: a diagram, in this case a diagram of her own mind."[140]

Thinking in Pictures was published almost a decade after *Emergence* by Doubleday, a much larger outfit than the earlier work's niche educational publisher. It offers its readers insight into autism without the expectation that they will already be intimately familiar with the diagnosis. By 1995, Grandin's profile had risen beyond the specific world of autism, and her work—both concerning autism and cattle handling—received coverage in local and national media.[141] Neurologist and writer Oliver Sacks first brought Grandin into wide public attention

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[139] Osteen, "Introduction,", 26.

[140] Stacey D'Erasmo, "The Comfort of Strangeness," *The Village Voice*, November 7, 1995.

[141] Elizabeth Abbott, "Book Review Thinking In Pictures: And Other Reports From My Life With Autism," *The Globe And Mail*, December 4, 1995; Ellen J. Bartlett, "Moozak In Barnyard — Who's Listening? There's No Proof, But Most Are Sure Animals Love It," *The Boston Globe*, January 1, 1990, Sec. Health And Science; Alison Bass, "'Rain Man' Illuminates Autism," *The Boston Globe*, December 23, 1988, Sec. Living; Harvey Blume, "Autistics, Freed From Face-To-Face Encounters, Are Communicating In Cyberspace.," *New York Times*, June 30, 1997, Sec. Business; Brent Bowers, "Cracking The Shell: An Intensive Therapy For Autistic Children Yields Gains And Hope," *The Wall Street Journal*, May 20, 1992; Susan Campbell, "Autistic Woman Gives Strong Description Of Life," *The Columbian*, November 12, 1995, Sec. Life; D'Erasmo, "The Comfort Of Strangeness"; "Hardcovers In Brief," *The Washington Post*, January 28, 1996, Sec. Book World; Laurie Goering, "Top Cattleman Is Out To Rope In More Beef Eaters: Association Attempts To Ride Herd On Public's Opinion Of Red Meat," *Chicago Tribune*, June 5, 1994, Sec. Business; Warren King, "Breaching The Barriers Of Autism," *Los Angeles Daily News*, March 10, 1996, Sec. News; Mary McGrory, "Silence From The Heart," *The Washington Post*, April 21, 1991, Sec. Outlook; Billy Porterfield, "Petty Desolations Of Daily Life Take Biggest Bite Out Of The Human Spirit," *Austin American-Statesman*, December 30, 1993, Sec. City/State; Anne Raver, "Qualities Of An Animal Scientist: Cow's Eye View And

through his 1993 *New Yorker* profile of her, “An Anthropologist on Mars,” subsequently republished in Sacks’ book of the same name. G. Thomas Couser describes *An Anthropologist on Mars* as “probably the book on which Sacks’s contemporary reputation rests.”[142] The title came from Grandin’s description of how she felt navigating and observing human interactions. Sacks described Grandin as “one of the most remarkable autistic people of all,” emphasizing her professional and academic accomplishments.[143] Sacks was clearly impressed by Grandin, and his profile is both flattering and insightful about her condition and her life. He writes about the status of *Emergence* within the autism community as a work that merited both suspicion and awe:

> I had, of course, heard of Temple Grandin—everyone interested in autism has heard of her—and had read her autobiography, “Emergence: Labeled Autistic,” when it came out, in 1986. When I first read the book, I could not help being suspicious of it: the autistic mind, it was supposed at that time, was incapable of self-understanding and understanding others, and therefore of authentic introspection and retrospection. How could an autistic person write an autobiography? It seemed a contradiction in terms.[144]

Sacks’s initial suspicions led him to wonder if the particularly notable qualities of *Emergence*—“its coherence, its poignancy, its often “normal” tone”[145]—were Grandin’s coauthor, Scariano’s doing. His mind changed when he read more of Grandin’s writings and became convinced of her quality of her mind and her abilities.

Autism,” *New York Times*, August 5, 1997, Sec. Science; “Specialist: Cattle Raised Humanely,” *The Associated Press*, December 8, 1997; Kimberly A. C. Wilson, “Attitude Main Factor In Humane Livestock Slaughter,” *The Associated Press*, August 12, 1994.

[142] Couser, *Vulnerable Subjects*, 105.

[143] Oliver Sacks, “An Anthropologist on Mars,” *The New Yorker*, December 27, 1993.

[144] Sacks, “An Anthropologist on Mars.”

[145] Sacks, “An Anthropologist on Mars.”

In the foreword to *Thinking in Pictures*, Sacks reflected on the significance of *Emergence* as the first book by an autistic author, describing it as:

> extraordinary, unprecedented, and… unthinkable. Unprecedented because there had never before been an "inside narrative" of autism; unthinkable because it had been medical dogma for forty years or more that there *was* no "inside," no inner life, in the autistic, or that if there was it would be forever denied access or expression; extraordinary because of its extreme (and strange) directness and clarity. Temple Grandin's voice came from a place which had never had a voice, never been granted real existence, before—and she spoke not only for herself, but for thousands of other, often highly gifted, autistic adults in our midst. She provided a glimpse, and indeed a revelation, that there might be people, no less human than ourselves, who constructed their world, lived their lives, in almost unimaginably different ways.[146]

Sacks writes about Grandin as an example of the "'higher' forms of autism" identified by Hans Asperger in 1944, requiring readers of her memoir to reconcile Grandin's achievements, insights, and appeal with their existing, likely-negative conception of autism. Sacks compares *Emergence* to *Thinking in Pictures*, finding the latter superior as a written work and as a more emotionally complex work.[147] Sacks's foreword emphasizes Grandin's difference from non-autistic readers:

> If Temple is so profoundly different from most of us, she is no less human for being so, but, rather, human in another way. *Thinking in Pictures* is finally a study of identity, the "who-ness" no less than the "what-ness" of a most gifted autistic person. It is a deeply

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[146] Oliver Sacks, "Foreword," in Grandin, *Thinking in Pictures*, 11.
[147] Sacks, "Foreword," 14.

> moving and fascinated book because it provides a bridge between our world and hers, and allows us a glimpse into a quite other sort of mind.[148]

According to Sacks, Temple Grandin is remarkable because of the uniqueness of her mind, which makes her both fully human and yet fully apart from the expectations of the non-autistic mind.

Unlike the recovery narratives of earlier autism memoirs and ongoing parent narratives, *Thinking in Pictures* anticipates a new paradigm for understanding autism: neurodiversity. Informed by the social model of disability, Australian sociologist Judy Singer coined the term neurodiversity, from neurological diversity, while writing her honors thesis in the late 1990s. In 1999, Singer wrote, "The key significance of the "autism spectrum" lies in its call for and anticipation of a politics of neurological diversity, or neurodiversity. The "neurologically different" represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability."[149] Singer's call to recognize the significance of diversity within the way the mind works offered a paradigm shift for autistic adults: rather than viewing autism as a pathological problem that requires interventions—medical and otherwise—to fix, the neurodiversity movement accepts all forms of autism as valid and worthwhile ways of existing in the world, arguing that "disability results not from autism itself but instead from living in a society which tends to be physically, socially and emotionally inhospitable towards autistic people."[150] This radical reordering of the meaning of autism—not

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[148] Sacks, "Foreword," 16.

[149] Judy Singer, "Why Can't You Be Normal for Once in Your Life? From a 'Problem with No Name' to the Emergence of a New Category of Difference," in *Disability Discourse*, ed. Mairian Corker and Sally French (Buckingham, England, and Philadelphia: Open University Press, 1999), 64.

[150] Jacquiline den Houting, "Neurodiversity: An Insider's Perspective," *Autism* 23, no. 2 (February 1, 2019): 271.

intrinsically damaged, but a valuable site of differences that are made disabled through the failures of society—aligns with Temple Grandin's presentation of her own and others' autism throughout *Thinking in Pictures*.

Conclusion

Between the 1960s and the 1990s, autobiographical life writing from authors with Down syndrome and autism reflected major transitions for the rights, meaning, and experience of people with these two conditions in American society. For the earliest works by writers with Down syndrome, Nigel Hunt and Paul Scott, the publication of their writing aimed to demonstrate the educability of children with Down syndrome. Throughout both Hunt and Scott's texts, a third-party voice—Hunt's father in the former; a professor of education in the latter—interjects, explaining the meaning of certain passages and asserting the literary, educational, or personal significance of the writing. This mediator furthers the intention behind the books: to offer a representative success story for Down syndrome who proves that children with Down syndrome can and should be educated.

While both works received some critical acclaim, *The World of Nigel Hunt* in particular found recognition of its significance from parents, critics, and disability scholars. *Yesterday Was Tuesday, All Day and All Night* was perhaps a victim of Paul Scott's literacy, so remarkable in his time. Born in the 1920s, amidst widespread institutionalization and two decades before parent advocacy around deinstitutionalization, education, and community inclusion would begin, Scott's educational opportunities and access were singular. His diary, kept over decades, was unbelievable in the early 1960s, even to some advocates for disability education. In contrast, Nigel Hunt's birth in the late 1940s gave him and his parents entre into the burgeoning movement of parent advocacy. His parents' refusal to institutionalize Nigel and dedication to his education aligned with the actions of other families. Nigel's successful authorship of an autobiography gave evidence to the work of these parents and the professionals who did support them. Furthermore, Douglas Hunt could and did position Nigel's story as one in opposition to institutionalization, using his and his wife's commitment to their child as proof of the value of community integration and mainstreaming in education. May Seagoe, the UCLA special education professor who edited and published Paul Scott's diaries, did not argue for such a clean, anti-institutional message. Her conclusions about Scott's case reflect a belief in the inevitability of institutionalization and a justification for parents and professionals who continued to institutionalize their children. Seagoe's ambivalence around institutionalization coupled with the unprecedented nature of Scott's literacy made *Yesterday Was Tuesday* a less obviously inspirational or reassuring book for parents than *The World of Nigel Hunt*.

Three decades later, Chris Burke, Mitchell Levitz, and Jason Kingsley had all benefitted from the expansion of educational opportunities afforded to children with Down syndrome. Their writing no longer reflected a need to prove itself as authentic evidence of the intellectual capacity of people with Down syndrome. Instead, Burke's biography offered an inspirational narrative about the accomplishments of the most prominent actor with Down syndrome in history, while Kingsley and Levitz offered readers their reflections on life, love, family, disability, and even politics. As parent and English professor Alison Piepmeier wrote of *Count Us In,* "It shows people with intellectual disabilities in a different light, as capable of complex thoughts, feelings, desires, and concern for others."[151] Other parents and scholars share Piepmeier's belief in the influence of *Count Us In* to challenge the stigmatization of Down syndrome and intellectual

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[151] Alison Piepmeier with George Ostrich and Rachel Adams, *Unexpected: Parenting, Prenatal Testing, and Down Syndrome* (New York: NYU Press, 2021), 14.

disabilities more broadly and the power of self-representation in Down syndrome life narratives to reflect the complexity of people with Down syndrome. Ignoring the earlier writings of Nigel Hunt and Paul Scott, in *Life as We Know It*, Michael Bérubé heralded the development of the Down syndrome autobiographical genre as an important political act: "Until these books appeared, people with Down syndrome had to rely for their representation on the talents and goodwill of people without Down syndrome; henceforth Jason and Mitchell and Chris and their peers can—and will—speak in their own voices."[152]

Across a much shorter time span, autistic autobiographies emerged in the late 1980s into the existing landscape of autism literature of recovery narratives, dominated by parent memoirs. Early works, including autobiographies from Temple Grandin and Donna Williams, conformed to an expectation of recovery, their books shaped by the message that autism can be overcome. While the autistic autobiographical text from these authors tended to be more ambiguous than a clear conversion narrative, the framing of such publications in introductory materials, book jacket quotes, and media coverage was unambiguous about the promise of recovery that these works contained. Controversial parent researcher Bernard Rimland, well known in the autism parent advocacy and research community, wrote forewords for both Grandin's and Williams's first books describing them as adults recovered from autism.

These recovery narratives quickly gave way to a new paradigm for understanding autism, which would come to be known as neurodiversity. In her second book, 1996's *Thinking in Pictures*, Temple Grandin—writing without a co-author—unambiguously describes herself as autistic and shares throughout the book how she "adapt[ed] to autism," rather than how she

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[152] Bérubé, *Life as We Know It*, 263.

recovered from or overcame autism.[153] The difference between *Emergence: Labeled Autistic* and *Thinking in Pictures and Other Reports from My Life with Autism* is evident from the books' titles. In the former, Grandin was labeled autistic—a description, not an identity—and she has since emerged into the non-autistic world. In the latter, Grandin emphasizes a major aspect of her life with autism—her visual thinking—and promises to share others. The title emphasizes Grandin living with autism, rather than suggesting she has overcome it. This is consistent with the foreword for *Thinking in Pictures*. Unlike *Emergence*'s reliance on Bernard Rimland, *Thinking in Pictures* features Oliver Sacks's meditation on Grandin as an autist and the ways that she exists in the world.

Autobiographies of autism and Down syndrome share certain narrative features. Works in both genres emphasize the achievements of the authors, particularly sharing ways in which they have found success in adulthood and with the potential to create narratives that promote the image of the disabled author as a "supercrip." However, these life narratives differ in the arguments that they make for the relationship of each diagnosis to society. Within Down syndrome narratives, authors stress their own assimilation into the institutions of contemporary American life. Rather than highlighting the particularities of life with Down syndrome, they focus on the commonalities of life between people with and without Down syndrome. Autism autobiographies differ whether in appealing to a recovery narrative or fostering the neurodiversity paradigm. Early autism narratives' emphasis on recovery used the authors' adult successes as evidence that they had overcome autism—unlike the writers of Down syndrome narratives, for whom Down syndrome was a constant, under this narrative structure the diagnosis of autism no longer applied to such writers. Temple Grandin's *Thinking in Pictures* marked a

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[153] Grandin, *Thinking in Pictures*, 35.

change in the autism autobiography that articulated the distinctiveness of autism throughout the lifespan. Rather than either assimilation or recovery, Grandin and others cultivated a new meaning for an autistic identity through the understanding of neurodiversity.

EPILOGUE

By the year 2000, the landscape for autism and Down syndrome looked radically different to fifty years earlier. The emergence of the neurodiversity movement offered autists a discourse for expressing the sense of autistic identity that they had developed over the 1990s. Events like autistic activist Jim Sinclair's 1993 speech to the International Conference on Autism in Toronto, "Don't Mourn for Us," recast autism not as a tragedy, but as a different way of being. Sinclair invited parents to cease grieving over autism as a tragedy, but to join autistic adults in understanding what autism is, celebrating their children's strengths, and advocating for autistic people's needs.[1] Neurodiversity gave a name to this understanding of autism and a united purpose to autistic activists.

In the compilation *Loud Hands: Autistic People, Speaking*, psychology professor and disability scholar Nick Walker defines the neurodiversity paradigm in contrast to the pathology paradigm. The pathology paradigm assumes that there is a rigid, narrow range of “normal” neurological configuration and functioning and any deviation from that standard reflects an inherent wrongness, which leads to the definition of autism as a disorder, a crisis, an epidemic, requiring interventions that train an autist to act “normal.” According to Walker, the neurodiversity paradigm has two fundamental principles:

> 1. Neurodiversity—the diversity of brains and minds—is a natural, heathy, and valuable form of human diversity. There is no “normal” style of human brain or human mind, any more than there is one “normal” race, ethnicity, gender, or culture.

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[1] Jim Sinclair, “Don’t Mourn For Us,” *Our Voice*, 1993, http://www.autreat.com/dont_mourn.html.

2. All of the diversity dynamics (e.g. dynamics of power, privilege, and marginalization) that manifest in society in relation to other forms of human diversity (e.g., racial, cultural, sexual orientation, and gender diversity) also manifest in relation to neurodiversity.[2]

Although the neurodiversity paradigm incorporates the full breadth of human neurological variation, including intellectual and developmental disabilities, it is most commonly associated with autism.

At the same time as the neurodiversity movement grew, the rate of autism diagnoses was increasing.[3] The media breathlessly covered the autism "epidemic."[4] Parents organized around the goal of finding the cure for autism, forming groups including Autism Speaks and Defeat Autism Now! While neurodiversity advocates called for the recognition of autism as a valid and valuable aspect of human diversity, parent organizations promoted an idea of autism as a looming threat that would steal away America's children and ruin families.[5] Etiological theories that blamed vaccines for causing autism flourished in the space that parents had created through the twentieth century for their authoritative voice.

The histories of Down syndrome and autism diverge in the twenty-first century. While autism's cultural relevance has grown at an accelerated rate since 2000, Down syndrome has not experienced a similar lasting prominence. In the 1990s, mainstream cultural depictions of Down syndrome suggested a promising future—the primetime ABC family drama *Life Goes On* starred

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[2] Nick Walker, "Throw Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm," in *Loud Hands,* 228.
[3] Eyal et al, *Autism Matrix.*
[4] For example, Morton Ann Gernsbacher, Michelle Dawson, and H. Hill Goldsmith, "Three Reasons Not to Believe in an Autism Epidemic," *Current Directions in Psychological Science* 14, no. 2 (April 2005): 55–58; Sandra Blakeslee, "Prevalence of Autism Growing," *New York Times*, December 31, 2002, sec. Health; "A Mysterious Upsurge in Autism," *New York Times*, October 20, 2002, sec. Opinion.
[5] Carey, Block, and Scotch, *Allies and Obstacles*, 95-100.

an actor with Down syndrome. Jason Kingsley and Mitchell Levitz's *Count Us In* seemed to promise further written works directly from authors with Down syndrome. Such promises have not materialized—although actors with Down syndrome have appeared in supporting roles on network television, *Life Goes On* remains the only show of its kind; Levitz and Mitchell's work stands as a solitary offering, rather than part of a robust genre. Questions of the morality and legality of prenatal diagnosis and selective abortion for Down syndrome continue to center the condition as a concern of pregnancy, rather than examining the lives and experiences of children and adults with Down syndrome. After Gerber selected the first Gerber baby with Down syndrome in 2018, a Washington Post opinion writer used the event in the lede to her editorial, "I would've aborted a fetus with Down syndrome. Women need that right."[6] While parent memoirists have worked to cultivate positive expectations of what life with a child with Down syndrome is like—the message that such a child is a blessing, or an eternal innocent, or a source of joy—their efforts have failed to establish a meaningful, dominant cultural recognition of Down syndrome as an expected, worthwhile element of humanity. As one mother wrote in her 2016 memoir, when considering amniocentesis, she did not know much about Down syndrome: "I just knew that Down syndrome was part of the list of things you don't want your kid to have—right up there with spina bifida and Tay-Sachs—and that my unborn child had a 1 in 214 chance of getting it, according to this doctor."[7]

For parents of children with autism and Down syndrome in the twenty-first century, the Internet has transformed the available avenues of information gathering and community building

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[6] Ruth Marcus, "I Would've Aborted a Fetus with Down Syndrome. Women Need That Right.," *Washington Post*, March 9, 2018.

[7] Amy Silverman, *My Heart Can't Even Believe It: A Story of Science, Love, and Down Syndrome* (Bethesda, MD: Woodbine House, 2016), 14.

that are easily accessible. Facebook groups, blogs, YouTube videos, message boards, Twitter, and Reddit are among a panoply of ways to connect with other parents in addition to—or instead of—joining a parent organization or reading memoirs and guidebooks. These opportunities for establishing what Nikolas Rose and Carlos Novas call "an active scientific citizenship" allow parents to engage with each other, the medical establishment, and a vast body of biomedical information to create their own expertise on the subject of autism or Down syndrome.[8]

The genre of parent memoirs has continued to grow in the twenty-first century. Earlier works reflected the specific concerns of their time, including parents' rejection of the refrigerator mother theory, their support for anti-institutionalization and the educability of children with autism and Down syndrome, and various beliefs in treatment options. The motivations of more recent, popular memoirs share certain aspects with earlier memoirs, including what Alison Piepmeier identified as "excessive grief" over the child's condition.[9] They also illuminate specific ways that the experience of parenting a child with autism or Down syndrome, and the meaning of each diagnosis, has changed, as well as the significance of the history of parent narratives to creating the spaces that parents currently occupy in the autism and Down syndrome community. In this epilogue, I will explore two memoirs to illustrate these differences, recognizing that the expansive material published by parents alone in the past two decades cannot be adequately covered here.

The most prominent parent advocate for autism in the twenty-first century has been Jenny McCarthy. McCarthy is an actress, writer, and television host whose son was diagnosed with

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[8] Nikolas Rose and Carlos Novas. "Biological citizenship," in *Global assemblages: Technology, politics and ethics as anthropological problems*, Eds. Aihwa Ong and Stephen Collier (Malden, MA: Blackwell, 2005), 439–463.

[9] Piepmeier, "Saints, Sages, and Victims."

autism in 2005. In 2007, she published *Louder than Words: A Mother's Journey in Healing Autism*, her story of she cured her son's autism through her reliance on her "mommy instinct" and rejection of the medical establishment's prescriptions on diagnosis, treatment, and causes of autism. After her son, Evan, had several seizures and received a diagnosis of epilepsy, McCarthy searched for a diagnosis that fit with her beliefs about his condition, finding a neurologist who diagnosed him with autism. With this diagnosis, McCarthy turned to other mothers and the Internet for information about autism and strategies to treat her son, describing her method of research as "the University of Google."[10] She concluded that Evan was born with a weakened immune system, which led to vaccines causing him to develop autism. In her memoir, McCarthy recalls seeking a variety of treatment options for her son, including behavioral and speech therapy, along with alternative treatments including a restrictive diet, antifungal drugs, a homeopathic metal detox, and a scent therapy called mapping. Following these treatments, when a state evaluator comes to assess Evan for his eligibility for disability services, she finds Evan’s improvement shocking, saying, "This isn't autism anymore. I don't understand what happened. We have never seen a recovery like this."[11] By the end of the book, McCarthy writes that Evan is "no longer stuck in the world of autism... for the most part, you would never be able to pick him out of a crowd as being a little unique."[12] *Louder than Words* reached number three on the New York Times best seller list, and McCarthy promoted the book and her message in a variety of media, including appearances on the *Oprah Winfrey Show*, *Larry King Live,* and *Good Morning*

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[10] Jenny McCarthy, *Louder Than Words: A Mother’s Journey in Healing Autism* (New York: Dutton, 2007), 166.
[11] McCarthy, *Louder than Words*, 186.
[12] McCarthy, 186-87.

America, and cover stories for People magazine.[13] The ubiquity of her story in American culture led one journalist to write after her book's publication, "McCarthy's impact on the autism community... has been so dramatic that some are referring to this period as 'After Jenny.'"[14]

Louder than Words fit neatly into the recovery narrative path that so many autism parent memoirs follow. McCarthy built upon the mistrust of the medical establishment that had grown among parents of autistic children since the days of Bettelheim and the refrigerator mother theory. Her insistence on her maternal instincts as the guiding force for her son's recovery recalls the second-wave feminist health activists who wrote the 1978 parenting guidebook *Ourselves and Our Children* as a follow-up to *Our Bodies Ourselves*, based on the belief in the collective wisdom of parents, rather than experts.[15] Her reliance on alternative treatments and belief in vaccine causation recalls Bernard Rimland's promotion of such ideas through his Autism Research Institute and written work. As a prominent, albeit controversial, figure in the autism community, McCarthy situated herself in a space that parents had already created and amplified their messages.

McCarthy's trust in other mothers, many of whom she found on the Internet, reflects a key change in the circulation of information on autism. While earlier parents found community through parent organizations, memoirs, and guidebooks, mothers by the 2000s could find all the information, community, and advice they ever wanted on the Internet. Historian Elena Conis describes online websites, forums, and gathering spaces as both "an invaluable source of community" and "also a powerful tool for creating and disseminating 'experiential knowledge,'

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[13] "Best Sellers," *New York Times*, October 14, 2007, F30; Jenny McCarthy, "My Autistic Son," *People* Vol. 68 Issue 14, October 1, 2007, p120-129.

[14] Julie Deardorff, "Jenny McCarthy Touts Autism Hope Against Tall Odds," *Chicago Tribune* October 21, 2007.

[15] Conis, *Vaccine Nation*, 114.

the form of knowledge production cultivated by the women's health movement three decades before."[16] While this online activity has one set of roots in feminist health activism, it also develops an ongoing process of parental expertise-making that has occurred within autism parent communities since at least the foundation of the National Society for Autistic Children in 1960 and the publication of *The Siege* in the 1960s and *A Child Called Noah* in the 1970s: by this standard, parents, not professionals, are the best experts on autism.

McCarthy dedicated her following book, *Mother Warriors*, to her fellow parents fighting for their autistic children. She expressed her belief in the value of her and other parents' experiences of autistic regression following vaccination and her dismay that practitioners would reject such parent knowledge. "This is how black and white it is for us kids who have children with autism. We had healthy beautiful children who climbed up stairs perfectly until one stair caused them to fall. We have witnessed the neurological downfall of our children after certain vaccinations, but when we tell the doctors what we saw, they don't believe us. Can you imagine how frustrating this is?"[17] Elena Conis and Mark Largent have examined McCarthy's significance to the debate over the vaccine-autism link, placing her within a longer history of anti-vaccination movements in the United States.[18] Her memoirs, and related media coverage, further illuminates her place in a longer history of autism and the role of autism parent memoirs in establishing parental authority over the meaning of autism to American society. McCarthy insisted upon the validity of her belief that vaccines caused her son and other children to develop autism despite the scientific consensus that such a link was unfounded and such arguments were

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[16] Conis, 214.

[17] Jenny McCarthy, *Mother Warriors: A Nation of Parents Healing Autism Against All Odds* (New York: Dutton, 2008), 21.

[18] Conis, *Vaccine Nation*; Mark A. Largent, *Vaccine: The Debate in Modern America* (Baltimore: Johns Hopkins University Press, 2012).

dangerous for spreading infectious diseases. Literary scholar Chris Foss describes *Louder than Words* as "much more about a Mother's Journey than it is about autism."[19] However, I argue that this centering of the mother in the autistic child's story is entirely consistent with the history of autism memoirs. McCarthy's form of memoir continues earlier works' prioritization of curing autism and belief in the inherent tragedy of the diagnosis, even as the efforts of neurodiversity advocates have fought for the recognition of autism as a valuable aspect of human diversity. In 2012, disability rights activists and founder of the Autism Self-Advocacy Network (ASAN) Ari Ne'eman questioned the people and organizations that certain aspects of the autism community, including parents, have held as heroes:

> Should we admire Bernie Rimland, who mocked community integration as a pipe dream and peddled a steady diet of quack cures to desperate parents forced to shell out thousands? Should we admire Jenny McCarthy, who has tried to revitalize a sagging career by plunging the autism community further into a discredited obsession with vaccines? Should we continue to support Autism Speaks, which uses corporate and celebrity influence to milk dry the autism community while returning only a tiny fraction of the money it raises for services in the communities from which it was raised?[20]

For Ne'eman and others in the autism self-advocacy community, McCarthy—and Bernard Rimland—represented the failings of parents to recognize the humanity of their autistic children. In her insistence on viewing autism as a tragic, pathological problem, McCarthy firmly established herself in contrast to the neurodiversity movement.

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[19] Foss, "Emerging from Emergence."

[20] Ari Ne'eman, "The Future (And the Past) of Autism Advocacy, or Why the ASA's Magazine, *The Advocate*, Wouldn't Publish This Piece," in *Loud Hands: Autistic People, Speaking,* ed. Julia Bascom (Washington, DC: Autistic Self Advocacy Network, 2012), 95.

While Jenny McCarthy reflects one type of parent memoir with roots in certain aspects of the genre, another vein of parent memoir has emerged: the academic parent memoir. These works highlight very different considerations in the writing of memoir, the nature of disability, and the experience of parenthood. While academics and professional writers are overrepresented in the history of memoir generally, academic parent memoirs about a disabled child have specific elements that separate the subgenre. In particular, these texts use parenting a child with a disability as the entry point into questions of disability ethics, history, philosophy, and genetics, blending their experiences with research and analysis pulled from a breadth of sources. Michael Bérubé's *Life as We Know It* is an early example of the genre, and a child with Down syndrome has motivated a number of these works—for example, George Estreich, *The Shape of the Eye: Down Syndrome, Family, and the Stories We Inherit*; Alison Piepmeier, *Unexpected: Parenting, Prenatal Testing, and Down Syndrome*; and Rachel Adams, *Raising Henry: A Memoir of Motherhood, Disability, and Discovery*.[21] Bérubé has since published a follow-up text, *Life as Jamie Knows It*.

Adams's 2013 memoir is an exemplar of the academic parent of Down syndrome. Adams was a tenured professor of English and comparative literature at Columbia University when she gave birth to Henry. Her first book had been about the history of freak shows, a lifelong obsession of hers. She writes that her reason for writing about freak shows is "much crazier" than

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[21] Piepmeier's work is somewhat different to the other two, as she coupled her own experiences with interviews of parents of children with Down syndrome and parents who terminated a pregnancy after prenatal diagnosis. However, unlike a text like *Testing Women, Testing the Fetus*, in which Rayna Rapp's personal experience initiated her research but are not a narrative throughout the book, Piepmeier's experiences continue to shape each section of the book. Piepmeier died while the manuscript was incomplete and Adams and Estreich completed it.

the explanations people expect: "I think I wrote that book to prepare me to be Henry's mother."[22] This orientation for the memoir shapes Adams's writing throughout the work, as she considers how Henry, and the life she wants for him, is not like the freaks she studied; how doctors made her feel like she and Henry were part of a freak show; and how studying freaks gave her years of thinking through the meaning of disability before she was confronted with the experience of living with a disabled child. Throughout her memoir, Adams draws upon her own academic expertise as well as medical anthropology, disability studies, narrative medicine, literary studies, and the history of medicine to situate Henry's and her experiences and explain her development into an advocate for her son and disability inclusion in the academy.

The question of prenatal diagnosis and how it has shaped the experience of parenting a child with Down syndrome runs throughout the book. Adams describes her decision not to get an amniocentesis with her pregnancy as surprising, calling it "shockingly risky behavior on the part of an ambitious, overeducated, overachieving woman like myself. Amnio was made for people like me, women with a deep need for order and control and perfection. Women who strongly believe in the right to abortion. Technology was supposed to liberate the woman who needs to know she will never have to be the mother of a child like Henry."[23] Adams does not indicate whether she would have sought an abortion had an amnio indicated that her pregnancy had a chromosomal anomaly. She laments that despite the appreciation for diversity that her professional and social circles claim to profess, intellectual disability remains outside of such constructions of disability. She recounts—but does not name—a prominent scholar of disability

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[22] Rachel Adams, *Raising Henry: A Memoir of Motherhood, Disability, and Discovery* (New Haven: Yale University Press, 2013), 15.

[23] Adams, *Raising Henry*, 98.

studies who expressed shock at Henry's birth, asking her, "Didn't you get tested?"[24] Her obstetrician cries when Henry is diagnosed with Down syndrome, an action that Adams initially interprets as empathy for the difficulty of navigating the unexpected, but later realizes reflects the doctor's belief that Henry’s birth is a mistake.

Adams's work has one instructive moment that clearly distinguishes it from earlier memoirs. In her discussion of the utility of genetic knowledge, she compares her son with an acquaintance’s child, who has trouble feeding and sleeping, has tantrums at any change in her environment, and rocks and flaps her arms. The friend's daughter is diagnosed with a condition on the autism spectrum—with qualities that are markedly different from Henry's Down syndrome and against which Adams views Henry’s development positively. Autism had become useful as a comparison against which to measure Down syndrome.

Adams expresses a strong sense of optimism about the future for children with Down syndrome born in the same era as her son. Much of the book is spent discussing the progress Henry makes in intensive early intervention treatments, including speech therapy, physical therapy, and occupational therapy. She holds onto the promise of a fulfilling future for Henry that older children and adults with Down syndrome give her, particularly in media depictions of Down syndrome. Adams describes a scrapbook she has made of success stories from people with Down syndrome, including media coverage of an actress with Down syndrome in a supporting role on *Glee*, a homecoming queen in Texas, and a restaurant owner in Albuquerque. The scrapbook features a prized possession: a signed publicity photo of Chris Burke from *Life Goes On*. She writes, "People with Down syndrome have gained a new visibility, if you know where to

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[24] Adams, 107-108.

look."[25] Adams's scrapbook illuminates the specific level of visibility of Down syndrome in the twenty-first century: one does need to look for these models of Down syndrome adulthood. The overriding message that Adams gets from the culture around her, including her colleagues, her friends, and her doctors, is that Down syndrome is rare and strange and a decision they do not understand. She needs the scrapbook to prove otherwise.

Adams and McCarthy wrote very different memoirs, with different audiences, purposes, and receptions. *Louder than Words* was excerpted in *People* magazine; *Raising Henry* received a positive, but not glowing, review in the *New York Times*. The two books do share a certain number of features that are foundational to parent memoirs, including an activist purpose, skepticism towards the medical establishment, and the development of the author over the course of the narrative as much as the child. The activism espoused by each is markedly distinct: McCarthy was committed to cultivating the autism-vaccine debate and pursuing curative treatments for autism, reflecting the belief that autism is a tragedy and that preventing and ending its occurrence is of the utmost importance. Adams ties her work to a belief in neurodiversity and demands full disability inclusion, forcefully admonishing a friend for considering facial plastic surgery for her son with Down syndrome and shifting her professional work into the field of disability studies. As examples, they suggest further avenues for study of parent engagement with disability in the twenty-first century, with roots that extend into the narratives that parents of the twentieth century established.

Parent memoirs continue to construct meaning for childhood disabilities, offering the public a lens through which to view the experience of life with autism or Down syndrome. In the twenty-first century, such memoirs exist alongside a broad array of alternative forms of life

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[25] Adams, *Raising Henry*, 102.

narratives and representations from people with autism and Down syndrome and their parents alike. The expansion of the television landscape through streaming channels and reality television has given adults with Down syndrome and autistic adults new opportunities to represent themselves to the public. Shows like the Emmy-winning A&E docuseries *Born This Way* (2015-2019), which followed a group of adult friends with Down syndrome, and the Netflix reality series *Love on the Spectrum* (2020), about the dating lives of autistic adults, allow for distinct forms of self-representation aimed at a broad audience. Notably, *Born This Way* includes a cast member with mosaic Down syndrome, a form of the condition in which the Trisomy 21 variation is only present in some cells. The show reflects diversity within its seven-member cast of adults with Down syndrome, showing viewers a variety of personalities and interests as well as the variation of Down syndrome presentations that occurs within the community.[26] The opportunities afforded to adults with Down syndrome and autism to self-represent through reality television, as well as through social media, autie-biographies, and other media portrayals.

These reality-based life narratives are joined by fictional portrayals of autism and Down syndrome. Works such as the 2003 novel *The Curious Case of the Dog in the Night-time*, the long-running CBS sitcom *The Big Bang Theory* (2007-2019), the Netflix series *Atypical* (2017-2021), and the ABC medical procedural *The Good Doctor* (2017-2021) feature main characters who are openly autistic or broadly interpreted as autistic.[27] Two high school series—the Fox musical dramedy *Glee* (2009-2015) and Netflix's *Never Have I Ever* (2020-2021)—feature recurring characters with Down syndrome. Such works challenge the association made by many

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[26] Bekah L. Olson, "Down Side Up: Representations of Down Syndrome in *Born This Way*," MA Thesis, University of Alaska Fairbanks, 2018.

[27] For more on fictional representations of autism, see Murray, *Representing Autism*; and Osteen, *Autism and Representation*.

parent memoirs of Down syndrome and autism with childhood, offering narratives of adulthood that center the complexity and humanity of people with these disabilities across time. However, the lack of representation behind the camera and in writing rooms of people with Down syndrome and autism can lead to fictional portrayals that reflect stereotypes rather than the complex life narratives that self-representation offers.

An examination of autism and Down syndrome in the twenty-first century should reckon with the ways that parents have continued to influence the meaning of these conditions, as in the case of Jenny McCarthy, the continued growth of parent organizations, and parent narratives through both memoir and gathering spaces on the internet. Such work should also consider how self-representations and self-advocacy have grown and challenged parents' dominance, whether through autie-biographies, reality television, or self-advocacy organizations, along with the growth in fictionalized depictions of these diagnoses. The position of parents in asserting authority over the meaning of autism and the best care for Down syndrome is neither inevitable nor unchanging, and the experiences of adults and children with autism and Down syndrome in the twenty-first century offer a complex site upon which to trace the development of the meanings of these two diagnoses in the recent past.

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