RELATIONAL REPRESENTATION: CONSTRUCTING NARRATIVES AND IDENTITIES IN AUTO/BIOGRAPHY ABOUT AUTISM

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Relational Representation: Constructing Narratives and Identities in Auto/Biography about Autism

Abstract

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This dissertation explores the use of relational writing practices in the textual representation of life with autism. While people with autism are often seen as isolated and as so different from the norm as to lie outside the realms of personhood and selfhood, incapable of producing stories of their own lives, attention to relationships in the construction of both life stories and identities works against such limitations, instead demonstrating the ways that people with autism are connected with others and acknowledging the coexistence and legitimacy of both normative and nonnormative ways of being. I define relational life writing as a set of textual practices that draw upon, and draw attention to, the significance of relationships among people, voices, and discourses, in the narration of lives and the construction of identities. These practices include the use of metaphor to seek to understand the experiences of others; the challenging of norms through life stories that resist conventional narrative models; attention to communication beyond the verbal through rhetorical listening and interpretation; and the use of autoethnographic techniques to respond to and resist others’ representations of oneself and one’s sociocultural group. By examining a variety of forms of auto/biographical writing about life with autism, including parent memoirs, collaborative texts between parents and autistic children, and single-author texts by autistic writers, I argue that relational life writing makes possible new ways of thinking and writing about autistic experience and identity.
Chapter 1

Relationality and the Construction of Identity in Autism Life Writing

“Jessy cannot tell her story for herself. Though she can speak nothing but truth and her memory is unerring, I must tell it for her, today as when she was eight years old. Once I was naïve enough to think she might; when I wrote that account of her first eight years I changed her name to Elly so she need never be embarrassed. I know now how effortful is her reading, how partial her understanding, how questionable her embarrassment. I know too that she’d never read such a story even if she could, or understand why it might be worth the telling. So I can tell it freely, in its continuing strangeness and its increasing, precious ordinariness, as Jessy enters, more and more fully, yet never entirely, the world in which we live, all of us, together.”

- Clara Claiborne Park, Exiting Nirvana (208)

“Was it possible there was more to Carly’s personality than we had thought? After all, Carly was autism. Autism, tantrums, and neediness. ... [T]here was a wall that couldn’t be breached, locking her in and us out. Bit by bit, now a few stones were beginning to crumble.”

- Arthur Fleischmann, Carly’s Voice (116)

“I always had a voice. It was just inside of me. I would talk to myself and even reply back to people sometimes even though they couldn’t hear me.”

- Carly Fleischmann, Carly’s Voice (360)

“I’ve told Cam’s story from my own viewpoint, yet I’ve also tried to speak for my son, who can’t speak for himself—to convey what I believe he felt, desired, and thought. But I can’t really know how it feels to be Cam. In that sense, his story may never be told.”

- Mark Osteen, One of Us (262)

“The restoration of spirit that I achieved through belonging...is no different for autistic people than it is for all other people who need companionship. It is this sense of companionship that validates one’s experience from afar. It is crucial for our sense of well-being and the awakening of our potential. But it is also, after this kind of healing, essential for our emergence as individuals.”

- Dawn Prince-Hughes, Songs of the Gorilla Nation (33)

Introduction

The representation of the lives of people affected by autism, including those diagnosed as autistic as well as those in relationships with them, presents both significant challenges and opportunities for autobiographical writing. Autism, a developmental disability that encompasses a broad spectrum of abilities and impairments, has over the
past few decades become an increasingly substantial presence in many areas of discourse, including medical, psychological, educational, literary, and, most notably for my interests, autobiographical. One major factor in this increasing discursive presence is the growing number of people diagnosed as autistic since the condition was first designated by psychiatrist Leo Kanner in 1943; initially considered a rare disorder, the most recent estimates indicate that 1 in 68 children in the United States now falls somewhere on the autism spectrum (CDC). As the number of people diagnosed as autistic has steadily grown, so has the drive to understand what it means to live with autism, for individuals, families, and communities.

However, the realities of autism often make the representation of autistic subjects, both by themselves and by others, complex and challenging. One of the most common manifestations of autism is impaired communication, which may make self-representation in language difficult or impossible, presenting obstacles to conventional modes of autobiography. This means that for the written representation of life with autism to take place, it must often be undertaken or mediated by non-autistic family members or “proximate others” (Couser, Vulnerable Subjects 40), a practice that may be called into question by readers and critics due to its not being perceived as conventional self-representation of an individual. Even when an autistic subject is able to produce his or her own life narrative, such a narrative often is seen as challenging normative notions of selfhood and credibility because of the significant neurological and behavioral differences that autism can entail. Because of autistic individuals’ differences from the norm, non-autistic others, including medical experts, often question whether a person with autism can be considered a “person” or a “self,” and whether he or she is capable of
writing or communicating about his or her own life. Oliver Sacks, for instance, tells of his initial response to Temple Grandin’s groundbreaking 1986 autobiography *Emergence: Labeled Autistic*: “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” (*Anthropologist* 253, emphasis original). Similarly, Uta Frith and Francesca Happé, in a discussion of autistic autobiographical texts, warn that “there are grave limitations with this type of material. While the accounts are intriguing, it might be a mistake to take what is said at face value” because of autistic individuals’ lack of “Theory of Mind” and resulting inability to recognize other people’s feelings or the needs of readers (18). In his own work of life writing about raising his autistic son, Michael Blastland describes his son Joe as “a child possibly lacking almost all the philosopher’s traditional definitions of what it is to be human” (7). This failure, or at least difficulty, in recognizing people with autism as human creates a problem for autobiographical writing by and about these nonnormative individuals. How can those who do not meet traditional requirements for personhood and selfhood produce, or participate in the telling of, their own life stories?

An additional complicating factor is the broad variety of experiences for individuals with autism. Manifestations range from Asperger’s syndrome, often labeled a “mild” form of autism, which can consist of differences in social behavior and information processing but also high intelligence and often the ability to participate in conventional educational and employment settings, to more “severe” autism, the
symptoms of which may include impairment of speech, learning difficulties, and violent or self-injurious behavior. While these represent some of the commonly recognized forms of autism, autistic experience can vary widely and is not necessarily a question of “more” or “less” autistic, but one of different combinations of abilities and disabilities. The current trend is toward referring to “autisms” as many, related forms of the disorder, rather than “autism” as one singular diagnosis (Boggs). The multiplicity of manifestations and experiences of people diagnosed as autistic both produces great variety in the representations of autism that are generated in life narrative and calls for different, more relational forms of life writing, beyond the traditional understanding of autobiography as a single-authored text about the life of a single individual (e.g., Misch 13).

In its attention to relationships between individuals and their own and one another’s life stories, including collaborations in the writing process as well as dialogues among discourses about the meaning and implications of autistic life and experience, life writing about autism demonstrates that both the production of life writing and the construction of identity are relational processes, not ones occurring in isolation. Relational writing, as I make use of the term, is a set of textual practices in life writing that foreground the relationships between multiple people, voices, and discourses. In autobiographical writing about life with autism, these textual practices include the use of metaphor to construct relationships between disparate lives and experiences; the challenging and complication of conventional narrative structures to better reflect nonnormative experiences; rhetorical listening and interpretation of another’s experience in narrative; and autoethnographic writing which negotiates relationships between
individuals, representations, and normative and nonnormative ways of being. These strategies, and likely others that lie beyond the scope of my exploration here, constitute the category of relational life writing, a form of writing which works to counteract conceptions of individuals with autism as lacking the qualities required to be recognized as a person, to be an autobiographical self, and to participate in normative human social relationships. The use of these techniques in life writing provides a means for individuals with autism and those in relationship with them to claim the right and ability to tell stories that expand the field of lives and stories worth telling. This consideration of the role of the relational also profits from a bringing together of the study of life writing with the growing field of disability studies, which developed out of the disability rights movement beginning in the 1970s and has gained traction as an academic field since the 1990s. Because of its emphasis on the value of interdependence—mutual dependence and relationship among people with and without disabilities—as well as its indictment of the disabling forces of many social structures, disability studies makes possible an examination of how relationality may be employed in the telling of life stories about disability and the representation of the disabled self.

The genre of life writing about disability, and critical attention to such writing, has grown substantially in recent years. G. Thomas Couser in particular has noted the rise of the disability memoir, beginning with his study of illness and disability narratives in his book *Recovering Bodies* (1997). This text calls attention to the growing number of published life stories of illness and disability, especially HIV, breast cancer, paralysis, and deafness. Building on, and diverging from, critical work on illness narratives like Arthur Frank’s *The Wounded Storyteller* (1995), Couser has made further explorations
into life writing about disability in *Vulnerable Subjects* (2004) and *Signifying Bodies* (2009), including some consideration of the representation of subjects with mental disabilities, such as fetal alcohol syndrome and mild developmental disability. Susannah Mintz’s *Unruly Bodies* (2007) examines the ways that disability life writing by women presents the writers’ bodies as products both of text and of lived experience, connecting disability studies with feminist autobiography. Offering a historical perspective, Sara Newman’s *Writing Disability: A Critical History* (2013) extends the view of disability memoir beyond contemporary literature to consider how people with disabilities have represented themselves in writing for centuries. These texts, among others, have made significant contributions to the study of disability life writing; however, there has been little concentrated critical attention upon life writing about autism, and this dissertation seeks to fill that gap by considering the ways that autobiographical autism narratives’ use of relationality, manifested through a variety of relationships and textual practices, contributes to understandings both of the field of life writing as a whole and of the narrower but developing field of disability life writing.

Life writing about autism takes a number of forms, most notably parent memoirs about life with children with autism, collaborative texts between a person with autism and a proximate other (most commonly a parent), and autobiographical texts by autistic subjects. The earliest forms of autism life writing might be traced to case studies published by autism researchers, including Leo Kanner, in the 1940s and 1950s, and Bruno Bettelheim, in the 1960s.\(^1\) These sorts of medical case studies offer a particular,

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\(^1\) See Mitzi Waltz’s article “Reading Case Studies of People with Autism Spectrum Disorders: A Cultural Studies Approach to Issues of Disability Representation,” in which Waltz analyzes the representation of autistic children in early psychiatric case studies by Kanner, Bettelheim, and Melanie Klein, as well as more recently by Eric Courchesne *et al.*, in 1998.
limited view of the autistic subject, aimed at highlighting the individual’s impairments for the purposes of recognizing symptoms, testing treatment options, and communicating findings to other researchers. The genre of the parent memoir, as I discuss in Chapter 2, effectively began with Clara Claiborne Park’s _The Siege_ (1967), an account of the first eight years of Park’s life with her autistic daughter Jessy. Texts such as Park’s offered a more intimate, and more relationally-focused, perspective on life with autism than that of medical case studies; Park tells her own story as a parent and presents Jessy as an individual and a daughter, rather than as a patient or test subject. She also, as I will argue, claims the right to speak about her own and her daughter’s stories, in resistance to the “experts” who seemed to possess all the knowledge and authority about autism. The genre of autobiography by people with autism came into being significantly later, with Temple Grandin’s _Emergence: Labeled Autistic_, published in 1986 and followed less than a decade later by Grandin’s more thorough _Thinking in Pictures: And Other Reports from My Life with Autism_ (1995). Donna Williams’s _Nobody Nowhere_ (1992) was another significant early autobiographical text, and collaborative memoirs, such as Judy and Sean Barron’s _There’s a Boy in Here_ (1992) began to appear around the same time. Accounts such as these paved the way for the publication of other autobiographical accounts by people diagnosed as autistic, challenging preconceived notions such as that noted by Oliver Sacks, above, that autistic people were incapable of the very abilities needed to produce reflective writing about their lives.

While understandings of autism have developed significantly in recent years, and the number of available autobiographical accounts by people with autism has skyrocketed, autistic writers have continued to face many challenges, from both general
readers and “experts,” to their ability to narrate their own lives, to prove themselves to be “authentically” autistic, and to demonstrate that they are worthy of consideration as full persons and unique selves. I argue that the use of relationality in the telling of life stories has the potential to productively confront such challenges to autistic selfhood and storytelling through textual and rhetorical moves that demonstrate how stories and lives are constructed in relation to one another, making space for the representation of autistic individuals whose experiences or ways of being may be different from the norm. By calling attention to the reality, and importance, of relationships in the lives of those affected by autism, life writing has the potential both to make available life stories that might otherwise go unwritten, and to expand the ways identity can be developed through relationship and dialogue among people and discourses. Relationality as a practice of writing life stories is, of course, complicated, and does not always have unmitigated positive effects on understandings of the lives and stories of people with autism. At times, the use of relationality can also result in applying normative standards to another’s life story or personhood, perhaps pushing the limits of knowing another person’s story (see epigraph, Osteen) or knowing whether that person wishes to share that story (see epigraph, Park). However, attention to relationality also has the power to amplify seldom-heard voices like Carly Fleischmann’s (see epigraph) through collaborative narrative and to both supplement and challenge the stories of non-autistic others (see epigraph, Arthur Fleischmann). Relationality can call attention to how people with autism relate to others in ways that may be overlooked and underemphasized, as when Dawn Prince-Hughes (see epigraph) uses autoethnographic writing to show how she has developed her own sense of identity through relationship with others, both autistic and
non-autistic. By attending to how relationality is used in life writing, readers can gain insights into the complexities of relationships, stories, and identities for those affected by autism, destabilizing common narratives of people living with autism as isolated, incapable of self-representation, or hopelessly inaccessible.

Relationality in life writing about autism, as I see it, is a textual practice that highlights relationships between autistic and non-autistic people that are often unnoticed, especially when dominant modes of understanding autism focus on the social isolation of the autistic individual. When isolation and inaccessibility are emphasized in conceptions of autism, relationships become difficult to recognize, when in fact, as I argue, relationship and interdependence among people with and without disabilities are key not only in everyday life, but also for the reconstruction and communication of those lives through relational life stories. Acknowledging relationship through life narrative can make possible broader recognition, both on a personal level and a sociocultural one, of individuals who are not always recognized as valuable persons or unique selves, while also calling attention to the ways complicated relationships between individuals and discourses can be negotiated and represented in writing. Rather than reifying autistic identity as a separate, cohesive category, I hope to show how an emphasis on relationality among individuals, and an expansive view of personhood, can undermine such separate identity categories and make possible greater recognition and textual representation of life stories and identities that do not fit particular norms. As lives and selves are narrated that might otherwise have gone untold and unrecognized, social and textual norms which constrain the representation of the realities of life with autism may increasingly be challenged.
The stories that are told in autism life writing in general, and in those texts I examine here, are not necessarily representative of all autistic lives, nor are they in any way more significant than the stories that remain untold. However, accounts of life with autism have the potential to expand the possibilities for the types of stories—and types of lives—that are represented. In order for relationality to function in this way, the life writer must acknowledge the interdependent relationships between him- or herself and others, whether between a parent and a child with autism or between an autistic writer and the various communities of which he or she is a part. Relationality, then, translates into textual moves on the part of the writer(s) that attend to the ways in which one’s life narrative and identity are each constructed in relationship with that of others. To some extent, relationality is present in any life story; however, my contention is that it has particular resonance in autism life writing because of the nature of the discourse surrounding autism, which often emphasizes isolation, and because of the tendency for stories about life with autism not to fit or resolve in the ways that most conventional narratives do. By reading these narratives with attention to textual practices of relationality, readers can both come to acknowledge alternatives to common models of narrative and identity, and begin to recognize the role relationality plays in all life stories and narratives in some sense. Through increased agency for people with autism to tell their own stories (whether independently or interdependently), expanded possibilities for life narratives, and greater openness to nonnormative forms of personhood and selfhood, relationally-focused life writing about autism can make a difference in the ways autism, and people living with autism, are perceived and received in text and in society.
Relationality and Auto/Biography

Traditionally, the term “autobiography,” which came into usage around the end of the eighteenth century, has been used to refer to a particular type of life writing focused on the representative life story of a unique, independent self. Georg Misch, a prominent figure in early autobiography criticism, in 1950 defined autobiography quite literally, as “the description (graphia) of an individual human life (bios) by the individual himself (auto-)” (5). While this seems a fairly broad definition, Misch and other early critics placed emphasis on not just any “individual human life,” but on one that might be seen as representative and exemplary, the life of “an eminent person who has himself played a part in the forming of the spirit of his time” (Misch 13). This emphasis limits the scope of the type of life to be represented in autobiographical writing to the prominent public figure and, as suggested by the gendered pronoun as well as by the constraints of public life for much of history, to men. Georges Gusdorf (1956) went even further, suggesting that autobiography is a Western phenomenon, only possible in societies which emphasize individuality over collectivity. Gusdorf explains his view of the uniqueness of autobiography to modern Western civilization:

The conscious awareness of the singularity of each individual life is the late product of a specific civilization. Throughout most of human history, the individual does not oppose himself to all others; he does not feel himself to exist outside of others, and still less against others, but very much with others in an interdependent existence that asserts its rhythms everywhere in the community. (29, emphasis original)
The “specific civilization” to which Gusdorf refers is, of course, Western civilization, and the other sort of setting, which does not distinguish the self significantly from others, may be located in “primitive societies such as ethnologists describe to us” (30). If the bounded, individual self, or *bios*, is eclipsed by, or at least shares prominence with, a more collective or relational conception of self, the sort of autobiographical writing valued by critics like Misch and Gusdorf cannot exist. However, other forms of life writing and construction of selfhood, less focused on the self in isolation from others, are certainly possible despite the failure of such critics to countenance them.

Over the course of the late twentieth and early twenty-first centuries, the public and critical consideration of what “counts” as proper life stories that may be represented through autobiography has expanded substantially. Some of this expansion is due to changing social attitudes as a result of civil rights movements calling for racial, gender, sexuality, and disability equality, which have made space for previously marginalized voices and stories (Gilmore 16). As Linda Anderson points out, it was not that these groups did not have stories to tell in the past, but that their stories were not considered worthy of publication and dissemination because they were not recognized as historically or culturally representative (86). Similarly, many colonized and oppressed populations gained political and literary freedom during the twentieth century, and autobiography provided a channel for communicating their formerly silenced experience. Such voices began to destabilize the hegemony of the Western male subject in favor of minority or marginalized subjects whose stories may represent not the dominant majority but rather the diversity of human experience. As the range of lives deemed worthy of representation in autobiographical writing expanded, the way in which such texts
represented individuals began to expand as well. Julia Watson calls attention to what she calls the “bios-bias” in traditional autobiography studies, an attitude that privileges a particular sort of mainstream or exemplary life story. She writes, “To privilege bios is to accept that one’s cultural status as a subject is externally authorized in this way. Bios, then, is not synonymous with identity, but signals the significance of a life within authorized traditions of representing lives in Western culture” (58). Watson’s point is that clinging to a particular culturally-authorized conception of bios reinforces the idea that only the sorts of lives represented in the traditional autobiographical canon—eminent men such as Augustine, Rousseau, and Montaigne—are worth telling. Rather than seeing the lives of women, minorities, and people of various cultures as “other,” Watson argues that readers and critics must “renegotiate bios and locate the ‘I’ in the common cultural life as an appropriate historical witness” (79). Watson’s claim for a renegotiation of the concept of lives worth telling also interrogates the historical focus of autobiography on a particular image of the self as coherent, bounded, and isolated from others.

The growing interest during the late twentieth century in women’s autobiographical writing, and in the ways it might diverge from the traditional Western male model, led to a new focus on relationality, or the involvement of other people’s lives and selves in the construction of one’s own life story and identity. Mary G. Mason, for instance, identifies patterns in the life writing of four early women writers—Julian of Norwich, Margaret Cavendish, Margery Kempe, and Anne Bradstreet—which she argues “established patterns of relationship and self-identity that were to be followed by later women” (208). Though Mason acknowledges the possible pitfalls of separating writing patterns by gender, she argues that men’s and women’s life writing reflects an apparent
difference in the ways men and women come to understand their own identities. Her analysis indicates that “the self-discovery of female identity seems to acknowledge the real presence and recognition of another consciousness, and the disclosure of female self is linked to the identification of some ‘other’” (210), whether a divine being, a spouse, a family, or a community. Susan Stanford Friedman extends the theoretical reach of Mason’s emphasis on relationality in the writing of women’s lives, using feminist theories of selfhood to argue for the ways that “individualistic paradigms of the self [like that identified by Gusdorf] ignore the role of collective and relational identities in the individuation process of women and minorities” (35). Friedman explores the manifestations of this relational individuation in a number of women’s autobiographical texts, by writers such as Gertrude Stein, Maxine Hong Kingston, and Audre Lorde, many of which are strikingly different in content and form from the traditional Western male autobiography. Friedman’s work demonstrates how these women writers explore and construct identity in relation to other women; to family, with particular emphasis on mothers and daughters; to racial, cultural, and religious communities; and to romantic partners. Friedman makes clear that women’s life writing, not only despite but because of its frequent focus on relationship, should be considered autobiographical and seen as representative of women’s lives and identities, pushing against the “conditions and limits” set out in Gusdorf’s influential essay.

While Mason’s and Friedman’s work on relationality in women’s life writing offered important challenges to the standard conceptions of the self in autobiography, they limited this reconceptualization to women, and suggested that all women’s life writing differed from men’s in this way. Watson cautions that “[i]n speaking of a model
Friedman seems to essentialize ‘woman’ and to privilege the maternal bond” (70), observing that these emphases on interpersonal relationships and motherhood are by no means present in all women’s autobiography. I would agree with Watson’s critique and add that the recognition of relationality in life writing need not draw firm lines between genders, or between people who identify as belonging to different groups. On the contrary, relationality has the potential to bridge gaps between those who might be labeled differently. Indeed, Paul John Eakin, while acknowledging the significance of the increased attention to women’s autobiography, pushes against the idea that there is a fundamental difference between men’s and women’s life writing. He notes that in contrast to the gender binaries set up by criticism such as Mason’s and Friedman’s, he sees more continuity across genders than has previously been recognized. Rather than relationality being a unique characteristic of women’s life writing, Eakin argues that “All selfhood…is relational despite differences that fall out along gender lines” (“Relational Selves” 67). He draws upon the childhood development theories of psychoanalyst Jessica Benjamin which emphasize the intersubjective nature of the development of autonomy; as Benjamin argues, “The need for recognition entails this fundamental paradox: at the very moment of realizing our own independence, we are dependent upon another to recognize it” (Benjamin 33). Eakin tells of his own shift in recognition of what “counts” as autobiography due to a new attention to relationality; he proposes the category of the relational life, “a term I use to describe the story of a relational model of identity, developed collaboratively with others, often family members” (69), identifying both male and female writers whose works fall into this category, including Edmund Gosse, Virginia Woolf, Maxine Hong Kingston, and
Philip Roth. He also adds to the range of texts that may be recognized as autobiographical writing by considering works that include “not only the autobiography of the self but the biography and the autobiography of the other” as well as what Eakin refers to as “the story of the story,” which explains the process of collaboration in the production of the text (71, emphases original). He identifies the ways in which telling another person’s life story provides “a measure of self-determination, for the other’s story, the other’s life, is possessed—indeed created—by the recording self” (72). Eakin’s work calls attention to the construction not only of one’s own identity in relation to others, but also of another’s identity in relation to oneself, processes which are happening across all types of autobiography but were hitherto largely unacknowledged. Such relational constructions can take many forms but include the interconnected life stories of two parties, as in Art Spiegelman’s Maus: A Survivor’s Tale (1986; 1991), a set of graphic novels in which Spiegelman tells his father’s story about life during the Holocaust, narrated orally by his father but written and illustrated by Spiegelman; or the sort of slippage between the stories and identities of writer Maxine Hong Kingston and her mother and female ancestors in The Woman Warrior (1975).

As relationality has become an increasingly recognized aspect of life writing, it has also become problematized. Couser, for instance, considers the ethical dilemmas inherent in writing about the lives of other people, especially when those others have disabilities or other conditions, such as youth or age, that prevent or complicate their own self-representation. Such collaborative or mediated works of life writing certainly fall within the sort of relational life story set out by Eakin, but raise ethical questions about the rights of the other person in his or her representation, and the potential for a writer to
misrepresent or unfairly expose another person. Couser explains in *Vulnerable Subjects*, “The closer the relationship between writer and subject, and the greater the vulnerability or dependency of the subject, the higher the ethical stakes, and the more urgent the need for ethical scrutiny” (xii). While Couser takes a bioethical approach in his book that I am less interested in specifically, his study demonstrates that questions about the implications of relationality are particularly applicable to life writing about disability.

According to the social model of disability, disability is socially constructed by attitudes and environments that limit access for people with nonnormative physical and mental capabilities. As a result of the combination of impairment with an unaccommodating environment, people with disabilities are often made dependent upon others for assistance with many life activities. In societies which place high value on individualism, the need for assistance is seen as a sign of weakness or as an obstacle to independence and consideration as a full person or citizen. Dependence in this context is typically framed as a negative characteristic. However, disability studies has sought to call attention to the interdependent nature of all social life, a quality which resonates soundly with the interdependent aspect of autobiographical writing identified above by Eakin. Tobin Siebers writes that disability studies “represent[s] human society not as a collection of autonomous beings, some of whom will lose their independence, but as a community of dependent frail bodies that rely on others for survival. Notice that dependence does not figure here as an individual character trait…but as a structural component of human society” (182). While Siebers continues to use the word “dependence” here, I prefer the term “interdependence” to indicate the intersubjective nature of human social dependence; not only is one person (i.e., the disabled person) dependent upon
(nondisabled) others, but all members of society are (inter)dependent upon and with one another. Rather than figuring people with disabilities as wholly dependent and people without disabilities as wholly independent, the concept of interdependence emphasizes the universal nature of dependence. When the universality of interdependence is recognized, the relational quality of all individuals’ construction of identity, and the reflection of this relational process in life writing, becomes more readily apparent.

This issue of independence and interdependence is a complex one, and while I certainly do not claim to have resolved all of the inherent tensions, I do find relationality to be a helpful way to work through textual representations of relationships among people of different abilities and identities, and to bridge gaps between them while also recognizing the sometimes substantial differences in experience. Anna Mollow, critiquing the reliance on identity politics and individualism in Siebers’ work, points out,

The Foucaultian account of subject formation, according to which the ‘individual is an effect of power,’ poses a challenge to the claims of identity politics, which grant a privileged epistemological status to individual experience…. Claiming that people with disabilities have privileged access to knowledge may have the potential to subvert assumptions that we need others’ advice and intervention. But by over-emphasizing our difference, the strategy risks contributing to our excessive individualization, a process which Siebers accurately identifies as a primary means of our oppression.

Relationality, in my view, has the potential to balance an emphasis on individual difference with a renewed attention to the ways in which relationships with others may be
helpful and even essential to an understanding of the self. If excessive individualization is a means of oppression, and I agree that it is for many people with autism, then there is a benefit to reducing the emphasis on that individuality while also continuing to acknowledge the individual’s experience. Nonnormative cognitive or bodily experience does not necessitate that one be isolated from those with more normative experience; rather, relationality offers a means to consider the more complex ways that a person with a disability such as autism exists both as a unique individual with experiences that may lie outside the norm and as a person enmeshed in relationships with the people, discourses, and social contexts surrounding him or her.

Similar to Couser’s focus in *Vulnerable Subjects*, I am interested in relational writing about life with disabilities that may challenge norms of communication, cognitive ability, social interaction, and relationships, as well as personhood, selfhood, and agency. However, while Couser concentrates on the ethics of relational autobiography involving disability, I am more concerned with how a relational approach manifests itself textually in a variety of forms of life writing about disability, specifically autism. My particular interest lies in how this subgenre continues to expand conceptions of the function of relationality in narrating the lives and constructing the identities of oneself and others with whom one is in relationship. As I have discussed above, autism is a disability that calls into question many conventional notions of these areas of human experience, and for that reason its translation into life writing is particularly complicated, and particularly interesting. Since many examples of life writing about autism are written by or in collaboration with non-autistic others, many if not most of these texts would be considered relational by Eakin’s standards. Parent memoirs of raising children with
autism may involve parents telling their own life stories, but the basis of the story is their relationship to their autistic child, and it is impossible to write such a life narrative without also including some, or a great deal of, biography of the child. Many parent narratives include some mediated self-representation of the autistic person, whether through the inclusion of his or her written or spoken words or, as is the case with Jessy Park in Clara Park’s *Exiting Nirvana*, artwork. These parent memoirs, as well as texts that involve collaboration in the writing process between autistic and non-autistic family members, are inescapably relational, and they approach the portrayal of the life stories of the individuals involved in relationships in a variety of ways, from the productive to the problematic. Parent-authored texts must also navigate the construction of selfhood for another person with whom the author is in relationship, which efforts, while complex for the reasons that Couser points out, I argue are both possible and potentially illuminating in their acknowledgment of the personhood and selfhood of people with communication impairments and their life stories. Collaborative texts carry an additional layer of complexity because of the presence of multiple authors, whose constructions of the relational life stories and the identities of the individuals involved may conflict with and challenge one another, presenting not only multiple life stories but multiple voices and versions of those stories. For single-author texts by an individual with autism, there may be fewer complications in terms of representing others’ life stories, but people with autism frequently have difficulties engaging in normative social interaction with others, while at the same time their impairments often require them to be dependent upon other people in order to be successful in an ableist society. Autobiographical texts by people diagnosed with autism, therefore, tend to be highly relational in their narration of the
development of identity, demonstrating complicated relationships of interdependence. In my analysis of each of these types of texts, I examine the authors’ textual efforts to make use of relationality in their construction of their own and others’ stories and identities, including the variety of ways in which these efforts are made and the variety of effects they have for the authors’ and others’ relational life stories.

With my emphasis on the relational aspect of autobiography, and with the evolution of the meaning of the term “autobiography” throughout its history, I would like to say a brief word about my use of terminology. For some, the use of the word “autobiography” is problematic because of its association with the sorts of restrictions placed upon the genre, reflected in the work of critics like Misch and Gusdorf, until the second half of the twentieth century. According to Sidonie Smith and Julia Watson, “While autobiography is the most widely used and most generally understood term for life narrative, it is also a term that has been vigorously challenged in the wake of postmodern and postcolonial critiques of the Enlightenment subject” which the traditional use of “autobiography” evokes (3). Indeed, a great number of terms have been proposed over the past several decades to replace or supplement “autobiography” as a blanket term, including autogynography (life writing by women), autopathography (life writing about illness), and autothanatography (writing about one’s own death), to name a few. While I recognize the problems with the term “autobiography” as it was formerly used to privilege a particular kind of subject and to exclude those who lacked power and status, I would argue that the evolution of the field of life writing to include new types of subjects also calls for an evolution in the way “autobiography” can be understood. In response to the sort of critique noted by Smith and Watson above, David Huddart acknowledges that

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2 See Appendix A of Smith and Watson’s Reading Autobiography for a much more expansive list.
“[t]he term [autobiography], broadly understood or not, can seem imprecise, but it has been persuasively argued that this imprecision is actually rather useful, and is an apparent weakness that can be converted into a strength” (3). I find this to be a constructive way of thinking about the term, which, in spite of the appearance of many other options, refuses to fade from use.

Reclaiming the term “autobiography” for those who would not have been recognized as autobiographical subjects in the past, but who have now claimed the right to tell their own stories, contributes to the broadening of the horizon of traditional definitions of the genre. Therefore, I continue to use “autobiography” to refer to any form of writing about one’s own life and identity, even while also using more general terms such as “life writing,” a concept that I see as much more broad, including not only autobiography or self life writing, but also the genre of “biography,” writing about another person’s life story, and all the gradations of relational writing that fall in between. The one twist I make on the traditional is the addition of a slash, using the term auto/biography to emphasize the fluidity between one’s own and another’s life story in the forms of relational life writing with which I am concerned here. For my purposes, auto/biography is life writing that both includes and highlights the relational, and so indicates a movement away from the traditional focus on bios, the bounded self living a singular, representative life, and toward the representation of diverse individuals and their interdependent relationships with other people and life stories.

**Configuring Self and Relationship in Autism Life Writing**

As these relational auto/biographical texts depict life with autism as interdependent, and construct the writer’s identity in relationship with those of others,
they must also contend with challenges to the personhood and selfhood of people with autism due to their differences in behavior, social interaction, and communication.

“Personhood” and “selfhood” are often used synonymously; I see the two concepts as closely linked but with subtle differences. Personhood, for my purposes, refers to the tendency for others to see an individual as a full human being, someone worthy of recognition as an equal. Daniel Dennett, for instance, observes that in general, “we recognize conditions that exempt human beings from personhood, or at least some very important elements of personhood. For instance, infant human beings, mentally defective human beings, and human beings declared insane by licensed psychiatrists are denied personhood, or at any rate crucial elements of personhood” (175). People with autism can be classified as having mental disabilities (as a broad category distinguished from physical disabilities), which many might construe as being either “mentally defective” or “insane.” Dennett sets forth six “conditions of personhood” that have often been used to determine whether or not someone should be considered a person, including rationality, intentionality, the ability to adopt and reciprocate attitudes toward others, verbal communication, and a particular quality of consciousness. Lack of verbal communication largely precludes the detection of many of these other “conditions,” making it difficult for nonverbal autistic people to claim or be granted recognition of

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3 Both Cynthia Lewiecki-Wilson and Margaret Price make use of this broad category, including cognitive, neurological, and psychiatric impairments under its umbrella. Lewiecki-Wilson explains, “I group mental illness and severe mental retardation under the category mental disabilities. Despite the varieties of and differences among mental impairments, this collective category focuses attention on the problem of granting rhetoricity to the mentally disabled: that is, rhetoric’s received tradition of emphasis on the individual rhetor who produces speech/writing, which in turn confirms the existence of a fixed, core self, imagined to be located in the mind” (157). I find this grouping of disabilities to be useful for the classification of autism, particularly because it is such a difficult condition to pin down—various descriptions have identified it as psychological, emotional, cognitive, neurological, and developmental in nature. As Lewiecki-Wilson implies, the exact scientific basis of the disability may be less important than its effects, which for most mental disabilities includes diminished rhetorical power and a resulting skepticism by others about the personhood and/or selfhood of the disabled individual.
personhood. It may also be necessary to reconsider the sorts of “conditions of personhood” that are used to determine whether someone merits recognition as a person. This is one basis on which life writing by people with autism may be called into question, particularly single-author autobiography, because these writers may not be recognized as persons in the first place. However, relational auto/biography has great potential, in my view, for demonstrating the personhood of individuals who might otherwise be denied it, through the mediation and the inclusion of the life story and contribution of the disabled individual in relationship and collaboration with a nondisabled other.

The concept of selfhood is closely interrelated with that of personhood. While personhood describes one’s capability of being recognized as a fully human person, with rationality, consciousness, communication, and the ability to interact meaningfully with others, I use selfhood to refer to an individual’s own self-consciousness and unique thoughts, emotions, and sense of one’s own life story. These are qualities that may not be apparent to others, particularly if an individual lacks communication abilities; however, they can be, and should be presumed to be, present even in the absence of direct communication. Such a presumption is similar to Douglas Biklen’s argument for “presuming competence” when interacting with autistic people with limited communication; he writes, “In its simplest articulation, presuming competence means that the outsider regards the person labeled autistic as a thinking, feeling person” (72-73). Such recognition of selfhood can often be narrated and represented in life writing. In his book *Living Autobiographically*, Eakin explores the ways selfhood is constructed by narrative; his overarching claim is that “our life stories are not merely about us, but in an inescapable and profound way are us” (x, emphases original). Here and elsewhere, Eakin
draws upon psychologist Ulric Neisser’s “fivefold model of the nature of selfhood” (Eakin xii), outlined in Neisser’s essay “Five Kinds of Self-Knowledge.” Neisser defines five aspects of selfhood: the ecological self, interpersonal self, extended self, private self, and conceptual self or self-concept (36-50). According to this model, there are many aspects of one’s “self” as it is constructed in relation to the surrounding physical environment, social environment, past and future, and inner world. The “interpersonal” aspect of self in particular is relevant to the sort of relational construction of self-identity that I see taking place, in a variety of ways, in auto/biographical writing, but the relational can also help to shed light on other aspects of autistic individuals’ selfhood, again helping others to recognize both the selfhood and personhood of someone in whom these characteristics might otherwise go unrecognized. Self, then, is a broad term that describes what makes an individual unique and distinguishes him or her from other persons. Eakin suggests, “Self [as opposed to identity]…is the larger, more comprehensive term for the totality of our subjective experience. … [O]ur identities may erode but we remain selves of some kind as long as consciousness continues” (xiv, emphasis original). Selfhood describes and constitutes individuality, and some, though not all, aspects of selfhood may be conveyed in some fashion to others, if there is a means and openness to communication. As Eakin explores in Living Autobiographically and as I expand upon in this dissertation, auto/biographical writing is one particularly powerful means of establishing an individual’s selfhood for other people. Eakin argues that “when we perform these stories [which he refers to as identity narratives], we establish ourselves for others as normal individuals” (4)—or rather, we seek to do so. Narrative identities define individuals for others in social settings, and by writing about
oneself or one’s life in a particular way, one can make an effort to be recognized by others as a person and as a unique self. For people with autism in particular, recognition as an individual—not just as an autistic person—is particularly important, and the creation of narrative identities by and of autistic individuals can allow for recognition of diverse possibilities for lives and selves with autism, rather than a fixed type.

Auto/biographical representation of the personhood and/or selfhood of individuals with autism has been considered by a number of critics, though none extensively or exclusively. In a 1996 essay, Sidonie Smith examines autism as one of a number of “limit cases” which challenge conventional understandings of life writing. Such “limit lives,” she argues, “are profoundly disorienting, for they pressure our notions of the subject and its determinations, of the relationships of persons to experiential history, and of the integrities of life storytelling” (“Taking It to a Limit” 228). For Smith, autism is a sort of ultimate limit case, because of the current conception of autism as a neurobiological condition which alters the formation and function of the brain and consequently the way the autistic person perceives, behaves, and communicates.

According to this model, the ability to narrate one’s life is inevitably affected, and perhaps even precluded, by these characteristics. Autistic subjects’ differences in, or lack of, communication abilities can make it difficult for others to acknowledge or understand their life experiences, their sense of self, or their relationships to other people, because they frequently do not or cannot narrate them. Though, as I have noted, there are many ways in which others may narrate the life stories of people with autism, including relational auto/biographical writing by family members as well as less relational genres such as medical case studies, Smith claims compellingly that nonverbal autistic people
“trouble the belief in humanist selfhood. In addition to being a condition in need of an explanation, autism becomes a more general problem in need of a solution—in this case a silence in need of a story” (233).

In her discussion of the work of two of the early, now perhaps canonical, autistic autobiographers, Temple Grandin and Donna Williams, Smith finds that the restrictions placed upon autobiographical selfhood, particularly in the sense of the “bios-bias” identified by Watson, make it practically impossible for autistic subjects to narrate themselves in a way that is both recognizable to others (i.e., Eakin’s “normal selves”) and actually representative of their autistic selfhood. Smith argues of Williams’s *Nobody Nowhere,* “[I]n the process of defining herself as autistic, [Williams] exceeds the definition of an autistic subject… The autistic/recovering autistic subject becomes an autobiographical subject. In this way she situates herself both within and without the diagnostic label” (239). In Smith’s view, then, at this early point in the history of autistic auto/biography, the field of life writing had not yet made room for the variations on traditional selfhood that autistic experience might require. Some shifts have occurred since then, most notably in the quantity of life narratives about autism that have been published, as well as, I would argue, an expansion of the possibilities for life writing and for selfhood and personhood through increased focus on relational themes and textual practices in auto/biographical narratives. I find it important to note that the primary problem Smith identifies for autistic writers like Williams is that they do not fit the “definition of an autistic subject” constructed by others, whether through medical discourses or popular ones. In Williams’s case, she may “exceed” such a definition; other writers might seem to fall below it. An expansion of the definition(s) may help
make space for an increasing number of narratives and subjectivities that simply do not fit the constructed notion of an autistic subject.

Other critical approaches to the representation of autistic life and experience include Mark Osteen’s edited volume *Autism and Representation* and Stuart Murray’s sweeping study *Representing Autism* (both 2008). Osteen’s introduction to his book calls for greater attention to the experience of autism, not only in the form of strict single-author autobiography, which he acknowledges is not produced by a great number of autistic people, but also in the works of those close to individuals with autism who seek to advocate for them. He rightly points out that much writing about autistic people is “not truly representative: it too often misleadingly implies that most autistic people are savants while also suggesting that autistic people are worthy only if they overcome their disorder” (8-9, emphasis original). The question of the “representativeness” of accounts of life with autism is a contentious and important one. I would argue that there is no such thing as even an ideal “representative” account of autism; the problem that Osteen identifies here might be better described as a limited set of available models of autism, such as the savant and the trope of “overcoming” disability. As more diverse accounts of life with autism are published, more models will be available, and less attention will be focused on a few limited examples.

Osteen also draws upon Cynthia Lewiecki-Wilson’s concept of “mediated rhetoric,” particularly useful for my discussion of relational auto/biography. In her essay “Rethinking Rhetoric through Mental Disabilities,” Lewiecki-Wilson identifies the frequent denial of rhetorical power to those with disabilities that impair communication since, she argues, “communication…generates and marks subjectivity” (159). She
formulates mediated rhetoricity as a way to work toward rectifying this absence, defining it as “language used for the benefit of the disabled person that is (co)constructed by parents, advocates, and/or committed caregivers who know the disabled person well” (161); in other words, communication as a combined effort between the disabled person and proximate others. Osteen broadens the scope of Lewiecki-Wilson’s mediated rhetoricity to include scholarly work about disabled subjects by those close to them or by disabled subjects themselves. He terms this sort of work, examples of which he has gathered in *Autism and Representation*, as “empathetic scholarship,” explaining that “it not only captures the aim of speaking with those unable to communicate entirely on their own, but also describes this volume’s larger project: to combine rigorous scholarship with the experiential knowledge our non-autistic contributors have gained as family members and friends of autistic persons” (8, emphasis original). While I find Osteen’s concept of empathetic scholarship important for understanding academic work, particularly in the humanities, on the subject of autism (including my own efforts here), it is too academically-focused to be applied to most of the auto/biographical texts in my project. These texts often do, on the other hand, offer examples of mediated rhetoricity, and I believe that efforts at both mediated rhetoricity and empathetic scholarship can work productively toward representing life with autism, though through somewhat different modes.

Stuart Murray’s *Representing Autism: Culture, Narrative, Fascination* also makes a significant contribution to the study of the representation of autism in popular culture, particularly in the way Murray conceptualizes autism as an object of representation. He analyzes the treatment of autism in a variety of cultural texts, including fiction, film,
photography, journalism, parenting literature, and auto/biographical writing. Throughout the book, Murray foregrounds the concept of autistic presence, which he explains as follows:

It is autistic presence, in all its many forms, that is the core of all attempts to discuss agency and legitimacy in those subjects for whom autism is in some way part of their representational existence. It is also autistic presence that resists the many discourses that would simplify or ignore the condition. The material nature of such presence, the excess it creates when confronted with any idea of what “normal” human activity or behaviour might be, stubbornly refuses to be reduced to any narrative—medical, social, or cultural—that might seek to contain it without reference to its own terms. (xviii)

I would argue that the search for an understanding of this sort of autistic presence—the “reality” of autism that, while so difficult to identify and describe, is persistent and irreducible to any simple formula—is what drives much of the relational life writing that I examine in this project. Importantly, Murray points out that autistic presence goes beyond that which can be communicated verbally; he claims that “those who do not communicate in these ways are no less a presence. Their individuality is a narrative of its own; their physicality and character are statements of human integrity” (16-17). In spite of the seeming impossibility of pinpointing exactly what life with autism is or means for individuals and families, efforts toward recognizing and understanding autistic presence in whatever ways it is expressed—verbal, nonverbal, autobiographical, mediated, collaborative—are essential not only for the disability studies project of
“destabiliz[ing]…dominant ways of knowing disability” (Mitchell & Snyder 47) but also for the auto/biography studies project of understanding how complicated subjects may be represented in narrative.

Like Smith, Murray examines some of the more well-known autistic life writers, Grandin and Williams, alongside more radical self-advocates such as Amanda Baggs, whose texts include a blog as well as a much-viewed YouTube video about her experience as an autistic person, titled “In My Language.” He contrasts the ways these writers present themselves as autistic subjects, as well as the ways their experiences might inappropriately be accepted as representative of all autistic people; he notes that it is useful to remember that “Grandin’s position as a subject is contested because the meaning and value of autism are themselves contested” (40). For Murray, auto/biographical autism narratives tend to offer a more diverse representation of life with autism than do fiction or media depictions; he argues, “In these [fiction or media] narratives, autistic presence is predictably characterized by a succession of stereotypes, aspects of characterization and narrative function that work by reducing the multiplicities of the autistic subject to the portrayal of a type that is repeated, sometimes with subtle variations and occasionally with additions, across stories” (45). Auto/biography about autism, then, may have the ability to capture autistic presence in a way that representations disconnected from real life with autistic people are unable to do. Indeed, as Murray continues to examine cultural representations of autism, he observes that “the majority of commentaries on the condition presume that those who are autistic are not listening, or reading, or watching. … This is, of course, simply not true; even severely impaired, non-verbal, autistic individuals communicate. What these individuals say must
be the first source of any understanding of the ways in which the condition functions in the world” (60, emphasis original). Relational life writing, whether produced by an individual with autism or by a proximate other (or a combination of the two), is well situated to convey what autistic individuals have to say about their lives and experiences. This does not, of course, mean that all of these texts do so equally well or in the same way, but that the potential for the construction of personhood and selfhood in relationship with others may be greater in auto/biographical texts than in fictional or journalistic ones constructed at a distance. These texts also have the potential to address the problem, identified by both Osteen and Murray, of a few limited models being seen as representative of all people with autism, by creating more, and more nuanced, narratives, which demonstrate not “the” way of being autistic, but the multiplicity of ways that life with autism is experienced.

The consideration of relationality in the construction of life stories and identities is not only a topic of deliberation in the field of auto/biography studies, but in many other fields as well, particularly psychology. Ulric Neisser’s models of selfhood, discussed above, reflect a cognitive psychological approach to understanding the self and how it is constructed through various means and types of relationships. While Neisser recognizes the influence of a number of factors, including the physical environment, other people, memory and anticipation, and one’s private, inner life and theory of self-concept, others have focused more exclusively on a single aspect of coming to know and identify oneself. Psychologist Kenneth Gergen, also investigating the concept of the self, has placed great emphasis on the relational construction of identity, beginning with his work on social
constructionism in the 1980s and continuing to his most recent scholarly writing. While in *The Saturated Self* (1991) Gergen expressed concern over what he saw as the dissolution of the individual self in a world of unremitting social contact—“[T]he very idea of individual selves,” he wrote, “is now threatened with eradication” (x)—his subsequent work has moved toward both greater recognition, and increased acceptance, of a relational understanding of self and identity. In *Relational Being* (2009), Gergen observes, in a similar vein to many of the autobiography critics cited above, that “the view of the individual as singular and separate…is of recent origin. It is a conception of human nature that took root only four centuries ago, during a period that we now view as the Enlightenment” (xiv). Gergen, considering the concept of the singular, bounded self to be a social construct, argues that in fact “there is no isolated self or fully private experience. … We are always already emerging from relationship; we cannot step out of relationship; even in our most private moments we are never alone” (xv). Far from the tone of warning present in *The Saturated Self*, in this text Gergen embraces the concept of relationality; he goes on to suggest that “the future well-being of the planet depends significantly on the extent to which we can nourish and protect not individuals, or even groups, but the generative processes of relating” (xv). Gergen’s positive view of the potential of relationality resonates well with my own project of examining the potential of the co-construction of life stories and relationships in auto/biography for the expansion of available models of life narratives and textual representations of personhood and identity. Attention to relationality in both narrative and identity formation diminishes the reification of segregated groups and emphasizes the connections between individuals across group identities.
Gergen draws inspiration from the sociologist Erving Goffman, whose work on the social construction of stigma has also been highly influential to disability studies, asserting that “[f]or Goffman human action was largely social performance, and thus, the self was a byproduct of the theatrical conditions of the moment” (xix). Gergen argues quite convincingly that much—if not all—of human behavior and even emotion is shaped by what is considered intelligible by one’s culture. Similarly, he posits the concept of “co-action,” in which an idea is called into being through social agreement (intentional or unintentional), offering the example of attention deficit disorder, which, he says, did not exist when his children were young, but today “there are over 500 authoritative books on the subject, over 9,000,000 websites featuring it, and the drug, Ritalin, is a multi-billion dollar business” (36-37). In addition to concepts like illness and health which may be viewed as socially constructed, Gergen also sees emotions, even those we generally consider to be personal and interior (Neisser’s “private self”), as only possible in particular relational settings. In order for actions and emotions to be intelligible to others, they must originate and have specific meaning in a social context (Gergen 74). I find these claims to be quite relevant to autism, but also challenged by it, because of the frequent perception of autistic behavior as unintelligible, and, conversely, the unintelligibility of much “typical” human behavior for autistic people. The difficulty for many autistic people to engage in normative social interaction puts them, in a sense, outside the standard relationship that Gergen identifies. For instance, Gergen comments, “A failure to understand is not a failure to grasp the essence of the other’s feelings, but an

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4 Gergen’s idea of co-action in the construction of pathological conditions is very similar to the sort of social construction of the condition of autism which Majia Holmer Nadesan outlines in her book Constructing Autism: Unraveling the “Truth” and Understanding the Social (2005). I am inclined to agree with Nadesan’s argument that “the idea of autism is fundamentally socially constructed” (2, emphases original).
inability to participate in the kind of scenario the other is inviting” (165). Indeed, many people with autism struggle to participate in the kinds of scenarios to which others invite them, making social interaction complicated on both sides. Gergen’s concept of relational being, then, might be an ideal rather than a natural state for many people with autism, as they seek to build and develop relationships with others and participate more fully in social interactions.

I find that Gergen takes the universality and exclusivity of “relational being” a bit further than I am inclined to do, as he aims to, in fact, “eradicate” the individual self in favor of a fully “relational being.” He makes clear that while “many of the existing attempts represent a weak relationality, or social inter-action [sic]…the attempt here is to generate a ‘strong relationality,’ one in which there is no condition of independence” (xxi). While I find Gergen’s emphasis on interdependence and relationality to be movements in a positive direction, particularly for the recognition of full membership in human society for people with disabilities like autism, an absolute shift to “relational being” at the expense of the individual self also seems problematic to me for the representation of autistic subjects. As I have noted above, I see auto/biographical writing as having positive potential for conveying to readers evidence of autistic individuals’ personhood (their recognition by others as fully human persons), which might well fall into the category of relational being, as well as their selfhood (their unique individuality, thoughts, and feelings), which gets dismissed to some extent by Gergen’s model. While I recognize the merit of his claim that our behaviors and emotions are largely the product of our cultural settings, and are “only intelligible within a particular tradition of relationship” (102), I also find it essential to recognize individuality, particularly for
those whose personhood and selfhood may often be overlooked. Claiming, as Gergen does, that “there is no isolated self or fully private experience” (xv) undermines the potential of auto/biographical writing to foster greater recognition of the autistic self. Additionally, since full participation in the relational setting where behavioral and emotional norms are constructed can be challenging for many autistic people, they may not always be able to produce the sorts of “intelligible” behaviors with which Gergen is so absorbed. Instead of valuing the relational at the expense of the individual, I see the two as ideally in balance with one another. Life writing about autism calls attention to the relational in ways that help us to see how identity can be constructed, and co-constructed, in relation to other people—parents with autistic children, autistic people with non-autistic people—and stresses the value of viewing all human identity and relationships as interdependent. However, equally important, for me, are the ways that the relational reflects back upon the individual, in the sense of Neisser’s “interpersonal self”; through relationship, people construct a sense of who they are as individuals. Those individual selves may be “always already emerging from relationship” (Gergen xv), but they are also always selves within relationships. In much auto/biography about autism, relationships, as well as the self constructed through and with relationships, are both highlighted through attention to relational life storytelling and identity formation.

“Defining” Autism: Pinning It Down, Opening It Up

The search for answers about autism—what it is, what it means for people and families whose lives are in some way affected by it, and what should (or should not) be done about it—has existed since Leo Kanner proposed the diagnosis in 1943, and there are no definitive answers in sight. The general consensus about its etiology has evolved,
over the past seven decades, from the psychogenic hypothesis, based upon a belief in psychological harm caused by parental neglect (publicized by Kanner and Bruno Bettelheim), to a neurobiological approach, based on neurological differences, genetic predisposition, and possible environmental factors (originating with Bernard Rimland’s work in the 1960s and developed further by Uta Frith, Lorna Wing, Simon Baron-Cohen, and many others). However, there is still much that is unknown, and a wide variety of views persists, even among people labeled autistic and their families. These views range from the so-called “anti-vaxxers” (though few would label themselves as such), who suspect that the mercury used as a preservative in some vaccines play a role in the onset of autism, to those who view autism as an element of “neurodiversity,” part of the natural range of human brain function, perhaps not “neurotypical,” but no less valuable for being different. There is much friction between those with differing opinions about autism, in large part because of the extreme variations in experience, ability, and impairment among people in different positions relative to the autism spectrum. Parents of severely autistic children rarely wholeheartedly embrace the concept of neurodiversity, seeing their children’s differences as disabilities, not assets, while people with milder forms of autism, such as Asperger’s syndrome, who are able to become educated and manage fairly well in society, often place value upon the skills or insights that their differences provide (Temple Grandin, for instance, credits her autism for enabling her to “think in pictures” and visualize the world from the perspective of animals, leading to her success in designing livestock-handling facilities and completing a Ph.D. in animal science). This tension between different understandings of autism and the many discourses surrounding these different views is in part what makes autism such a source of
“fascination,” as Murray suggests. It is also what makes life writing about autism so diverse and deserving of further study. As this is not in any way a clinical study, but a study of the forms and effects of auto/biographical literature, I am not out to establish a precise definition of autism, but rather to examine the ways that life writers understand and construct it in the context of their own and one another’s lives. With that said, I do want to offer some indications of how I understand autism as a condition.

My general view of autism is as a developmental disability, which I see as falling into the category of mental disabilities. For me, “developmental disability” implies that an individual may develop at a different pace or in a different manner than nondisabled people. While growth may occur at unconventional rates, and perhaps with different end points, those with developmental disabilities absolutely do grow and develop, and continue to do so throughout their lives. Those with autism frequently have differences—neuroatypicalities—in their sensory perception, information processing, social interaction, and communicative expression. As the auto/biographical texts that I examine in this study make clear, every person with autism has a unique set of experiences, and in some cases, people with autism or their families argue that different areas of the autism spectrum should in fact be entirely different diagnoses (e.g., Kedar 63; Stagliano 183). I will leave clinicians and researchers to explain more thoroughly the current theories of autism’s biological mechanisms, and I make no attempts to diagnose anyone with autism or evaluate anyone’s diagnosis or prognosis, but I find the variation in approach to the autism label to be both complicated and compelling. As I take a disability studies approach, I do largely fall on the side of seeing autism as a way of being human that is worthy of understanding and respect, rather than as an illness in need of a
cure. I see little value in concentrating on how to erase differences, as this is generally both an impossible and a troublingly intolerant approach, and find it much more valuable to foster acceptance of individuals as they are and to collapse boundaries restricting what it means to be “normal.” This is where I see a great deal of potential in auto/biographical writing to legitimize the personhood and selfhood of individuals who differ from the norm, which can also lead to innovative and productive textual means of representation. I am also less inclined to see the recent surge in autism diagnoses as an “epidemic” than as an increase in awareness and an evolution in the construction of autism as a condition; the recent changes in the diagnostic criteria and language in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) provides a vivid example of this ongoing evolution.5 On the whole, my chief concern is how auto/biographical writing about autism, from the perspective of the autistic person, his or her family members, or a combination of the two, navigates these tensions and differences in perspective to construct an understanding of the self in relation to others—and in relation to the label of autism.

I am drawn to Douglas Biklen’s use of the phrase “labeled autistic” to describe people represented in his book, *Autism and the Myth of the Person Alone*, who have in fact been given this label. He reports that “one of the contributing authors objected vigorously to my using phrases such as ‘people with autism’ or ‘autistic persons,’ preferring instead phrases such as ‘classified autistic’ or ‘diagnosed as being on the autistic spectrum,’ thus keeping in the foreground recognition that autism is a concept *developed and applied, not discovered*” (12, emphases original). I appreciate Biklen’s

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5 See Chapter 5 of this dissertation for further discussion of these changes as evidence of the constructed nature of dominant understandings of autism.
point that autism is, in fact, a diagnostic label rather than an independent reality; the continuously evolving views of the nature, criteria, study, and treatment of autism reinforce the fact that autism is a construct, created at a certain point in history and adapted over time through changing medical and social environments as well as new knowledge about those who are diagnosed with it. Majia Holmer Nadesan makes a similar point in her book *Constructing Autism*, commenting that her work “does not attempt to locate the ‘truth’ of autism because, as I argue, there is no fixed, universal biological truth to be located” (7). Instead, the many “truths” about autism and its meaning are constructed through a variety of discourses, including, significantly, the sorts of life writing that I will examine in the following chapters.

I respect Biklen’s decision to describe individuals as “labeled,” “diagnosed” or “classified” as autistic; however, at the same time, I recognize, as he does, that there are many options for language use regarding autism, and no universal agreement about which option is best. Two of the most common choices are “person with autism” and “autistic person.” The former became popular with the advent of “person-first language,” which many see as preferable when describing someone who has a disability—i.e., “person with a disability” rather than “disabled person.” The aim of person-first language is to emphasize that an individual is a person who *has* a disability, rather than one who is *defined by* his or her disability. Many people prefer this terminology, including Ido Kedar, who writes, “[S]ince I learned to write and point [others] see me as a boy with autism, not as an autistic boy” (65), associating others’ ability to see him as a “boy first” with their recognition of his personhood, as opposed to their seeing only his autism. However, many other self-advocates find person-first language, particularly in regard to
autism, to be problematic. Jim Sinclair, co-founder of Autism Network International (ANI), explains the perspective that “autistic person” is preferable to “person with autism”:

1. Saying “person with autism” suggests that the autism can be separated from the person. …

2. Saying “person with autism” suggests that even if autism is part of the person, it isn’t a very important part. …

3. Saying “person with autism” suggests that autism is something bad—so bad that [it] isn’t even consistent with being a person.

For Sinclair, autism is an integral part of identity, and therefore there is no reason it should not be used as an introductory adjective rather than an appendage. Similarly, an autistic blogger named Zoe comments, “As with my other traits, I refer to my disability with an adjective-noun construction which is common to the English language. I would also describe myself as a long-haired woman. So far no one has come forward to demand that I instead refer to myself as ‘an individual with long hair,’ or accused me of ‘defining myself by my hair length’” (“Disability First”). My point in citing these examples is that there are, in my view, good reasons for the use of each of these different terms to describe people affected by autism, and I leave it to individuals living with the label to decide which term to apply to themselves. In my own usage, I take a similar approach to that of Stuart Murray, who acknowledges that in Representing Autism, “I found myself alternating between the two phrases [‘having autism’ and ‘being autistic’], seeing both as enabling. I have not been precise about this usage, so it may well be the case that one features more than the other, but they both appear here as positive terms that help us to
think better” (24). Like Murray, I have not been systematic in my application of these terms, though I have tried to be conscious of the language I am using throughout this dissertation. I am open to, and make use of, various terms to describe people living with autism, as I find this approach to be optimal to fostering the widest range of possibilities for individuals to draw upon in their construction of their own self and experience, in relation to other people and to the discourses surrounding autism.

**Exploring Relationality in Textual Practice**

Each of the four body chapters of my dissertation explores a different theme of relationality and how it is manifested in published auto/biographical writing about life with autism. In each chapter I focus on a particular form of relationship between individuals and discourses and examine the textual practices that such relationships inspire, or make possible, for the writers of these texts. Contending with the dynamics of these relationships in the construction of their life stories and identities leads each of these writers, or sets of writers, to make use of a variety of rhetorical moves that bring relationality into their texts. These relational moves are both revealing in regard to understandings of personhood, selfhood, and nonnormativity for individuals living with autism and productive for understandings of how stories and identities can be constructed in life writing in general in the context of relationality.

Chapter 2, “Clara Claiborne Park’s *The Siege* and *Exiting Nirvana*: Shifting Conceptions of Autism and Authority,” examines relationality through questions of expertise, authority, and voice in the telling of life stories about autism. Here I focus on two auto/biographical texts, separated by forty years, about Park’s experience living with her autistic daughter Jessy. In these texts, relationality in the form of the relationship
between non-autistic mother and autistic daughter, as well as the tension between expert and non-expert perspectives, is manifested in the text through the negotiation of and resistance to authoritative discourses and the assertion of the amateur’s own form of authority. As I analyze the ways that these two texts show an evolution in both Park’s life narrative and her understanding of autism in relationship to the shift in larger social and medical discourses surrounding autism, particularly through her use of metaphors to explain autism’s effects on Jessy and the family, I also explore how Park’s sense of relationality with Jessy, and Jessy’s life story, develops over time. As Park grows in her understanding of autism in general and of her relationship with her daughter in particular, her narrative expands to include Jessy’s voice and experience in the ways she is able to contribute, through her speech, her art, and to some extent, her own writing. Park’s work, I argue, both demonstrates the evolution of one writer’s sense of relationship to other people and discourses in her approach to autism and her own life story, and indicates a movement toward a more relational approach to auto/biographical writing that begins to make space for autistic people whose impairments may make independent self-representation difficult.

Chapter 3, “Transformative Narratives: Double Voicing and Personhood in Collaborative Life Writing about Autism,” continues many of the themes of Chapter 2, as here I discuss further the extension of authority and voice from the “expert,” to the parent, to the autistic individual him- or herself. Here the relationship between parent and child becomes even more central, as these texts are each co-authored by a non-autistic parent and an autistic son or daughter, and this relationship is developed textually through the double-voiced narratives of each collaborative memoir. In my examination
of two collaborative texts, *There’s a Boy in Here* by Judy and Sean Barron, and *Carly’s Voice* by Arthur and Carly Fleischmann, I argue that these works carry great potential to resist normative limitations on personhood and selfhood through their double-voiced or dialogical nature. Since each text contains both writers’ unique narrative viewpoints, the double narratives both complement and conflict with each other as they tell relational life stories from different perspectives. While the parent narratives focus on a story of recovery, in which the autistic child “breaks through” autism’s impairments and gains the ability to be recognized as a full person and unique self, the co-existence of the son or daughter’s narrative serves to counteract the limitations of the recovery narrative and demonstrate evidence of personhood prior to communication. In collaborative memoirs, then, the dialogical telling of life stories by individuals with autism and their families can enable greater recognition of the relational construction of identity both by autistic people themselves and by others with whom their lives and stories intersect. Attention to both sets of stories, and the ways in which they engage with one another, can reveal more about the lives and identities of those involved than can either set of stories alone.

In Chapter 4, “Expanding Possibilities for Personhood and Narrative: Parent Memoir about Life with Severe Autism,” I focus on auto/biographical texts in which the parent is the primary, or only, contributor because the child’s severe autism prevents him or her from communicating effectively, or at all, through speech or writing. Whereas in Chapter 3 the autistic individual who gains the ability to communicate has the power to influence representations of his or her self, personhood, and life story, here relationality in life writing is less collaborative, but not less central. As parents construct life stories and identities for themselves as parents of children with severe autism, they also, by
extension, construct life stories and identities for their sons and daughters. In their efforts to represent their relational stories of living with autism, these parent writers often struggle with the tensions between available models of normative life stories and personhood, and their own experiences and those of their children. Parent memoirs must navigate these tensions in a variety of ways as they seek to represent textually the reality of life with autism, which is often unpredictable, nonnormative, and without conventional narrative closure or resolution. The use of rhetorical listening to nonverbal forms of communication, and parents’ efforts to interpret the meaning of that communication in their narratives, can help to make space for the nonnormative embodiment and enmindedness, or mental presence, of their autistic children. Though they do so in varying ways and to different effects, the parent memoirs I examine here, including those by Mark Osteen, Kim Stagliano, Michael Blastland, and Kate Rankin, negotiate relationships with their severely autistic children, sometimes accepting but often challenging existing models of narrative and personhood and working to create space for nonnormative life stories, identities, and forms of personhood that do not fit the standard models.

Chapter 5, “Autistic Autoethnography: Articulating Self, Locating Culture,” focuses closely on the writing of individuals with autism themselves. While the writing processes here may be largely (though often not entirely) independent, the autistic lives that these writers depict are very much interdependent in nature, and their stories are decidedly relational ones. In fact, while the literal meaning of the word “autism” is rooted in the self, these autoethnographic texts by autistic writers subvert such

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6 Paul Eugen Bleuler, a Swiss psychiatrist, first used the term “autism” in 1911 to describe an aspect of schizophrenia (the name of which he also coined). He wrote, in an article in German titled “Dementia
expectations by highlighting the ways in which autistic individuals are, in fact, integrally involved with other people in relationships and communities. Through the textual practice of literary autoethnography, these writers seek to construct their own identities with and for other people, as well as to demonstrate their own membership in social and cultural settings. For my purposes, I define the term “autoethnography,” which has its roots in both literature and anthropology, as auto/biographical writing that engages in the representation of the self and the self’s positioning within culture, and that consciously seeks to respond to others’ representations of one’s self and cultural group. These autoethnographic texts, by Dawn Prince-Hughes, Kamran Nazeer, and Ido Kedar, all diagnosed as autistic, not only demonstrate that autistic people should be seen as members of larger social and cultural communities, but also break down the binary oppositions between normative and nonnormative ways of being, using autoethnographic techniques to create space for the normative and nonnormative aspects of autistic identities and relationships to coexist.

Finally, in Chapter 6, I conclude by bringing together the various threads of relational textual practice developed in each chapter and considering how these techniques might be recognized in other forms of auto/biographical writing, most notably the growing genre of online writing about life with autism. In a close reading of selections from the multi-author autistic activist blog We Are Like Your Child, I gesture

Praecox oder Gruppe der Schizophrenien”: “The [...] schizophrenics who have no more contact with the outside world live in a world of their own. They have encased themselves with their desires and wishes [...] they have cut themselves off as much as possible from any contact with the external world. This detachment from reality with the relative and absolute predominance of the inner life, we term autism” (qtd. in Parnas, Bovet, and Zahavi). Both Leo Kanner and Hans Asperger, in the 1940s, went on to apply the term “autistic” to children whose symptoms were similar to our current understanding of autism, which was long considered a form of “childhood schizophrenia.”
toward the future of auto/biographical writing—about life with and without autism and other disabilities—and the promise of relationality for textual practices of life writing.

As I hope to show in this dissertation, life writing about autism is simultaneously exceptional in its attention to the relational nature of the representation of disability—especially autism, which is often figured as isolated and isolating—and comprehensive, in that it helps expand the recognition of relationality in life writing in general, following up on the project begun by feminist critics of life writing in the late twentieth century. While I agree with Eakin’s claim that all life stories and selves are to some extent relational, I also wish here to call attention to the ways that life writing about autism makes use of relationality through textual practices that can change conversations about life and people with autism through the relational, interdependent, and collaborative construction of life narratives and of the personhood and selfhood of the individuals being represented. Such textual moves in response to relationships between people and discourses have the potential to contribute to better understandings of those living with autism as far from isolated, but as selves in relationship with other individuals and communities. At the same time, these auto/biographical texts demonstrate the potential of relational textual practices for constructing life stories and identities in ways that reflect the realities of interdependence, not only for lives in which disability is present, but for all human relationships and life stories.
Chapter 2

Clara Claiborne Park’s *The Siege* and *Exiting Nirvana*:
Shifting Conceptions of Autism and Authority

**Introduction**

In the mid-twentieth century—early in the history of autism—those considered “experts” on autism were almost invariably professionals, whether physicians, psychologists, psychiatrists, or scientists. Case studies by people like child psychologist Leo Kanner, who created the diagnosis of early infantile autism in 1943, and pseudo-psychoanalyst Bruno Bettelheim, 7 who popularized the notion of the cold, distant “refrigerator mother” as the cause of autism, formed the basis of the production of authoritative knowledge about autism. Autistic people and their parents were often put in the position of being passive recipients of this professional knowledge, or were not considered worthy of participation in the sharing of such knowledge at all, and certainly not in the generation of it.

While sources of authority on autism continue to be debated, often heatedly, among the many different interested parties, including individuals diagnosed with autism, parents and family members, medical professionals, therapists, educators, and more—notable shifts have occurred in the location of authority and the assigning of expertise since the earliest days of autism’s existence as a diagnosis, and with those shifts have come significant developments in knowledge and in the production of meaning surrounding autism. The shift in the weight of authority from so-called “experts,” primarily doctors and scientists, to “amateurs” in the form of parents, began with parent

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7 Bettelheim has since been outed, most notably by Richard Pollak in his biography *The Creation of Dr. B.: A Biography of Bruno Bettelheim* (1997), as a poseur who did not actually have degrees in psychology or psychiatry, casting even greater suspicion upon his theories about the psychogenic origins of autism and his comparison of autistic children traumatized by parental neglect to adults in Nazi concentration camps.
memoirists such as Clara Claiborne Park, who published her first book on life with her autistic daughter Jessy in 1967. Park’s book, *The Siege*, as I will argue in this chapter, played an important role in subtly resisting the dominance of “expert” knowledge and asserting the authority of the parent who, though not formally trained, has experience and firsthand knowledge of the autistic child that the professional does not. Considered by many to be the first true parent memoir about autism, Park’s text works to challenge the traditional sites of expertise and begins to claim the right to shape discourse and representation of autistic life and subjectivity outside of those accepted sites.

Park’s second full-length memoir of life with her autistic daughter, *Exiting Nirvana*, published in 2001, depicts significant shifts in Park’s understanding of autism and of her daughter, influenced both by changing scientific, professional, and popular conceptions of autism in the surrounding environment as well as by Park’s experience with Jessy over an additional three decades. In writing a much-later sequel to her significant early account, in which she updates, revises, and develops their shared story, Park offers a unique opportunity to examine the ways in which parents of autistic children draw upon and engage with existing discourses about autism in order to generate their own narratives, especially as those outside discourses themselves shift and evolve. While Park is more accepting of “expert” discourse in the later text, she does not surrender her own “amateur” authority, continuing to negotiate her understanding of autism and her representation of life with an autistic daughter through the contentious notion of expertise. The influence of “expert” discourses and Park’s relationship to these discourses also affect the literary devices Park uses in constructing her daughter’s story, particularly through the controlling metaphors of each book. Though related, the
metaphors of the “siege” and “Nirvana” reflect different ways of conceptualizing autism and the autistic person at two very different moments in time. In her negotiation of and resistance to dominant authoritative discourses about autism, Park demonstrates the value of the parent memoir in constructing a sense of what autism is and what it means for both the autistic person and for his or her family. Although Park herself does not identify as autistic or disabled, I see her memoirs as auto/biographical texts of disability that make an important contribution to an understanding of the ways autistic lives can be constructed in life narrative. Her inclusion of Jessy as a participant in the production of her second memoir also extends the realm of expertise from the professional to the parent and ultimately to the autistic individual him- or herself. By contesting and rethinking the relationships between discourses and between herself and other people, Clara Park claims the authority to speak about her own experience and pushes the boundaries of both expertise and autobiography, helping to create new ways of understanding and writing about life with autism.

*The Siege*

Published in 1967, *The Siege* is considered by many to be “the first ‘inside’ (as opposed to clinical) account of an autistic child’s development and life” (Sacks, “Foreword,” *Exiting Nirvana* ix). While there were several other accounts written around the same time, these other accounts tended to be either quite brief, such as Rosalind Oppenheim’s 1961 *Saturday Evening Post* article “They Said Our Child Was Hopeless,” or else written through a professional lens, like Jacques May’s 1958 *A Physician Looks at Psychiatry*, which, in part, discusses his twin boys, both diagnosed as autistic. Park’s memoir is not only among the earliest but also one of the most thorough, based on
carefully-kept records and providing detailed descriptions of her daughter’s behavior and progress, even without any formal psychological or medical background. The book follows the Park family’s journey from the birth of their youngest daughter Jessy (called by the pseudonym Elly in this text\(^8\)) through her early childhood, as indicated by the book’s original subtitle, *The First Eight Years of an Autistic Child.*\(^9\) Following what has since become a familiar pattern in parent memoirs, *The Siege* details the Parks’ realization of Jessy’s difference, their attempt to find answers through visits to doctors and psychiatrists, and Clara Park’s efforts to help her daughter learn and grow. These efforts are framed as the “siege” of the title, an attack on Jessy’s autistic “citadel” and an attempt to bring her into contact with the world around her. The book chronicles not only the story of Jessy and her family as they strive to understand and help her, but also the development of Clara Park’s understanding of her own position within the discourse and construction of meaning surrounding autism. As she learns more about the world of so-called “experts,” she begins to resist the monopoly these people claim on the production of knowledge about autism as well as their treatment of “amateurs” such as herself.

Through her own research into the scientific literature about autism, her interactions with medical professionals in the course of seeking care for Jessy, and her hands-on experience living and working with Jessy on a daily basis, Park comes to create her own dynamic, relational understanding of autism and of her autistic daughter, and to use her

\(^8\) Though Park uses the pseudonym “Elly” for her daughter throughout the original text of *The Siege*, she reveals that her real name is Jessy in the Epilogue added to the book in 1982, and uses this name throughout the 2001 text of *Exiting Nirvana*. To keep things as clear as possible, I will call Jessy by her real name throughout my discussion, and substitute “Jessy” for “Elly” in quotations from the earlier text. I discuss Park’s explanation for her use of the pseudonym below.

\(^9\) Later editions changed this subtitle to *A Family’s Journey into the World of an Autistic Child* (Stevenson 207), shifting the focus from the individual’s experience of autism to that of the family as a whole, an indication of Park’s growing attention to the relational, shared experience of life with autism, challenging the image of isolation implied by the autistic “citadel.”
own “amateur” status to claim a new kind of authority over the construction of meaning about autism.

*The Siege* begins with Jessy’s birth in 1958, quite early in the history of autism, which was established as a discrete diagnosis by Leo Kanner in 1943. Jessy is David and Clara Park’s fourth child, so Park is an experienced mother when Jessy arrives, but Jessy is a very different child from the older three. Like any mother, Park compares infant Jessy’s behavior with that of her other children, and with her friends’ children who are Jessy’s age.10 Park places herself squarely within the majority group of mothers of the time period, “the mothers of the forties and fifties for whom Dr. Spock had replaced the conventional wisdom. Of professional ability, most of us, we had made motherhood our profession. We read, we discussed our problems with each other. We were very knowledgeable” (*The Siege* 15). Colin Ong-Dean corroborates the shift during this period toward parental trust in “experts” like Dr. Spock, noting that “[b]y the 1950s, parenting became something that was to be guided mainly by the scientific knowledge of the doctor,” a preference that was fostered by both “the suburban isolation of post-World War II mothers and the 1950s’ faith in scientific expertise” (145). This trust in “scientific expertise” over “conventional wisdom” encouraged mothers to seek professional advice not only for their ordinary parenting questions, but also for guidance on understanding and handling a child who has a disability, as Park gradually comes to realize is the case with Jessy. Ong-Dean observes that “advice books for parents of disabled children, while instructing parents on the characteristics of disabilities, were likely to do so in a way that

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10 For example, a friend’s baby who “had lacked oxygen” during birth and whose “brain had been affected” functions at a higher level than Jessy, and a neighbor’s son whose speech is slow to develop will “come out of it” though Jessy has not yet, by age 8, “come out of” her difficulties with speech and communication (*The Siege* 6-7).
strongly emphasized the primacy of professional authority and the danger that parents’ (in particular, mothers’) judgments might be clouded by emotion” (146). Park, indeed, comes to struggle with the tension between professional authority, which dictates that autism is the fault of the parents, and her own tentative claim to expertise, tempered by her acceptance of the danger that her own emotions may get in the way of sensible judgments or treatment of her child. As objective and formally trained third parties, doctors and scientists were, for Park and other mothers of the time, the logical place to turn for informed advice on parenting.

Leo Kanner was the first and still one of the most dominant authorities on autism at the time of Jessy’s diagnosis and Park’s writing of The Siege, and his work plays a prominent role in Park’s own efforts to understand autism and its effects on Jessy’s and the family’s lives. One of the most influential aspects, for Park, of Kanner’s work on autism was his emphasis on what he considered the typical parents of autistic children. In a 1955 article, Kanner and Leon Eisenberg presented the “undisputable fact that the [autistic] patients came from intelligent, sophisticated stock… The majority of the parents, though competent in their chosen vocations, were cold, detached, humorless perfectionists, more at home in the world of abstractions than among people, dealing with their fellow men on the basis of what one might call a mechanization of human relationships…” (228). Indeed, throughout Kanner’s case studies, he described the parents of one patient after another as highly educated, professionally successful, and either emotionally detached, obsessive, or both. In his 1943 article, “Autistic Disturbances of Affective Contact,” Kanner proposed that the similar intellectual ability and emotional detachment he detected among parents of autistic children suggested not
that the parents’ traits caused their children’s autism through psychological damage but that the autistic children might be genetically predisposed to a certain kind of difficulty in making emotional connections with others. He concluded, in this article, “We must, then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicap. … For here we seem to have pure-culture examples of inborn autistic disturbances of affective contact” (250, emphases original). Kanner’s initial hypothesis, then, was that autism was biological and “inborn” and that if there was significance to the apparent pattern of “highly intelligent parents” with tendencies toward obsessiveness and lack of emotion, it was a possible sign of inherited traits that contributed to a child’s autism. As Kanner observed in this first study, “The children’s aloneness from the beginning of life makes it difficult to attribute the whole picture exclusively to the type of the early parental relations with our patients” (250).

However, Kanner later introduced the concept that would become known as the “refrigerator parent” (more commonly “refrigerator mother”), the cold and distant parent who causes psychological damage to the child, thereby bringing about autistic withdrawal and behavior. With Eisenberg, Kanner proposed the idea that “the emotional refrigeration which the children experienced from such parents could not but be a highly pathogenic determinant of their early personality development, superimposed powerfully on whatever predisposition [sic] may have come through inheritance” (Kanner & Eisenberg 228-29). While still allowing for some genetic basis for autism, this suggestion opened the door to the hegemony of the so-called psychogenic hypothesis that
was popularized by Bruno Bettelheim. Although Bettelheim disagreed with Kanner as to the extent of the “parents’ superior intelligence and professional achievements” (Bettelheim 422), Bettelheim held fast to the idea that parents’ emotional neglect of the child (or the child’s perception of such neglect) was a major contributor to the development of autism as a psychological defense: he argued that “the autistic child, by not permitting any change, by not permitting himself to be an ‘I’…is complying with what he considers a parental wish that he should not exist” (429). This pervasive and insidious view dominated theories about autism during the 1950s and ’60s and beyond, and parents like Clara Park were forced to confront it as they learned about and attempted to make sense of their children’s diagnoses. As Jacques May observed after he and his wife received an autism diagnosis for each of their twin sons, “[W]e were being held responsible for the children’s situation. This was the accepted view, we found, the official doctrine, the only explanation offered and recognized, the sole basis for treatment” (40). The preeminence of psychoanalysis during the time period made a psychogenic etiology the most logical and easily accepted one, and, as May notes, psychiatric concepts of the period were “mere concepts, which means that they are nothing more than a mental interpretation of reality,” one which “cannot be supported by objective methods” (143). In May’s view, psychiatrists interpreted the facts to fit with their existing theories, rather than searching for better theories or testing their findings.

These are some of the influential contemporary theories about autism with which Park had to contend, and her narrative is shaped by her efforts to both draw upon and move beyond these views. Early in her narrative, Park acknowledges that many of the professional assessments about the parents of autistic children apply quite clearly to
herself and her husband. Both of them, for instance, are highly educated, especially for the era; David Park is a physics professor, and Clara has an M.A. in English. Park concedes, “[M]y husband and I, while scarcely typical of the population as a whole, were typical of the parents of autistic children” (The Siege 33). They are not only educated and intelligent but are also subject to “the acute shyness that defended itself as reserve” (128), fitting the description, to some extent, of emotional detachment. Further supporting the stereotype of parents of autistic children, Park explains that her pregnancy with Jessy was unexpected and not particularly welcome; after her three older children reached school age, Park had been thinking of returning to teaching, and she experienced some “initial depression as the gates clanged shut” on these plans (17), though she indicates that she moved on from this disappointment fairly quickly. She explicitly demonstrates her awareness of Kanner and Bettelheim and their views about the role of parents in the origin of autism, noting, “Bettelheim writes that parental rejection is an element in the genesis of every case of childhood schizophrenia he has seen. … Kanner’s original hypothesis was consistent with the psychiatric consensus. He considered that parents must play a large part in the genesis of infantile autism” (125-26). In addition, Park makes a point of including other factors in her narrative that could potentially play a role in Jessy’s autism:

[T]he measles [which Park had while pregnant with Jessy] and the colic and the bump on the head and the fact that I was an intellectual mother by

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11 Autism was long considered a form of childhood schizophrenia, and the two terms were often used interchangeably, by Bruno Bettelheim in particular. For instance, Bettelheim writes that “to develop childhood schizophrenia it is enough that the infant be convinced that his life is run by insensitive, irrational powers who have absolute control of his life and death. For the normal adult to suddenly develop schizophrenic-like reactions, this must actually be true, as it was in the [Nazi concentration] camps. The view is therefore proposed that infantile autism is a state of mind that develops in reaction to feeling oneself in an extreme situation, entirely without hope” (68).
no means totally accepting of her feminine role, who did not at all want another baby. … Every piece of potential evidence must be recorded in this account, not least the evidence that can be used against me. We need to know all we can if someone someday is to understand at last what is relevant and what is not. (23)

In this way Park demonstrates both her recognition of the current theories about causes of autism and her awareness that there is much that is still unknown. It is in her recognition of the unknown that she begins to cultivate some distrust of the current theories and of the locations of expertise that foster these theories.

Here and throughout the book, Park shows both humility and deference to the "experts" in allowing that she may indeed bear some responsibility for her daughter’s autism, but she also makes clear that she does not entirely buy into theories about parental rejection. Indeed, as Jessy gets older, Park and her husband seem to become less and less affected by professional opinion, surprising friends and doctors who encourage them to get counseling to work through feelings of guilt. Of a psychologist friend, Park writes, “I don’t think she believed me when I told her I never had any [feelings of guilt]. I should have. Even if I had not been a typical autistic parent, I had been far from welcoming my pregnancy with [Jessy]. I knew that and so did my friend. It would have made good Freudian sense for me to fear, as I slowly awoke to the severity of [Jessy’s] condition, that she rejected human beings because her mother had rejected her” (130).

While Park’s professed lack of guilt is somewhat unusual among parental memoirs of autism, particularly in the culture of the “refrigerator mother” by which she is surrounded, her experience parenting three children before Jessy helps bolster her
confidence in herself as a mother, as her parenting style has not changed significantly since her older children were young. She explains, “I knew I had been the same kind of mother. [Jessy] had been warmed, cuddled, tickled, and loved. Experience with three children had taught me that the mind-reading powers of babies are greatly exaggerated. I knew that [Jessy] had never guessed that (like so many mothers of normal children) I had not really needed another baby” (131). Park’s language here, twice asserting “I knew” and stating what her experience “had taught [her],” indicates her confidence in her abilities as a mother. This confidence in her own knowledge over the professional opinions of people like Bettelheim enable her, as Josje Weusten argues, to “[go] beyond established discourses on motherhood and autism” (54) and to claim her own sense of authority outside of those established discourses. Rather than accept professional opinion regarding her role in her daughter’s autism, Park begins to use her own experience as evidence toward the subtle assertion that the refrigerator mother theory is simply wrong.

Despite Park’s growing confidence, the professionals whom she and her family encounter in person present real challenges to their attempts to understand and claim authority over their experience of autism. The view of autism as a psychogenic condition caused by parental coldness, while fairly uniform among medical and psychiatric professionals, did not translate into any kind of common program of treatment or even advice beyond the recommendation of psychoanalysis for either the parents or the child.13

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12 I acknowledge that Park’s confidence and claiming of authority may be largely applied retroactively as she writes, rather than reflective of her attitude at the time described in the narrative. Park herself points out, “Experience as analyzed is no longer experience as lived” (The Siege 87). However, since the book is written when Jessy is only eight years old, Park’s attitude at that time demonstrates her growth since Jessy was first diagnosed.

13 Park knows from her research that Kanner found no evidence of improvement as a result of psychotherapy for autistic children, leading her to the conclusion that “[i]n the current state of knowledge there was nothing that medicine or psychiatry could do” (The Siege 122).
The staff at the unspecified psychiatric “Institute” that the Parks visit when Jessy is three years old is incredibly unhelpful, refusing to answer questions or provide much insight, giving the Parks the distinct impression that they are “on trial,” though Park notes, “Nothing had to be said about parental responsibility for infantile psychosis. I record it to the Institute’s credit that nothing was said. But the thought hung heavy” (136, emphasis original). Even when Park tries to demonstrate her knowledge of such theories, the Institute employees refuse to engage with her: “‘You’ve read that, have you?’ was all the social worker said” (136). Trudelle Thomas calls attention to the frequent practice, past and present, of professionals discouraging parents of disabled children from reading or informing themselves too much, “try[ing] to infantilize them by scolding, blaming, and talking down to them,” and creating an atmosphere in which “the only acceptable attitude on the part of parents was gratitude” (190). The professionals at the Institute clearly put the Parks in a position of ignorance and dependency, making them wait for an appointment, for the results of the evaluation, and for written reports to be sent to Jessy’s other doctors. Park summarizes the gap between what they need from the professional world and what they receive: “We wanted information and techniques. We wanted sympathy—not the soppy kind; we were grown-up adults—but some evidence of fellow feelings, which ordinary doctors give readily enough. And—was it so unreasonable?—we wanted a little reassurance, a little recognition, a little praise” (The Siege 142). However, offering recognition and praise might serve to downplay the position of power that the people of the Institute hold, and to weaken their authority by distributing it. Certainly, in light of the view that parents are at fault for their children’s autism, giving praise would seem to offer reward where punishment or rehabilitation was considered
more appropriate. Park’s direct experience with these people she dubs “refrigerator professionals” (143) leads her to begin to seriously question the findings of “experts” like Kanner and Bettelheim, since the professionals seem so far removed from the experience and mindset of parents like herself.

It is in a chapter titled, appropriately, “The Amateurs,” that Park begins to establish a claim to authority for the parents of autistic children. Park’s efforts help to create a new space for the construction of meaning about autism by people who may not have formal medical or psychiatric training, but whose life experiences give them a right to claim expertise that had been denied them by the medical professionals who had largely monopolized authoritative discourse on the subject.14 At this challenging moment in the history of autism, when much of the discourse surrounding autism was limited, misleading, or damaging, Park helps to shift the balance of authority out of the hands of “experts” whose work failed to help autistic children and their families, and into the hands of “amateur” parents who needed empowerment and encouragement to continue their efforts with their children and to gain the information necessary to help them. This shift in authority is aided by the presence of professionals who are on the cusp between expert/doctor and amateur/parent, such as Dr. Bernard Rimland. Park devotes far less space in her text to Rimland than to people like Kanner and Bettelheim, in part because his book, she writes, “hadn’t been written when our trouble came upon us. The field is as new as that” (The Siege 89), and she goes into very little detail about the content of his

14 I would like to note here that autistic people themselves certainly also fit the description of having life experiences that entitle them to a claim of expertise about autism; however, it was some time before any autistic people were publicly recognized as being able to speak for themselves or to contribute to the process of meaning-making about autism. Temple Grandin, whose first autobiography was published in 1986 (nearly twenty years after Park’s first memoir), is usually seen as the first autistic author to be recognized in this way. I discuss autistic autobiography and autoethnography more specifically in Chapter 5.
work. But Rimland, who was father to an autistic son and whose hypothesis about a neurological basis for autism began to slowly break down the foundations of the psychogenic view, was part of a new generation of “experts” who provided support to the “amateurs” who had been held back by the majority of psychiatric professionals. It was some time before Rimland’s book, *Infantile Autism* (1964), began to make an impact in the professional literature, but Park notes that it was “the exhaustive book we had needed so long. … We read in it with wonder of child after child who could have been [Jessy] herself” (89). This kind of professional opinion, which allowed for possibilities besides that of blaming parents, offered a more sympathetic environment for amateurs than did the other books and doctors the Parks encountered. This book provided some of the sympathy and “fellow feelings” that Park, above, states they needed so desperately.

Another example of a compassionate professional is the unnamed psychiatrist Park eventually finds to work with Jessy, who is both supportive and hands-off. Park explains that this doctor “is willing to accept that parents can be partners, even senior partners, in the treatment of their child. He does not consider that he presides over a privileged arcanum into which we are not qualified to set foot” (178). Experts who are willing to share authority, like this doctor and Rimland, help enable Park’s establishment of a claim to relational expertise for parents of autistic children.

Park’s own experience forms the basis of her claims regarding the important role of parents. From early in Jessy’s life, Park keeps meticulous records, which she draws

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15 Bettelheim’s *Empty Fortress* (1967), takes sharp aim at Rimland’s proposal of a “neural theory” of autism: “Rimland holds that the source of the autistic disturbance is to be found in the reticular formation of the brain stem. But a careful study of the evidence present in his book failed to convince me that autism has anything to do with an inborn dysfunction of this or any other part of the brain. And even if a specific neurological dysfunction should some day be found to correlate highly with the syndrome of infantile autism, it would still be compatible with the psychogenic hypothesis” (401). The prevalence of the psychogenic hypothesis made for significant resistance to Rimland’s neurological theory.
upon in writing the detailed accounts of Jessy’s behavior, limitations, and progress that make up much of the book. Oliver Sacks appropriately comments, “There is more ‘data’ on Jessy, I suspect, than on any other autistic human being who has ever lived” (“Foreword,” Exiting Nirvana x). Though on one hand Park’s obsessive record-keeping about Jessy feeds into Kanner’s observations of “a great deal of obsessiveness in the family background” of his autistic patients (“Autistic Disturbances” 250), on the other hand it is a practice that enables her to build a sort of database of information which she can draw upon in her work with Jessy not only as parent but as teacher and therapist. More pertinent and specific than the case studies included in the professional writings of Kanner, Bettelheim, and others, Park’s records about her own child help her to understand Jessy’s behavior, to see what has helped her and what has not, and to eventually share that information with other parents, as she does through publication of The Siege. Extensive personal experience is one of the key advantages which Park argues that parents have over professionals; as she puts it, the parent has “total familiarity with the case since birth” (The Siege 180) and “can observe the child in the complete variety of situations to which it is exposed, not merely in the artificial situation of the therapy hour” (181). In other words, parents have the advantage of being in relationship with their autistic children. Park recognizes how little doctors and psychiatrists are able to experience of Jessy in a brief appointment or testing situation, and how limited their recommendations for treatment must therefore be. In this sense, parents’ ability to speak for and about their children far surpasses the ability of the so-called experts. As Mitzi Waltz points out, Park’s account of her daughter “was intended to present a rational, well-researched counterpoint” to those of Kanner and Bettelheim (429)\textsuperscript{16} by offering a

\textsuperscript{16} I find Waltz to be overstating the case, however, when she claims that Park’s book was aimed directly at
nontraditional “case study” from the perspective of the highly experienced, if not highly trained, parent.

Park acknowledges the potential limitations of the parent-as-therapist, including those concerns raised by the professionals who had kept parents virtually silent thus far. The most obvious problem posed by the psychogenic theory is that parents themselves were thought to have caused or contributed to their children’s autism, so they could hardly be expected to alleviate a disability they created: Park writes, “[T]his popular wisdom is today massively reinforced by professional opinion. The last people who ought to be able to work with a ‘disturbed’ child are its parents, for whom, after all, disturbed it?” (*The Siege* 124-25). Even if one disputes, as Park subtly does, the claim that parents are the cause of autism, it would seem to be common sense that parents are too emotionally involved to work as well with their children as someone with professional distance might. Park agrees that dealing with emotions, particularly “the rejection that seems deliberate even after one knows it is not” (180) commonly encountered by parents of autistic children, may in fact be a challenge, but she argues that awareness of such difficulties is an important first step, and that the advantages, enumerated above, go a long way toward outweighing them. Another challenge is that parents like Park are, for the most part, untrained, so they would seem to lack important

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17 Bettelheim offers a clear illustration of this attitude: “Thus the child, who suffers most of all from not having acquired an autonomous existence as a person, is again not regarded as an autonomous being even in treatment efforts designed to help him become a human being in his own right. And as if to crown the irony, some treatment methods rely on efforts to understand and help the schizophrenic child through the very person who (it is assumed) kept him from developing normally in the first place—his mother” (408).
knowledge about how to deal with and help their autistic children. But Park’s experience
supports her view that the professionals actually know little more than the parents do.

The professionals who work with the Parks, even those who are sympathetic, have little
to offer them in terms of therapy or techniques for teaching Jessy; Park records her
astonishment after a social worker tells her, “I think…that we will be able to learn from
you” (159, emphasis original). Park finds that she knows more about teaching an autistic
child than do the experts working with her, because she has actually done it, and she has
a relationship with her daughter that makes her expertise of a different, more intimate
sort. Park also comes up with her own procedures, such as introducing Jessy to new
people by putting Jessy’s hand on the other person’s and letting them get to know one
another at their own pace. When a psychologist friend asks whether her psychiatrist
sanctioned this procedure, Park responds that she “hadn’t asked him, but that when he
saw [Jessy] he seemed very pleased with her progress. ‘It certainly is an unusual
arrangement,’ she said” (253). Park here takes ownership of Jessy’s care and education,
concluding that she does not need the approval of professionals in deciding how to treat
her daughter.

Park’s solution then, is to meet somewhere in the middle; she calls on
professionals to share their knowledge with parents, even as parents also offer the
information they gain about their children with their doctors, making for “a breakdown of
the separation between parents and the psychiatric profession” (189). Park’s own
contribution, the publication of her account of Jessy, is an attempt to bridge this gap
between the two sides and to blur the lines defining who may be considered an expert on
the subject of autistic children. And despite the fact that Park at times seems to have
superhuman patience in repeating the same activities with Jessy over a period of months before any changes in behavior take place (e.g., learning to put a doll to bed, “a process that, from the time she first caught sight of the crib, had taken fifty-seven days” [100]), Park is firm that she is not unusual, and that any parent would and could do the same for his or her child: “Let it be understood that I am no miracle worker. I am not ‘good with children’ or particularly fond of them. … Such qualified success as I have had must not be thought of as unique” (196). Her relationship with her daughter and her knowledge of Jessy’s abilities and needs, rather than prodigious professional knowledge or an ability to work miracles, enable her to help Jessy more than anyone else can. By publicizing her own story, Park offers a model that she believes other parents can follow, encouraging them to make use of their relational knowledge to claim authority and competence and to undermine the professionals’ domination of the sphere of expertise.

**Metaphorical Invasion**

In negotiating this sphere of expertise, Park constructs an image of autism that is in part a product of the professional discourse and in part the result of her individual experience with her daughter. The representations that Park creates of autism in this text, and of Jessy as an autistic child, are shaped by the metaphor of a “siege” upon the walls that Jessy’s autism has placed between her and the rest of the world, accompanied by the related language of “invasion,” “fortress,” and “citadel.” Park is a college English teacher and writer by training, and metaphors seem to come naturally to her in seeking to understand her daughter’s behavior and experience. Metaphors are a particularly fitting textual practice to employ in attempting to understand a life and experience significantly different from one’s own, as by definition a metaphor brings together and compares two
unlike things. In applying the metaphor of the “siege,” Park works to decipher Jessy’s experience by comparing it to something recognizable, an image of attack on a barricaded enemy. Even though such a struggle is obviously in many ways vastly different from the struggle to reach an autistic child, the recognizable elements of the image serve to make the new or unfamiliar experience more comprehensible. In this way, the use of metaphor helps Park bring Jessy’s nonnormative life experience closer to her own. Translating Jessy’s difference into a comprehensible metaphor helps move the nonnormative closer to the normative for both Park and her reader by providing a means for interpretation, even a rudimentary one. Throughout the memoir Park returns to the phrase “as if” as she seeks explanations behind Jessy’s behavior: “As if—yet we could not and cannot be sure. We cannot help interpreting. The words as if must function to remind us that we can be sure of no interpretation” (The Siege 46, emphases original). The siege is one form of interpretation; at various other points Park describes Jessy as a fairy or changeling, as a Martian, and as a “Holy Fool” of old Russia (“Epilogue,” The Siege 290), but the siege, as indicated by the book’s title, is the metaphor that seems the most fitting and powerful for her in understanding and addressing Jessy’s differences and what they mean for her family. In making the claim of expertise for parent amateurs like herself, Park explains and defends her approach using the language of the siege: “[Jessy] dwelt in a solitary citadel, compelling and self-made, complete and valid. Yet we could not leave her there. We must intrude, attack, invade, not because she was unhappy inside it, for she was not, but because the equilibrium she had found, perfect as it was, denied the possibility of growth” (12). Park’s description of Jessy’s world as a “citadel” that must be invaded is eerily similar to Bettelheim’s “empty fortress,” though Park later clarifies that the
similarity is an unintentional coincidence and only demonstrates the metaphor’s aptness to the realities of autism (Exiting Nirvana 10). Although Jessy appears to be content within her fortress, Park understands her to be incapable of growth while there because she is removed from relationship with others, echoing the “emptiness” of the fortress in Bettelheim’s formulation.

The metaphor of the siege is a suggestive one in that it has connotations of violence, of the force of one will against another, despite the fact that the “fortress” being attacked is only a little girl. Park’s imagery of breaking down the walls of Jessy’s citadel implies that Jessy has built these walls about her by choice, and that there is a reachable child within the outward trappings of indifference or lack of interest in human society. Park perceives Jessy’s autistic behavior as “a tiny child’s refusal of life” and asserts, “We had no choice. We would use every stratagem we could invent to assail her fortress, to beguile, entice, seduce her into the human condition” (The Siege 12). By forcing her to interact with them, by coercing her to into doing activities that she seems to refuse to do, the Parks seek to bring Jessy into the “real” or “human” world of family relationships.

Park’s perception throughout The Siege is that Jessy’s impairments are “willed,” and that therefore she may be persuaded or forced to behave differently. Park offers many examples of Jessy suddenly doing something that she apparently could not do before, including walking, drinking out of a cup by herself, or putting on her own shoes:

It is as if [Jessy] were more comfortable with an image of herself that could not do things. Her inabilities seemed not only willed but jealously guarded. I remember her at four, after considerable progress of the kind described here, getting ready for her bath. She cannot yet undress herself,
but for some weeks she has been taking off her shoes once I untied them. Today she refuses, laughing at me. … I wait, resisting the temptation to assist her. The shoe is on so loosely that it falls off. [Jessy], who “cannot” put on her shoes, sizes up the situation. Instantly and expertly she puts the shoe back on. She was not going to take it off and she didn’t!

(52-53)

Although Park acknowledges that “[i]t is a little too much to swallow—to accept than an infant can assess its situation…and decide that anything is preferable, even total withdrawal, to the risks of activity and growth” (46), for the most part she accepts the idea that Jessy makes the choice to stay where she is comfortable, creating a variety of “willed” disabilities (“willed weakness,” “willed blindness,” “willed deafness,” and “willed isolation,” as the titles of Chapters 4-7 suggest), and that she must be convinced otherwise in order to overcome these disabilities. In this sense, Park seems to accept the opinion of the “experts” like Bettelheim who see the autistic child’s behavior as a reaction to the world around her, although Park rejects the idea that the world or the people in it are necessarily harmful in the way that Bettelheim suggests. She sees Jessy instead as emotionally disabled, not knowing how to interact with the world around her in the way others do, and so the goal of the siege is to help her take the necessary steps to get beyond the emotional barriers that discourage her from interaction. Despite the outward appearance that Jessy has no interest in people breaking into her citadel, the Parks cling to glimpses of Jessy’s openness to being besieged: “It helped us, then, in our continual assaults upon [Jessy]’s sheer walls to remember that we had seen her welcome invasion. It sustained us to think that though she could not take the initiative she was
glad when initiative was taken” (93). Since “siege” is the technique Park has chosen to pursue as her daughter’s amateur therapist, she explains and defends her approach and uses her successes, gradual though they may be, to show that she deserves the right to authority that she has claimed for herself as an aspiring expert.

The siege metaphor also shapes the kind of narrative Park undertakes in her memoir. Debra Cumberland claims that “Park’s memoir follows the form of a quest for salvation” and that “[t]he male script she adopts is clearly evident in the title, The Siege, with its martial implications” (185). Although a “siege” certainly does have martial implications, I am not convinced that Park’s narrative adopts a “male script”; in fact, Cumberland backtracks somewhat, allowing that “this is the mother’s story. … [The father’s] absence implies that only the mother can ‘save’ her child, and this emphasis on the mother’s role actually places Park back in the position that the memoir strives to release her from: she is responsible” (186-87). In a way Park herself is under “siege” by the experts who impose this sense of responsibility upon her, and in using the metaphor of the siege to describe her efforts with Jessy, she strives to free herself from the attack of the professionals fixated on the theory of the refrigerator mother. I would argue that Park does achieve some success is breaking free of the responsibility that professional discourse about autism has placed on her, in part because of the authority she claims as a parent with knowledge and experience gained from her efforts to “besiege” Jessy’s autistic fortress. While Park accepts the possibility of her responsibility in causing Jessy’s autism, her denial of any real feelings of guilt and her active role in the therapy she almost single-handedly devises for Jessy suggests that far from feeling pressured by the script of the siege, Park is empowered by it to help her daughter learn and grow when
no one else seems able to do so, even the so-called experts. James Fisher discusses the “conversion narrative” in literature about autism, a prototype which bears resemblance to the “quest for salvation” that Cumberland invokes; rather than seeing Park’s narrative as a quest for salvation or conversion in the form of overcoming Jessy’s autism, he sees her text as a different kind of conversion—one which “center[s] on the non-autistic author’s transformed perceptions of normalcy [rather] than on the ‘recovery’ of the autistic subject” (62).

Certainly Park’s narrative does not follow the “recovery” plot that many later accounts by parents of autistic children do, such as Barry Kaufman’s Son-Rise, in which the intensive therapy that Kaufman and his wife engage in with their son appears to eliminate most of his autistic symptoms.\(^\text{18}\) The metaphorical siege that Park inflicts upon Jessy is effective in that it enables Jessy to make progress and helps Park better understand her daughter, but it does not “cure” her. Park reflects on the siege’s outcome (thus far) at the end of the original text of The Siege: “It has been a long siege. As a siege, it has been successful, for we have reached [Jessy]. … Yet we are not the first to discover that to reach another human being is not in itself to cure; we are not the first to learn that though the contact which seemed impossible may at length be made, it only opens the future to the work to be done. The expectation of a cure is a luxury we have learned to do without” (271-72). Though the process of working with Jessy is far from over at the end of this first book, when Jessy is still only eight years old, there is the beginning of a realization for Park that the concept of the siege can only take them so far.

\(^{18}\) In a note obviously added in a later edition of The Siege, Park refers to Kaufman’s 1976 book, allowing, “No doubt it happened. Miracles do. But I was in the presence of someone [a therapist] too wise to claim she could chart the processes to bring them about, or to allow herself or me the illusion that one was in preparation here” (164-65). Even in her later updates, Park never describes Jessy’s progress as miraculous or as an outright “recovery” from autism.
The recognition of “future work to be done” hints that rather than an attack on a fortress, living with autism is a lifelong and relational journey for the parent and the autistic son or daughter, both of whom should have the authority to share their reflections on that journey.

**Exiting Nirvana**

Park’s second memoir, published thirty-four years after the first, is motivated by very different purposes than *The Siege*, and demonstrates significantly different approaches both to autism and to Park’s relationship with her daughter Jessy. Park was certainly not silent on the subjects of Jessy and autism during the gap between the two books. She wrote several short pieces, including a book about coping with mental illness, co-written with Dr. Leon Shapiro, in 1976; an essay on finding a school placement for Jessy in 1977; a number of reviews of books dealing in some capacity with autism, including Bruno Bettelheim’s *Surviving and Other Essays* in 1979; and the Epilogue to *The Siege* in 1982. The Epilogue in particular provides a sort of bridge between *The Siege* and *Exiting Nirvana*, as it falls roughly midway between the two works. A well-developed essay of about 42 pages, with an insert of recent photographs of Jessy and of some of her artwork, the Epilogue offers Park’s reflections on the text of *The Siege* as well as updates in her thinking about autism and, most notably, in Jessy’s development. Park recognizes some of the limitations to her thinking that were the product of the knowledge of and discourse about autism in the late 1960s, and provides evidence of progress in the study of autism toward views a bit more recognizable to contemporary

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19 *You Are Not Alone*
20 “Elly and the Right to Education”
21 “Survive and Remember”
readers. She points out, “In fifteen years…much has changed. Research has not
discovered the cause of autism—it seems likely, in fact, that like cancer it will turn out to
have no single, simple cause—or cure. But…no one in touch with the latest
developments in the field any longer imagines that inside the autistic child there is a
normal child waiting to get out” (“Epilogue,” *The Siege* 291), a notion that was implicit
in the metaphor of the siege that dominated her first book.

Most captivating for the reader and most different from where *The Siege* left off
are the changes in Jessy over the fifteen years the Epilogue covers; she is now in her
twenties, has graduated from high school, holds a part-time job in a college mailroom,
and has made many improvements in her abilities to communicate with others and to
function independently. As Sheryl Stevenson observes, “The epilogue not only
summarizes the progress 23-year-old Jessy has made, but shows the mother’s possible
need to abandon and progress beyond the fundamental, organizing conceptions of her
own text” (206). Indeed, both the Epilogue and the later complete memoir, *Exiting
Nirvana*, demonstrate Park’s willingness to rethink and revise her conceptualizations of
autism and of Jessy. As we have seen in her first memoir, Park is interested in a dynamic
and evolving view of autism which allows for new social and medical interpretations as
well as an expansion of traditional sites of authority, and that dynamism applies to her
own views as well.

*Exiting Nirvana* reveals shifts in both Park’s conceptualization of autism and her
relationship to authority as she responds to significant changes in attitudes toward autism,
increased information about it (though, as she acknowledges, much remains unknown),
and greater social awareness. Unlike her first memoir, this book is not particularly
unique; by 2001, there are a considerable number of parent memoirs about autism, and even a number of published works by autistic people themselves, so Park is not providing a window into an unseen world in quite the same way that she was in 1967. However, in addition to adding usefully to the catalog of accounts of life with autism, Park’s second book is noteworthy in that it offers a follow-up to her first groundbreaking account, and so enables readers to recognize some of her own evolution in understanding between the 1960s and the early twenty-first century. While Park includes some of the current research on autism, she recognizes that it is far less necessary to do so now that the diagnosis is so much better known; at one point she interrupts her description of the manifestations of Jessy’s autism to say, “But that’s enough, there are many books about autism now, anyone can read the symptoms” (Exiting Nirvana 7). Rather than explaining autism to readers to whom it is unfamiliar, or advocating for parents of autistic children who have been maligned and silenced by insensitive professionals, Park’s aim in this book is to particularize the general knowledge about autism by detailing her life with Jessy over forty-odd years, and to demonstrate what she has learned in the more than three decades since her first memoir. As she notes early in the text, “It’s not my intention to survey what’s known about autism. There are many people better qualified to do that… It’s the experience of autism that I can write about—the initial bewilderment, and the slow growth of at least partial understanding” (24). While she revisits some of the early experiences with Jessy that she also covered in The Siege, most of the narrative is devoted to the “slow growth of at least partial understanding” of autism for Park personally and, as reflected in her experience, for the larger social, medical, and psychological environment. Park is notably more accepting of professional expertise in
this text; since theories about autism’s cause have progressed from the psychogenic to the neurobiological, the current research seems to appear much more reasonable to Park, and she draws upon it to inform her own understanding of Jessy. However, those expert opinions in and of themselves are not enough; Park asserts that “[a] description of autism must be anecdotal; without anecdotes there are words but not experience” (24). In *Exiting Nirvana*, Park provides this extra dimension by building on the detached “words” of professionals with the experience gained through relationship. She allows the professionals their own space of authority about medical views of autism, but uses them in the service of her anecdotal evidence as she develops her own, different kind of expertise, born of the experience of being in relationship with her autistic daughter.

Park gestures back to her challenge to the professional authorities of the time in *The Siege* by discussing how the once-dominant theories of Leo Kanner and Bruno Bettelheim have, finally, fallen out of favor. These giants’ fall from grace demonstrates, of course, the wisdom of Park’s efforts to upend, or at least counterbalance, the authority of the so-called experts. Park relates the empowering experience of hearing Kanner finally denounce the idea of “refrigerator parents”: “Twenty-five years later, before the National Society for Autistic Children (now the Autism Society of America), he would repudiate this explanation in words none of us who heard him would ever forget: ‘Herewith I especially acquit you people as parents’” (*Exiting Nirvana* 11). Though Kanner’s statement certainly did not mean the instant demise of the specter of the refrigerator mother, which still lingers today in, as Park puts it, “a few psychoanalytic
backwaters” (7),\(^{22}\) this was an important moment for many parents like Park who had lived through the era of blaming parental coldness for autism, especially since Kanner was the originator of the theory. However, as we have seen, it was Bettelheim who was largely responsible for the propagation of the psychogenic hypothesis, and Park is even more relieved at his downfall than at Kanner’s, though she is surprisingly merciful toward him. She refers in *Exiting Nirvana* to Bettelheim’s “journalistic skills” which made his defense of his views so convincing (7), and reflects, “It is painful to return to the book Bettelheim, with his gift of metaphor [not so different from Park’s own gift], called *The Empty Fortress*—and thank God and the rules of evidence, it has become unnecessary” (7). Park has commented on Bettelheim’s legacy in several other places as well, including her review of his 1979 book *Surviving and Other Essays* and of Richard Pollak’s 1997 biography *The Creation of Dr. B.*, in the latter of which she reflects on accounts of “what would now be called child abuse” in Bettelheim’s Orthogenic School at the University of Chicago as well as “the many discrepancies between what he claimed—Freud’s approval, 14 years at the University of Vienna, studies with Arnold Schoenberg, summa cum laude degrees in philosophy, psychology, and the history of art, service in the anti-Nazi underground—and the facts” (Park, Rev. 265). Finally, though, she is generous toward this man who caused the families of autistic children so much grief, acknowledging that he “was a brilliant, tormented, and tormenting man in a tormenting century” who “only popularized the psychogenic hypothesis that was nearly universally accepted” (266). Having triumphed over the limitations placed on parents by these early autism “experts,” Park seems to have made her peace with them.

\(^{22}\) One such “psychoanalytic backwater,” according to a number of sources, is France. Sophie Robert’s 2012 film *Le Mur (The Wall)* explores some French psychiatrists’ adherence to the psychogenic theory, as well as the lack of availability of non-psychoanalytic treatment for autism in France (Yudell).
As quoted above, Park is well aware of the many researchers who are “better qualified” than she is to speak about the current state of knowledge about autism, and though she claims not to want to impinge on their territory, having her own source of expertise in her life with an autistic daughter, she makes use of many of this new generation of experts to supplement and support her own account. One of these experts is Lorna Wing, whom Park makes a point of noting is “herself a parent of an autistic child” (Exiting Nirvana 22). Like Jacques May and Bernard Rimland, Wing’s status as not only a doctor but also the mother of an autistic daughter seems to give her some additional, relational credibility in the eyes of parents like Park. Wing’s theory of a “triad of impairments” is a well-known and often-quoted piece of research on autism; according to this model of diagnostic criteria, people with autism have difficulty with the three areas of social interaction, communication, and imaginative activity (Wing 109). Park points out that Jessy, in keeping with Wing’s model, has “all the ‘classic’ symptoms” (Exiting Nirvana 23), particularly in language acquisition and use, accounts of which make up a large portion of the content of both The Siege and Exiting Nirvana. Jessy’s social interaction is similarly impaired, though Park sees Jessy’s job as an important factor in helping her learn to work with others as an adult. Park acknowledges that Jessy does have an imagination—she makes up stories, many of which are depicted in her drawings, and she is able to engage in make-believe activities. But, Park concludes, “Lorna Wing’s generalization held good: ‘imaginative activities,’ while not, as in some cases, ‘totally absent,’ were ‘copied from other[s],’ or ‘spontaneous but carried out repetitively or in an identical fashion” (115). Rather than use Wing’s research to shape her understanding of Jessy, Park tests the expert findings against her own observations of her daughter.
Continuing the project set out in *The Siege*, Park sees both professional and anecdotal types of expertise as necessary, and as most useful in combination and communication with one another, furthering the “breakdown of the separation between parents and the psychiatric profession” (*The Siege* 189).

Similarly, Park embraces Wing’s framing of autism as a continuum, a broad range of ability and disability that has become more commonly known as the autism spectrum. She quotes at length from Wing’s discussion of the subject, including the following points: “The continuum ranges from the most profoundly physically and mentally retarded person, who has social impairment as one item among a multitude of problems, to the most able, highly intelligent person with social impairment in its subtlest form as his only disability. … Any combination of skills and disabilities may be found and any level of overall intelligence” (Wing 111). Park emphasizes not only the different placements along the continuum that different people with autism might have, but also the fact that a person’s abilities and impairments as a child may not predict anything about his or her abilities as an adult. The wide range of experience possible for people with autism is one reason why Park so highly values the anecdote as a means of communicating the real-life experience of autism—in her case, of life with her autistic child. Without the stories of real people and relationships, the definition of autism is too broad and nebulous to grasp. Interestingly, in *The Siege* Park made use of the image of the continuum in a slightly different but related way, which may influence her acceptance of Wing’s use of the term and concept. In discussing the relationship between the professional and the amateur, Park explains, “I have come to see mental health and illness, soundness and defect, not as the separate entities the words seem to describe, but
as a continuum. The needs of the defective and the sick are more imperious than those of
the well, but they are not different in kind” (The Siege 192). Despite the antiquated
language of “defect,” Park suggests here that there are not, in fact, sharp separations
between autistic and non-autistic people, or between autistic people at one end of the
spectrum and those at another, but that all have different levels of need and all “need to
be respected” (192). Wing’s theories, which resonate thematically with Park’s own, help
Park to develop her previous ideas and apply more recent research as appropriate to her
interpretation of the anecdotes she tells about life with Jessy.

Though Uta Frith does not have the pedigree of being a parent of an autistic child,
hers work on autism has been greatly influential over the past several decades. Park
incorporates some of Frith’s significant theories into her narrative as well, particularly the
concept of theory of mind, which may be summarized as the inability to imagine what
others are thinking. Frith, a developmental psychologist and neuroscientist, made
significant contributions to the work begun by Rimland in the theorizing of a
neurobiological, rather than psychogenic, root of autism, and theory of mind seeks to
explain one aspect of how autistic people’s mental processes are different from those of
non-autistic people. Park accepts Frith’s ideas about “theory of mind” quite
unreservedly, applying them in her efforts to explain Jessy’s behavior and inability to

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23 Frith’s famous test of this ability is known as the “Sally-Anne” test, which Frith explains in this way:
“Sally has a basket, Anne has a box. Sally puts the marble into her basket. Sally goes out for a walk.
While Sally is out of the room, Anne (naughty Anne!) takes the marble from the basket and puts it into her
own box. Now it is time for Sally to come back. Sally wants to play with her marble. Where will Sally
think her marble is? Where will she look? The correct answer is: in the basket where she has put the
marble and where she must believe her marble still is. This answer presupposes an understanding of belief.
The results of the experiment suggested that autistic children did not understand the concept of belief.
They expected Sally to know that the marble had been transferred even though she was absent at the time.
They could not conceive of Sally looking anywhere but in the place where the marble was” (Frith, Autism
and Asperger Syndrome 18, emphasis original).
imagine other people’s perspectives. Indeed, Frith’s “theory of mind” hypothesis helps to lay some of Park’s questions about autism at rest:

Thinking of others, of course, is hard when you don’t have a “theory of mind” to allow you to see something from another point of view. Even in the unemotional, physical world, Jessy can’t do this. She locks the door behind her when she leaves for work, even though she knows I’m still inside and there’s no need to. She scraped the ice off the windshield on the passenger’s side, her side, leaving the driver’s side obscured. She thinks I can see what she sees; if she knows something, she thinks the person she’s talking to knows it too. … For years we wondered; now we know that in autism it is the cognitive, not the emotional, handicap that is primary. (Exiting Nirvana 148)

Again, Park demonstrates that by no means does she reject professional expertise outright; many of the findings of recent autism research have proven to be appealing to her and applicable to what she observes in Jessy. While certainly not everyone in the autistic community accepts theory of mind wholeheartedly (or at all), for Park it is a discourse that seems to apply to her relationship with Jessy, and so she adopts it into her repertoire of knowledge and weighs it against her database of experience. In this way Park shows the flexibility of her relationship with expert discourse; she is no longer at complete odds with it, nor does she embrace it unquestioningly, but considers and accepts or rejects it as she deems appropriate.

The expert whose work Park draws upon and uses to shape her understanding of Jessy’s behavior to the greatest extent is Eric Courchesne, a neuroscientist. Though a lesser-known name in the world of autism research than the highly regarded figures of Frith and Wing, Courchesne has done extensive research on the neurological roots of autism, and his work on the role of the cerebellum in the neurological differences observed in autistic people is particularly appealing to Park. As she summarizes it, “His hypothesis—and through magnetic resonance imaging he has amassed hard evidence for it—is that damage to particular locations in a baby’s cerebellum reduces the capacity to shift attention from one sensory stimulus to another” (48). Courchesne (et al.) elaborates in a 1990 paper that “[t]he developmental deficits in social and language comprehension in autism may, therefore, result in part from these attentional abnormalities” (Courchesne, Akshoomoff, and Townsend 120). Despite the still-debated status of this theory of cerebellar damage, it becomes an important piece of expert research for Park because, as she explains, it “allows us to make sense of so much that we’ve observed in Jessy: her problems with pronouns, with relational language, with perspective-taking, with people, with everything that requires her to respond flexibly and rapidly to change” (Exiting Nirvana 48, emphasis original). In addition to social interaction and language abilities, the idea that the damaged cerebellum makes it difficult for the autistic person to pay or hold attention is particularly striking to Park. It allows her to excuse, or at least explain, Jessy’s often frustrating behavior and lack of responsiveness: “She isn’t ignoring me. She isn’t inattentive. She isn’t contrary. She’s doing the best she can with the cerebellum she was born with” (50).
Hypotheses like Courchesne’s of the biological workings of the autistic brain contribute to Park’s understanding of autism not only as clearly not the fault of the parent, but also not the fault of the autistic person. This is one of the greatest shifts in Park’s understanding of autism between *The Siege* and *Exiting Nirvana*. As Stevenson notes in her discussion of Park’s self-revision, Park’s focus in *The Siege* is on what she perceives as “her daughter’s ‘emotional orientation to the world’ (not her cognitive impairment)” (206). Many of the chapters in *The Siege* develop this earlier view of Jessy’s behavior as intentional emotional withdrawal from the world through what Park describes as “willed” weakness, blindness, deafness, and isolation. Recognizing that Jessy behaves the way she does not purely by choice, but because of the way she is made, is helpful to Park: “No wonder she perseverates; it’s hard for her to disengage her attention” (*Exiting Nirvana* 50, emphasis original). As obvious as this might seem, this was a significant development in understandings of autism. In *The Siege*, Park poses the question, “[W]hich is primary, disorder of affect—roughly, feeling or emotion—or dysfunction of cognition?” (87); she concludes that there is not yet an answer to that query. In the 1982 Epilogue she reports, “The most recent research points to what Barbara Caparulo, working at Yale in the new field of psycholinguistics, calls ‘a blurring of the traditional division between cognitive and affective.’ It is not only unnecessary to choose between them; it is impossible” (306). And in *Exiting Nirvana*, as we have seen in her discussion of theory of mind, Park has come to recognize “that in autism it is the cognitive, not the emotional, handicap that is primary” (148). Research like that of Wing, Frith, and Courchesne helps Park reach and understand this conclusion, and she uses her
anecdotal study of Jessy to corroborate what these experts have found through their research.

**Nirvana as Journey**

Though much has changed in the time between *The Siege* and *Exiting Nirvana*, Park is still committed in this text to using metaphor to depict both autism and Jessy. The metaphors, however, have shifted somewhat in tone. From the rather violent image of the siege, an assault on her daughter’s autistic citadel, Park shifts to the much gentler image evoked by the title of *Exiting Nirvana*, in which Jessy is in the process of coming out of her inner world of isolation and contentment, not by force but of her own free will. Like in the image of the siege, here Park depicts Jessy as having a sort of “autistic” place (that is, as the word literally suggests, a place all to oneself), an inner world where she is safe and insulated from the outside world. Park refers to this inner world as “Nirvana,” a place of “serene equilibrium” (*Exiting Nirvana* 7). The term “Nirvana” in fact makes its first appearance, though just once, in *The Siege*, and the basic model holds true in the later book as well: “The world we would tempt her into [i.e., with siege tactics] was the world of risk, failure, and frustration, of unfulfilled desire, of pain as well as activity and love. There in Nirvana, why should she ever come out?” (*The Siege* 12). In this second memoir, Park demonstrates the results of Jessy gradually coming out of her world of Nirvana, though never forsaking it entirely. As Park begins to recognize at the end of *The Siege*, autism is a lifelong journey, and she notes near the beginning of *Exiting Nirvana* that “journey” has become a more appropriate metaphor for Jessy’s progress than “siege”: “The siege metaphor becomes transmuted into a more ordinary one. Siege into journey” (*Exiting Nirvana* 10). As the imagery of assaulting the autistic fortress falls
away, Jessy’s process of “exiting Nirvana” forms the structure of that journey. Stevenson sees this shift as Park’s “increasing ability to get past the ableism that assumes a one-way growth—Jessy’s movement forward into her parents’ world” (207), with Park instead beginning to envision both Jessy and the rest of the family and community on a journey to find acceptance and, perhaps, balance between Nirvana and the outside world, between the autistic and the non-autistic. In addition, Jessy’s role shifts significantly, from the object of attack in The Siege, to a valued partner on the journey in Exiting Nirvana. The symbolism of attack has almost entirely disappeared in Exiting Nirvana; Park is no longer under attack as a parent, and Jessy is no longer under siege as an autistic person. Instead, both are on a collaborative journey to live with and understand autism, at times in cooperation with the professional world that had previously silenced both of them.

Though certainly inner peace and happiness sound much more positive than the language of siege warfare in Park’s earlier text, Jessy’s happiness in what Park calls Nirvana also means perceived separation from the rest of the world, which Park and many of the experts on autism, past and present, see as problematic. This is why, whether by force or on her own initiative, Park considers it important for Jessy to learn how to “exit” this inner space. Park explains, “Is it not happiness to want nothing but what you have? Craving, the Buddha taught, is the source of all suffering, detachment the road to the serene equilibrium of Nirvana. But Nirvana at eighteen months? That’s too soon” (7, emphases original). In Buddhism and other Indian religions, Nirvana is an end goal, a freedom from earthly attachments that “end[s] the cycle of birth and rebirth” (“Nirvana”), something to strive for throughout life and reincarnation, not a place where a human being begins and remains. Jessy’s apparent existence in this sort of place of
contentment is figured by Park, then, as unnatural. In order to grow, Jessy must come out of Nirvana and into relationship with others at least some of the time. By the time of the writing of Exiting Nirvana, Jessy has exited her inner world and entered the outer one to a large extent; Park’s efforts with her as well as her experiences at school, at work, and with family, friends, and assistants have helped Jessy to learn to deal with the world outside of herself. This world, as Park’s narrative makes clear, is a frightening one because it is full of change and unpredictability. Jessy, like many autistic people, seeks order to help make sense of the world around her, and this “rage for order,” as Oliver Sacks refers to it, takes the form of many systems involving weather, numbers, colors, and flavors that are virtually incomprehensible to anyone besides Jessy. A 1974 article by Jessy’s father and one of his college physics students explores some of these systems; for example:

In the evening, when [Jessy] sets the table for dinner, she puts a tall glass by her plate. It is green, her preferred color, and it is divided into 8 equal levels by decorative ridges. Into this she pours her juice. It too is green. On most days she will fill the glass exactly to the sixth or seventh level. Sometimes it will be filled to the top; occasionally it will be lower. Ordinarily, the exact level is determined by the type of day with respect to weather and the phase of the moon. (Park & Youderian 316)

Even to scientists and mathematicians, the details of Jessy’s systems remain obscure, but to her their intricacies are meaningful and functional, at least for the period of time during which they are in use. As Park interprets them, “Her systems were designed to eliminate

25 This is, in fact, the title of Sacks’ television show about autism that features Jessy and the Parks, part of the Mind Traveller series on Sacks’ work with people with various neurological conditions.
the unexpected, to capture uncertainties in a net of connections, to reduce them to rule” (*Exiting Nirvana* 83). The systems seem to be Jessy’s attempts to create an equilibrium in the unpredictable outside world similar to that found in her inner “Nirvana.” As Jessy becomes more experienced in the social world, she seems to need the systems less in order to feel comfortable, but she also finds ways to incorporate aspects of her inner world into everyday life.

In *Exiting Nirvana*, then, Park shows Jessy taking much more control over her own interaction with the world around her than was possible at the time of writing of The *Siege*, and thereby making her own claim to expertise and authority over her own story. In 1967, Jessy was only eight years old and still struggling significantly with communication; by 2001 she is in her forties, can speak and read competently, and has regular responsibilities and everyday interactions with many different people. In describing Jessy’s journey from isolation in Nirvana to presence and social interaction in the “real world,” Park ascribes autonomy to Jessy. This autonomy is indicated by the active verb “exiting” in the book’s title, which indicates that Jessy is the one doing the action of moving and changing. This is a very different slant from the implied subject(s) performing the “siege” in the title of the first book—Park and the others who are attempting to draw Jessy out of her autistic state. “Exiting” also offers an interesting echo of the more commonly used and often problematized term in the discourse about autism, “emerging,” which has been used to indicate that an autistic person is no longer autistic, or has overcome his or her autistic traits. Temple Grandin’s first autobiography was called *Emergence*, a title which suggests what Bernard Rimland’s foreword to the book states explicitly: that Grandin is a “recovered (or recovering) autistic” (Rimland,
“Foreword” 1). Though Grandin does not herself claim to be recovered, and in an introduction to a later edition clarifies that hers, like most autistic people’s, has been “a gradual emergence as I learn more and more about the ways of the world” (20), the language of emergence was and is sometimes interpreted to mean “cure.” Stevenson argues that Park makes the claim in the Epilogue to The Siege that Jessy is no longer autistic, “a claim so utterly absent from Exiting Nirvana that its abandonment indicates the mother’s progress” (Stevenson 208). I agree that Park is not claiming here that Jessy has “overcome” or “recovered from” autism, but I would suggest that Park’s indication to that effect in the Epilogue is a qualified one. Her statement is that “Jessy has ceased to be autistic, if we give autism its root meaning. She is no longer immured within the self” (“Epilogue,” The Siege 286, emphasis added). Since the medical/psychological diagnosis of autism, as Park well knows, means far more than the literal meaning of being “immured within the self,” Park is hardly claiming here that Jessy no longer has autism. But she has begun to emerge from that autistic isolation, to exit the world of Nirvana and enter into the non-autistic world.

Further, Park indicates that as she continues to develop, Jessy has learned to function both within and outside of Nirvana. This understanding of Jessy as autistic is a significant advancement over the metaphor of the siege, which sought to completely draw Jessy out of her inner world. Though Park never abandons the belief that it is important and healthy for Jessy to be part of the world of other people, she begins to show greater interest in, and place greater value upon, Jessy’s inner world, demonstrating Park’s own movement toward acknowledging Jessy’s worth in being the way she is. I agree with Stevenson’s argument that in Exiting Nirvana Park makes progress in overcoming her
own, and the dominant culture’s, cognitive ableism, beginning to recognize the value in cognitive difference like Jessy’s (Stevenson 208-09). This becomes most prominent toward the end of the book, when Park explains that through activities like her painting and her explanation of her obsessions, Jessy offers glimpses of her inner world to the non-autistic outside world: “It’s such happy obsessions…that make visible the emotional intensity of her secret life. Realizing that, we realize that as we no longer even dream of a triumphant emergence into normality, we no longer even want her to exit Nirvana all the way. In a development we could never have envisaged, it looks as if she, and we, can have it both ways” (Exiting Nirvana 201). The movement here is toward greater acceptance of Jessy’s autistic difference, and a recognition that her rich, though enigmatic, inner life can coexist with her relationships with other people. Park’s use of the fraught term “emergence” here is revealing, since she indicates that she and the rest of the family no longer imagine or desire such a thing as complete emergence from autism for Jessy. Instead, they embrace a sort of balance between the two worlds. The final sentence of Park’s brief Afterword to Exiting Nirvana makes a final play on the language of “exiting” and “emerging,” as Park describes Jessy’s process of “enter[ing], more and more fully, yet never entirely, the world in which we live, all of us, together” (208). Jessy “exits” Nirvana (partially) and “enters” the larger world while not entirely “emerging” into normality. The final result is a sort of hybrid of the autistic and non-autistic worlds where each has something to offer and learn from the other, another way of combining diverse types of experience and expertise. Far from a forced siege, Park’s understanding and metaphorical representation of Jessy’s autism have evolved into a recognition of this journey as not just that of the mother who must reach the autistic
daughter, but also as the lifelong journey of the autistic person herself as she finds her own place in both her inner world and the social one around her. One aspect of finding that place, for Jessy, is contributing to the telling of her own story.

**Authority in Telling the Life Story of Autism**

Not only thematically, but textually, Park makes space in *Exiting Nirvana* for Jessy’s voice and actions to influence the narrative. In this way Park extends the claim of expertise about autism to her daughter; though the text is still written from Park’s perspective, the story that is told as well as the process of constructing the text are relational and shared by Park and Jessy. In the earlier text of *The Siege*, Jessy does not participate in the production of the narrative, probably in large part because of her young age and the realities of her communication impairment at the time. Though Jessy’s presence and existence certainly are the focus of that text, most of the content is filtered through the mother’s experience; while a relational text in that it tells the connected life stories of the mother and daughter, it is primarily a story about Park’s life with her daughter, not so much the story of Jessy’s life, and Jessy’s perspective is not clearly represented. In *The Siege* Park explains, “Even now, [Jessy] and I have not reached a level of verbalization which would enable us to say ‘Do you remember?’” (156), though they find other ways, particularly through drawing pictures of places they have been, to communicate and share common memories. However, there is no simple way as yet for Jessy to share her own experience verbally. By the time of *Exiting Nirvana*, Jessy has far surpassed this level of communication; though she still has some difficulties, she is able to speak and write competently. Park mentions several times throughout the text that Jessy is aware that her mother is writing a book about her and that she has contributed to
the process of gathering of information and memories to include in the text. For instance, in a chapter about learning from consequences, Park relates how Jessy has been “a delighted collaborator”; Jessy enjoys rereading her old self-imposed behavior contracts and “happily list[s] for me her recent rewards” (*Exiting Nirvana* 173). Park draws the bulk of the content of *Exiting Nirvana* from the detailed records she has kept of Jessy’s progress and accomplishments over the years, “bits of paper, slips I grab when Jessy does something, says something, that shows progress toward our world, demonstrates a new receptiveness, a new interest, a new understanding, or (the other side of the coin) that reveals how different her experience remains” (25). These slips of paper come directly from Park’s observations of Jessy, and the story she tells is built upon these observations, surrounded by her own efforts to understand and interpret Jessy’s thought processes and behavior. Whereas the emphasis of *The Siege* is on Park’s efforts to teach Jessy and to establish her own right as a parent to speak about autism, the focus of *Exiting Nirvana* is much more on Jessy’s life and experiences. Though Chris Foss asserts that “*Exiting Nirvana*, subtitled *A Daughter’s Life with Autism*, in fact reveals as much about *A Mother’s Life with Autism* as it does *A Daughter’s*” (“Emerging”), I see much more in this book of the mother’s attempts to portray and accept the daughter’s life as different from but as valuable as her own and to give her daughter a voice in the text through the inclusion of words and materials generated by Jessy herself. Whatever the subtitle, in my view both Park’s and Jessy’s related lives and experiences have an important place in this relational auto/biographical text.

Jessy’s written, drawn, and painted works form the backbone of Park’s narrative in *Exiting Nirvana*; the book could not effectively document Jessy’s progress from
Nirvana into relationship with the outside world without this evidence from Jessy’s life to support it. The title of each of the main chapters is drawn from Jessy’s own speech (“That is not sound” for a chapter on speech; “All different kind of days” for a chapter on Jessy’s classification systems; “The sky is purple-black” for a chapter on painting), demonstrating that Jessy herself is the main focus of the text and dictates its content, though Park of course edits and shapes it. Though Jessy does not contribute in writing to the actual text of the book, her drawings and words are included as illustrations throughout Park’s text, as epigraphs at the beginnings of chapters and where relevant to the content being discussed throughout. While Jessy is a talented painter (more on this in a moment), she also produces drawings which are much more utilitarian than artistic, done quickly and crudely in black and white and with stick figures. Reproduced pages from Jessy’s books and journals chronicle her efforts to write stories, record dreams, or practice certain behaviors. Park hypothesizes that Jessy’s books “were functional records; that was why, I think, she seldom bothered with color, why she took no trouble with her drawing… Color was for beauty, I think, though Jessy wouldn’t have said that either” (Exiting Nirvana 121), and she notes that Jessy’s drawings of human figures have not changed since she first began drawing them at the age of four (122). Whether artistic or not, Jessy’s drawings provide valuable illustrations of the person Park seeks to portray and interpret in her book; Jessy’s hand-drawn pictures and hand-written pages reinforce the immediacy of Jessy’s involvement for the reader.

Jessy’s paintings are the most impressive evidence of her abilities and personality that are featured in the book. In addition to a number of small black-and-white reproductions, four of her paintings are printed in full color, and Jessy’s descriptions of
these paintings are included in an appendix. Jessy’s art career began almost accidentally; though she had drawn and painted since childhood, it was not until she was twenty-one that someone saw a drawing of a building that she had done and offered to buy it. Park explains that the prospect of selling her work motivated Jessy to continue her painting: “For years she had had no reason to paint or draw. Concepts of creativity or fame, of course, were meaningless. Money didn’t mean much more. But numbers did, and she liked to see them rise in her checkbook” (Exiting Nirvana 126, emphasis original). Unlike her rough drawings that seek only to get across concepts or record ideas, Jessy’s paintings are incredibly detailed; most of them depict buildings or bridges and are highly accurate except for the colors, which are unnaturally bright and varied, and the frequent appearance of constellations or lightning in the sky, which, though correct, are added by Jessy’s imagination. Park includes these images in the book, allowing them to speak for themselves; she includes Jessy’s descriptions of the four color images, allowing Jessy to speak for them; and she offers some of her own analysis of the ways these paintings are expressions of Jessy. An example is her explanation of the lack of shading in Jessy’s brightly colored images: “No shading. No nuance. Like her speech. Like her simplified comprehension of what people say, of their expressions, their emotions and needs. … There is no shading in the way Jessy approaches the world.

26 These are the only extended examples of Jessy’s writing included in the book, and give some idea of her abilities as well as her impairments. Park explains that the descriptions began as a way for Jessy to practice both her writing and her “theory of mind,” since she had to think about what a viewer would need or want to know about the painting. Park assisted greatly with these descriptions for a long time, “[b]ut one night—seven years later? ten years? I can’t keep records of everything—I was going out. ‘We can’t write it tonight,’ I told her, ‘we’ll do it tomorrow.’ And when I came back it was done. It was a draft, we edited it a bit together, but Jessy had written it. So slow, so gradual, is the building of a simple essential skill” (Exiting Nirvana 133, emphasis original). One can see that writing is still a somewhat arduous process for Jessy, but also that it is a skill she has been developing, like so many of her skills, gradually over a long period of time.
Nuance means shading. Call it a metaphor of her autism, or more than a metaphor” (130, emphasis original).

Indeed, Park’s fondness for metaphor leads her to reflect on Jessy’s own type of symbolism and metaphorical thinking, and its difference from her own. As is made obvious through the discussion of Jessy’s “systems,” where types of days are determined by the weather, are translated into colors and flavors, and may dictate the type and number of breakfast foods Jessy eats, Jessy does have an understanding of symbolism, but her symbolism is very much her own and may not be subject to the same kinds of interpretation or analysis as that of other artists. In Park’s words,

Jessy’s codes are not ours. Once someone asked for happy colors and Jessy was nonplussed. Once someone thought she should be afraid of the dark. Once someone thought outer weather could symbolize inner weather. But symbols, if they communicate at all, carry socially attributed, agreed-upon meanings. For Jessy, things are what they are, and if they have meanings, they are wholly idiosyncratic. To understand her is to understand that. (134)

Importantly, then, Park does not claim to be able to fully interpret Jessy, her thinking, her behavior, or her artwork for others. But she offers Jessy as an example of autistic thinking, behavior, and life, and offers her own views from the perspective of a parent amateur-become-expert. Her authority, though certainly not complete authority over the making of meaning out of Jessy’s life, comes from her experience as Jessy’s mother for over forty years. Jessy’s involvement in the project, made clear throughout the narrative,
lends credibility to Park’s claims of expertise through relationship and the right to speak about life with autism.

Park explicitly addresses the fact that she is telling Jessy’s story, and not just her own, in the brief Afterword to *Exiting Nirvana*. Such a note does not appear in *The Siege*, perhaps because it seemed so obvious at the time that Jessy could not speak for herself that Park saw no need to express it. Jessy still could barely talk at age eight, much less write or tell her own story. In 2001, however, many things are different, not only Jessy’s abilities but also the social climate around autism. As discussed earlier, Park’s first book was groundbreaking in that it was a parent’s account of autism, an entry into an area of discourse in which previously only professionals were permitted to speak; the idea of autistic people speaking for themselves was still far in the future. However, by the time *Exiting Nirvana* is published there are at least a few well-known autobiographical accounts by autistic people, including Temple Grandin, Donna Williams, and Sean Barron. Park therefore seems to see a need to explain and defend her decision to tell Jessy’s story as the parent of an autistic person for whom communicating through writing is not only difficult but also undesirable. Her Afterword calls attention to but also complicates the relational account that is developed throughout *Exiting Nirvana*. It is worth quoting here in its entirety:

> Jessy cannot tell her story for herself. Though she can speak nothing but truth and her memory is unerring, I must tell it for her, today as when she was eight years old. Once I was naïve enough to think she might; when I wrote that account of her first eight years I changed her name to Elly so she need never be embarrassed. I know now how effortful is her reading,
how partial her understanding, how questionable her embarrassment. I know too that she’d never read such a story even if she could, or understand why it might be worth the telling. So I can tell it freely, in its continuing strangeness and its increasing, precious ordinariness, as Jessy enters, more and more fully, yet never entirely, the world in which we live, all of us, together. (208)

Park begins by declaring that Jessy is incapable of telling her own story. Since she follows that declaration with the acknowledgment that Jessy has an excellent memory and is truthful in her reporting, the barrier would seem to lie in Jessy’s writing or narrating ability, though Park does not directly address these factors here. Instead she focuses on Jessy’s difficulties with reading and understanding and her apparent lack of embarrassment at having others read her story. Perhaps more pertinent is the statement that Jessy would neither “read such a story even if she could” nor “understand why it might be worth the telling” (208). These reasons suggest more explicitly why Park, rather than Jessy, is the one to write this auto/biographical text: that Park is the one who wants to write it and sees value in sharing their story with others. While Jessy, as Park makes clear, is happy to participate in the project of gathering material for the book, it is not her own initiative to tell her life story. Despite this fact, I argue that Park’s text is a relational auto/biography that tells her own and Jessy’s intersecting stories and draws its strength from the contributions of each party in her own way.

Park’s narratives in both memoirs are defined by her relationship with Jessy, focusing neither solely on her own life story nor solely on Jessy’s, but navigating the relationship between them and constructing a story out of that relationship. The emphasis
falls more on Park’s identity and life story in *The Siege* and more on Jessy’s in *Exiting Nirvana*, but both elements are present, and indispensable, in each. Stevenson argues that Park’s books are “not autobiographies of disability” because Park herself is not telling the story of her own life with a disability, but instead are “acts of mediation that frame, and publicly disseminate, [Jessy’s] self-representation...incorporated in [the] text” (203). I would argue, however, that while Park’s memoirs may not be straightforward “autobiographies” of disability, they are “auto/biographies,” texts that are both autobiographical and biographical, highlighting relationships between the self and others and the ways in which their lives and stories affect and are affected by one another. Park offers her own autobiography, the story of her life with her daughter who has a disability; this element is a very important one in *The Siege*, where she is most clearly claiming her right to speak about her experience raising a child with autism. Park may not herself be disabled, but disability shapes her life as Jessy’s mother. At the same time, Park also offers the story of Jessy’s life from her own perspective; in *The Siege* this story is given almost entirely from Park’s perspective since, as we have seen, Jessy had limited ability at that time to communicate through language.

On the other hand, I think Stevenson’s point that Park mediates Jessy’s self-representation is an important one. In *Exiting Nirvana*, Park incorporates Jessy’s speech, artwork, and writing as texts generated by Jessy herself, not necessarily for the purpose of Jessy telling her own life story, but as material for Park’s efforts to do so. Though she does not create these works specifically for the text, Jessy contributes or at least consents for them to be included in her mother’s book, to some extent collaborating in the project of representing herself. Park’s inclusion of Jessy’s supplemental materials makes the
book at least in part Jessy’s as well as her mother’s; the authority to speak on the experience of life with autism is shared between them. I want to differentiate here between autobiography and self-representation. While it may be true, as Park argues, that Jessy is neither capable of nor interested in telling her life story—her literal autobiography—she is obviously capable of producing words, images, and behaviors that represent her in some way. These elements, produced by Jessy, are examples of self-representation mediated by Park as she includes them in her project of constructing a story that includes the two of them. I consider such mediation a form of Cynthia Lewiecki-Wilson’s “mediated rhetoricity,” communication as a combined effort between the disabled person and those who fall into Couser’s category of “proximate others,” people close to a disabled person who tell his or her story in isolation or in combination with their own (Vulnerable Subjects 40). The definition of “auto/biography,” as I apply it to Park’s texts, includes the telling of relational life stories as well as what Paul John Eakin calls the “story of the story” (“Relational Selves” 70), the encompassing narrative that draws these multiple stories together and makes a connection between the living and the telling, as both of Park’s memoirs do. By including the “story of the story” of Jessy’s contributions to the construction of the text and the origin of the words and images that appear within it, Park creates an auto/biography that highlights the ways that her own and Jessy’s life stories intertwine with one another and the growth that each has experienced over the course of their relationship. In addition to Park’s growing recognition that “the truest respect lies not in the wishful insistence that [Jessy] is really just like other people but in the recognition, and the valuing, of what she is” (Exiting Nirvana 204), the reader
has access to Jessy’s own growth through her art, her words, and her interactions with her mother and others.

Park’s memoirs, then, are works of auto/biography that tell her own story in relation to the story of her daughter, told about, and for, but also with, Jessy. Without her relationship to Jessy, Park’s story of her own life would not be the same as the one she tells in these narratives; as Thomas points out, Park’s memoir, like others by mothers of children with disabilities, “[o]n the surface…appears to focus on a child’s life” but “also tells the story of a mother’s life, especially her inward experience of self-in-relation—the mother’s subjectivity” (187). In this extension of Eakin’s relationality, the mother’s life cannot be told without the existence of the child, and Park’s experience as a mother is much changed after Jessy’s birth. In telling her own story as a mother, Park inevitably represents her daughter; as Eakin makes clear, one’s life story is inextricably linked to those of others, particularly for people as close as parent and child. Rachel Adams, herself the author of a memoir about raising a son with Down syndrome, remarks, “I am always careful to say that I am the subject of my memoir, but of course I am representing my son, as well as other family members and a broader community in which our lives unfold” (8, emphasis original). In auto/biography it is inevitable that one represents not only oneself but also the people and contexts with which one is in close contact, and this can be a complicated process, but Park’s representation of herself and Jessy becomes increasingly collaborative as Jessy grows in her ability to communicate through language and art. Perhaps the most problematic piece of the Afterword is Park’s claim to be able to “tell [their story] freely” because of Jessy’s inability to do so. I do think there is a responsibility on Park’s part to be as true as possible to Jessy’s interests and wishes,
which Jessy seems very capable of expressing, so Park is not entirely “free” to tell
whatever she likes without consideration of Jessy. Nor is her story the definitive or final
word on Jessy’s life story or her identity as an autistic person, and readers should always
keep such limitations in mind. However, the “story of the story” which Park includes in
her text serves to demonstrate not only Jessy’s participation in the process of writing the
book, but also the relationship between mother and daughter that helps create both their
relational life and this published narrative.

As a parent whose life is bound up with her autistic daughter’s, Park claims the
authority to speak about her own experience of life with autism and to represent her
daughter’s life to the best of her ability, with some degree of collaboration with and
mediated self-representation of her daughter. While this type of act, of one person
representing another who cannot or will not represent him- or herself, continues to be a
complex one for parents of people with autism, autistic self-advocates, and scholars of
autobiography and disability studies, Exiting Nirvana provides insight into how Park
constructs her own and her daughter’s stories through her relationship with Jessy. In the
introduction to his book about life with his son Jamie, who has Down syndrome, Michael
Bérubé reflects, “[I]t is part of my purpose, in writing this book, to represent Jamie as
best I can—just as it is part of my purpose, in representing Jamie, to ask about our
obligations to each other, individually and socially, and about our capacity to imagine
other people” (xix). These are important questions to ask and to continue asking, and
while they may not be easily resolved, parent memoirs such as Park’s, Adams’s, and
Bérubé’s can provide tentative and ever-evolving answers about the role relationships can
play in efforts to better understand and represent individuals with impairments that complicate their self-representation.

Conclusion

As I have shown, Clara Park’s first memoir, *The Siege*, contributed significantly to the extension of the authority to speak about life with autism beyond the traditional “experts” to parents like herself whose knowledge is different from but not less important (and perhaps even more so) than that of doctors and other professionals. Park’s text challenges discourses that value the detached medical or scientific perspective, highlighting instead the advantages of the parent/child relationship in understanding and narrating autistic life. In *Exiting Nirvana*, written nearly forty years later, Park shows the evolution of both professional discourses surrounding autism and her own relationship with those discourses, while also making space in her narrative for her daughter Jessy’s produced words and images. Through her use of evolving metaphors to interpret Jessy’s experience, Park seeks to understand and interpret the relationship between Jessy and her family, between the nonnormative autistic world and the normative “outside” one. Park’s text thus works to expand the possibilities for relationships with discourses and with other people in the construction of auto/biographical texts. By including Jessy in the process and, to some extent, mediating her self-representation, Park acknowledges the importance of relationship in her process of coming to understand life with autism in a new way. While her approach of course has its limitations, including in terms of her mediation of Jessy’s own self-representation, it does offer important insight into the potential of relationships in understanding and representing life with autism and contributing to the larger social discourse comprised of professional research, parent
memoirs, and self-advocacy. Clara Park helped carve out space in that discourse, first for parents, and later for her own autistic daughter, through her relational work of auto/biography.
Chapter 3
Transformative Narratives:
Double Voicing and Personhood in Collaborative Life Writing about Autism:

Introduction

The collaborative memoir, co-written by a person with autism and a non-autistic parent, is one of the most intriguing forms in the recent autistic memoir boom. While the level of collaboration in these works may vary in both degree and kind, such memoirs have the potential to make known life stories that might otherwise remain silent—what Sidonie Smith calls “a silence in need of a story” (233). Many if not most of the autobiographical narratives of people with autism in these collaborative memoirs would not be written without collaboration between the two parties for any number of reasons, from difficulties in communication to problems of access and questions about credibility or legitimacy for the autistic contributor. Such collaborative auto/biographies continue the project begun by parent memoirists such as Clara Claiborne Park to reclaim and reassign expertise from medical and psychological professionals to those who live with autism on a daily basis, expanding notions of autism by providing more, and more nuanced, accounts of what life with autism looks and feels like. These texts have the potential to lend voice, agency, and authority to autistic people who are often seen as so different in ability and cognition as to be outside the usual boundaries defining personhood and selfhood. In collaborative narratives of life with autism, the interaction of relational lives is manifested in the presence of multiple voices and versions of interconnected experiences, where the voice of the autistic individual can both supplement and amend the parent narrative.
Through the doubled-voiced or dialogical nature of collaborative auto/biographical writing, in which, as Susanna Egan writes, “two or more voices encounter one another, or interact” (3), the reader is provided with a more complete picture of the life story of those involved than a single-voiced narrative can offer, even, and especially, when those voices do not follow exactly the same trajectory. Many parent narratives about autism, including those contained within the two collaborative memoirs I will examine here, Judy and Sean Barron’s *There’s a Boy in Here* (1992) and Arthur and Carly Fleischmann’s *Carly’s Voice* (2012), follow common tropes for telling life stories of illness and disability. The most common of these is the restitution or recovery narrative (Frank 115; Couser, *Recovering Bodies* 185-86), often referred to as the “tragedy to triumph” plot. Such narrative patterns focus on the recovery of the ill person, or, in the case of autism, the seemingly “miraculous” breakthrough or emergence of the autistic person from the communicative impairments or behavioral patterns of autism.

While such narratives can be problematic in a number of ways and may offer strong negative views of autism, and of the autistic person, that are surmounted only by the so-called recovery, I argue that the voices of the autistic writers in these texts add additional layers of narrative and authority that can serve to counteract some of the limitations of the parental recovery narrative on its own. In telling their own stories and offering evidence of their own personhood and selfhood, these writers rework the recovery narrative structure in a new direction, calling the concept of “recovery” into question.

While each of the texts I examine includes a moment or period of “breakthrough” for the autistic individual, rather than somehow leaving autism behind, these young people gain through this breakthrough the ability to speak for themselves about autism.
and their own identity. Their “breakthroughs,” while on one hand emphasizing the limitations of autism and the need to “break free” of it, simultaneously make possible the transmission of important evidence of the humanity and individuality of the autistic person, including before he or she was able to communicate effectively. Though the parents in these texts do not appear to fully recognize their autistic children as valuable persons and selves until they are able to communicate meaningfully about their inner thoughts and feelings, the children’s narratives actually demonstrate that both before and after the “breakthrough,” they were and are persons with identities and stories. These stories cannot be easily communicated until the autistic individuals “find a voice” (literally, for Carly; functionally, for Sean). Through the autistic writer’s perspective the reader gains insight into a reality that transcends the limitations of the recovery story by showing that there is in fact no miraculous moment when the autistic individual becomes worthy of being granted personhood and selfhood; rather, the improved ability to communicate what are deemed “real” thoughts and feelings make it possible for non-autistic others to recognize the autistic child as a person. Narrative by the autistic person, gained through the so-called “breakthrough,” facilitates the recognition of his or her personhood while supplementing, and mitigating the dominance of, the parent narrative and pushing beyond the limitations of standard narrative models.

**Voice, Personhood, and Selfhood in Autistic Life Writing**

As many disability studies scholars have emphasized in recent years, it seems to be more productive to view disability at least in part as a socially-constructed identity than solely according to an individual, medicalized model which figures disability as a personal problem to be treated, fixed, or overcome. As Tobin Siebers characterizes it,
“the medical model defines disability as a property of the individual body that requires medical intervention,” while “[t]he social model opposes the medical model by defining disability relative to the social and built environment, arguing that disabling environments produce disability in bodies and require interventions at the level of social justice” (25). In the face of early views of the autistic person as suffering from a psychiatric or medical condition to be blamed on parental neglect and to be either cured through psychoanalysis or dismissed as hopelessly impaired (see Chapter 2), Clara Park’s claiming of authority as a parent was a movement toward a broader understanding of autism as social, a product of social constructions of illness and disability, as well as relational, a condition affecting not only the individual but also the those with whom he or she lives and interacts. According to the social model, the perceived definitions and limitations of autism are subject to change as levels of knowledge and tolerance evolve. Granting access to non-professionals to speak about life with autism allows for multiple perspectives to be considered, weighed, and compared and for more nuanced, but more complicated, views of autism to begin to emerge. Inherent in the movement from the medical to social model is the possibility for autism to be seen as something more than a “deficit…[or] an individual burden and personal tragedy” (Linton 11), and for people with autism to be understood in more multifaceted ways.

Extending expertise to the (typically) nondisabled parent is a positive first step toward a more comprehensive view of autism and of autistic people. The outpouring of memoirs by parents of children with disabilities, particularly autism, in the past decade or so is evidence that these parents have much that they wish to share about their experience, and that there is an audience for such work, made up in large part of other
parents of children with disabilities who are seeking wisdom, advice, and new ways to understand their children (I will discuss parent memoir in more detail in Chapter 4). However, while insights from family members who live with and care for people with autism can be extremely valuable, there is also a danger that they will eclipse or replace the voices and perspectives of autistic people themselves, particularly for readers and other members of society who construct their understandings of autism on such available texts. Potentially as damaging as the elision of parents’ experience by professional discourse, complete reliance on the narratives of nondisabled others—even sensitive proximate others—to tell the story of autism can reinforce the assumption that autistic people have nothing of value to say, and/or no way of saying it. As Melanie Yergeau has pointed out, “Autism has long been ‘understood’ as a trope for incommunicability (Pinchevsky 2005) and as an organizing metaphor for social isolation and bodily imprisonment (Bettelheim 1967)”; the common presumption is that autistic people, by definition, cannot tell their own stories. There are degrees of truth and untruth to this preconception, but it is a potentially damaging blanket stereotype which an exclusive focus on the parent’s perspective may serve to reinforce. The parent memoir can offer a valuable perspective, but by no means the only or most important one, and should not be seen as doing so.

In order to claim expertise and the authority to tell one’s own story, the self life writer generally must be perceived as having 1) a self; 2) a life story to tell; and 3) the ability to tell that story. People with autism have often been seen as lacking some or all of these requirements, posing obstacles to audiences’ acceptance or even acknowledgment of the possibility of the self-narration of autistic experience.
Predominant theories of autism frequently emphasize the strangeness of autistic people’s mental processes compared to those of non-autistic people, setting up obstacles to recognition of the person with autism as a “normal” person or self. Many leading autism researchers in the field of cognitive psychology, particularly Simon Baron-Cohen and Uta Frith, posit the lack of a Theory of Mind as a defining characteristic of autism. This concept maintains that autistic people are unable to understand or imagine the minds of others, a capability that is framed as “natural” for non-autistic people. Lacking this so-called Theory of Mind, autistic people are said to suffer from “mindblindness.” John Duffy and Rebecca Dorner point out that in Baron-Cohen’s formulation, “[t]he autistic mind…is so radically alienated from ‘normal’ modes of thought and communication that only through acts of great imagination can we, ‘normal’ people, begin to understand it” (208). Similarly, Yergeau, herself an autistic writer, takes issue with the idea that “theory of mind is one of the quintessential abilities that makes ‘us’ human” and that the attitude reinforced by this theory is that “[a]utistics are not people. How can a non-person assert her personhood?” Indeed, prevailing theories of mind and personhood, along with stagnant generic expectations about the narrating self, make the transmission and recognition of the autistic subject and his or her life story extremely fraught and complex endeavors.

Paul John Eakin’s discussion of “narrative identity” helps illuminate some of the issues at play here. In Living Autobiographically, Eakin defines the concept of narrative identity as a “close and dynamic relation between narrative and identity” in which “narrative is not only a literary form but part of the fabric of our lived experience. When it comes to our identities, narrative is not merely about self, but is rather in some
profound way a constituent part of self” (2, emphases original). According to this model, the stories we tell about ourselves help construct, both for us and for others, who we are. In regard to the three constraints for the self life writer I list above, having a narrative identity would seem to demand that one work backward through the list: by telling one’s life story, one demonstrates that one has a story to tell, and thereby constructs a self that can be recognized by other people. One significant goal of telling such stories about oneself, according to Eakin, is to “establish ourselves for others as normal individuals” (4). That is, in telling one’s life story, the self life writer seeks to be recognized by readers or listeners as a person worthy of recognition.

As I have explained in Chapter 1, I make a distinction between the related concepts of personhood and selfhood, and consider both to be at stake in the relational construction of autistic life stories and identities. Drawing upon theories such as Daniel Dennett’s on “conditions of personhood,” I define personhood as the recognition of an individual by others as fully human and worthy of recognition as an equal. Personhood might be seen as corequisite with selfhood, which I define as the perception that an individual has self-consciousness and unique thoughts, emotions, and an inner life. In order to be a self, one must also be a person; and often, in order to be recognized as a person, one must show evidence of selfhood. Autistic subjects, especially those with significant communication impairments, frequently struggle to be granted personhood and/or selfhood by others according to fluid and often unconscious sets of requirements. Eakin notes, “Talking about ourselves is also a kind of genre…with rules and penalties that bear on our recognition by others as persons; as with memoir, so in self-narration, the culture’s fundamental values are at stake” (22). The “rules” that must be followed in
order to merit recognition as a person are social and cultural, and specific to a particular
society and culture, but as Eakin points out, of all the infractions of the rules a self-
narrator may commit, failure “to display a normative model of personhood…can entail
the most serious consequence of the entire set: institutional confinement” (43). Those
who cannot demonstrate that they meet social and cultural norms of personhood may fail
to have their stories recognized as well as put themselves in danger of the revocation of
other rights, including the right to be considered a full member of society. People with
autism, whose ways of thinking, behaving, and communicating may be significantly
different from those of non-autistic people, may not fit into these norms and may
therefore have difficulty getting their stories, their lives, or their selves recognized by
others. As John Shotter explains, “What we talk of as our experience of our reality is
constituted for us very largely by the already established ways in which we must talk in
our attempt to account for ourselves—and for it—to the others around us…. And only
certain ways of talking are deemed legitimate” (141, emphases original). Part of the
challenge of auto/biographical writing about autism, then, is to tell one’s life story in a
way that is true but that also is recognizable to, and perceived as legitimate by, readers
and listeners.

It is important to note that there is a difference between self-narration and inner or
personal construction of self, on one hand, and external narration and construction of self
for other people, on the other. In discussing those who have limitations to their ability to
self-narrate, or who have memory loss and thus apparent lack of self history to narrate,
Eakin concedes, “I would not want to assent to the proposition that the de-storied person
has become de-selved. There are many modes of self and self-experience, more than any
self-narration or autobiography could relate…. Nonetheless, in social settings of any kind, it is our narrative identities that define us” (Living Autobiographically 30). While many individuals with autism are unable to narrate their own lives to other people through language, and so may be “de-storied” or without a discernible story or identity for that audience, this does not preclude the selfhood of the individual. An externally non-narrating individual still has the potential for self-experience and self-narration that defines his or her self for him or her. However, in the absence of external, social self-narration, the identity of the autistic person as a recognizable person and self may be more difficult for a non-autistic audience to recognize.

Self life writing about autism, though it ostensibly can only tell the life story of one particular narrator, may be able to change views regarding the personhood of autistic people more generally by creating for readers new ways of understanding autistic experience. Ian Hacking speaks to the possibility that autistic autobiographical writing may expand notions of legitimacy and personhood as it teaches readers more about how to understand autistic subjects. Hacking observes that “[t]he various regimes that help autistic people learn to understand most other people compensate in one direction,” while “[autobiographical autism] narratives teach many of us how to compensate in the other. That is, they suggest what to infer from autistic behaviour which on the face of it means nothing to us” (1472). I agree with Hacking’s assessment of this exciting potential of self life writing about autism; through increased recognition of the ways such narratives constitute some aspects of life with autism, readers and observers might grow in understanding of those who are difficult to place within historical, and current, categories of “normal” personhood. Hacking concludes, “If we took this point of view, we might
come to judge that less gifted autistic children and adults, who communicate very little, also understand, in a quite specific way, far more than is evident to the outsider. If we were to take this route, it would be a shift, perhaps a radical one, in our conceptions of and relationships to individuals on the spectrum” (1473). I would argue that both single-author and collaborative works of auto/biography about life with autism carry this potential, as they increase the pool of knowledge of autistic ways of thinking for non-autistic readers and increase the possibility that autistic individuals, including those who cannot narrate their lives for others, may be recognized as persons. Betty Bergland corroborates this view of the resistive potential of auto/biographical writing more generally: “Because autobiography has acquired power in the culture to legitimate certain subject positions, autobiographical studies can be a site from which to not only challenge essentialist notions of the human being, but also to examine the effect of discourses on subjects, both those that seem to guarantee prevailing social relations and those that critique them” (162). Auto/biographical texts about autism may help to shape readers’ understandings of and attitudes toward autistic subjects and to “challenge essentialist notions of the human being” and the social influences that perpetuate those notions. At the same time, the communication of self in such auto/biographical texts can take forms that contest the limitations of life writing, especially when the text includes the voices and perspectives of multiple people whose stories and identities are relationally interconnected with one another.

**Collaborative Texts and Interacting Voices**

Writing a traditional autobiography may be a difficult or impossible task for many people whose communication skills are not sufficient to write a text independently, while
a parent memoir, though potentially valuable, does not necessarily provide a way for autistic voice to be heard or personhood to be recognized. For my purposes, a collaborative memoir is one in which both (or all) contributing parties participate significantly in the writing and/or construction of the text. Such a text may take a number of forms; in the case of life writing about autism, it frequently involves an autistic person along with a nondisabled proximate other, most commonly a parent. The balance of writing on each side may vary, as may the writing and editing process, but each contributor’s voice must be a significant presence throughout the text (i.e., not limited to one part of the text, such as a preface or afterword), and have an influence on its trajectory and message. This may mean that the two voices have somewhat different trajectories and messages, which is what, I believe, makes many of these collaborations particularly powerful. Such collaborative memoirs are a form of auto/biography, which, as I define it, includes the related life stories of two or more parties, with attention both to the life stories of each person and to their interrelatedness. These auto/biographical texts foreground relationality, which, in Eakin’s words, emphasizes “the extent to which the self is defined by—and lives in terms of—its relations with others” and, accordingly, the need for recognizing such depictions of relationships between lives in autobiographical writing (“Relational Selves” 63). Emphasizing relationality in life writing echoes disability studies’ frequent emphasis on interdependence, the idea that people relying on and supporting one another is not only acceptable, but a positive model for successful lives and communities. Alison Piepmeier, for example, praises stories about raising children with disabilities which “articulate the importance of interdependence as a human condition, and that it should be recognized as part of what it takes to be a citizen and a
full person.” Relationality and interdependence are qualities whose presence can help mitigate cultural emphasis on individualism and independence, which are both unrealistic for many people with (and without) disabilities, and limiting for models of life, life narrative, and personhood.

An auto/biographical text may be relational without necessarily also being collaborative. A number of parent memoirs include the voice of the child in a final chapter, while the main body of the text is written exclusively by the parent; Jane Taylor McDonnell’s *News from the Border* offers a useful example of this type of memoir. On one hand, the afterword by McDonnell’s son Paul, a young adult at the time of writing, is considerable in length (about 50 pages) and offers insights into Paul’s experience, and autistic behavior, that McDonnell’s text does not, and cannot. Paul for instance, talks about his rocking, a common autistic “stimming” behavior, and other people’s possible reactions to it: “I realize that rocking would look very stupid to some people, and I sometimes feel self-conscious about it. Especially at twenty. But rocking helps me to relax, and I doubt that I will stop it any time in the near future. If other people think that it’s weird, that’s their own problem” (McDonnell 328). This afterword also gives Paul’s voice the final word in the book, leaving readers with his perspective rather than his mother’s and emphasizing that he does, in fact, have his own story to tell. On the other hand, however, the main text of the book is written entirely by McDonnell, and very much from her own point of view and about her own experience—as the mother of an autistic child, but also as an academic struggling with the demands of both scholarship and motherhood; the wife of a man who has difficulty dealing with Paul’s autism; and a

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27 Paul’s recognition of how others might view his rocking is one of many examples throughout these texts that would seem to resist Theory of Mind theorists’ insistence on the inability to imagine others’ perspectives as a defining autistic trait.
clandestine, and later a recovering, alcoholic. It is very much, as the subtitle proclaims, “A Mother’s Memoir of Her Autistic Son” (emphasis added), not a text which works to give voice or to share it in a substantial way with her son. It is McDonnell’s memoir about her life, centered on the experience of having an autistic son. Paul’s chapter is supplementary, and does not interact with or influence his mother’s narrative. While still a text that depends upon and emphasizes lived relationality, especially the relationship between mother and son, McDonnell’s memoir is not textually collaborative, but a single-author text with an insightful afterword.

The two texts which I will examine in this chapter, by contrast, each offer significant space and influence in the text to the person with autism, and so I consider each to be an example of collaborative auto/biography. The first text, There’s a Boy in Here, lists Judy Barron and her son Sean Barron as co-authors, and comes the closest of any such work of life writing about autism I have read to a balance in contributed content between the two writers. While the book is structured by Judy and begins in her voice (starting when Sean is born, a time that he obviously is unable to recall), nearly every

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28 I want to note here that throughout my discussion of There’s a Boy in Here and Carly’s Voice, I will be referring to each of the authors by his or her first name. This is in large part for clarity, since Judy and Sean Barron as well as Arthur and Carly Fleischmann share a last name, and using both first and last names would be cumbersome. However, there is also a sense in which the use of first names lends itself well to discussion of these auto/biographical texts. Since they are writing their own life stories, these writers’ narratives are necessarily personal, and preserving the use of first names, which are, of course, used in the narratives themselves, helps both to maintain the personal nature of the stories being told and to reinforce my argument that the personhood of each individual is demonstrated and furthered through the telling of his or her life narrative.

29 Though Sean does not seem to remember back quite this far, it is interesting to note that a number of autistic people write that they are able to recall their infancy and even birth. Dawn Prince-Hughes reports that she remembers details from the day of her birth that her mother has confirmed to be true. She reflects, “When I close my eyes, I can play it back like a three-dimensional tape, replete with the smells, the sensations, and my feelings about it. I have always had this photographic or eidetic memory, and all of my many recollections of the past have a quality that makes them seem almost more real than the present. They allow me to tell the story of my life” (16). Such vivid recollections suggest that for some autistic people, the genre of autobiography might be a particularly suitable one since they may be able to write quite accurately about long-past life experiences.
chapter includes Sean’s voice; passages written by Judy are followed by sections written by Sean, providing his memory or interpretation of incidents recounted and offering insight into his autistic behaviors. Throughout each chapter, Judy’s plain text is punctuated by Sean’s italicized sections, alternating between what the text and book jacket characterize as the “outside” and “inside” views of autism. This trope plays a significant role in much life writing about autism, particularly when communication barriers prevent the non-autistic parent or proximate other from understanding the autistic person’s thoughts and feelings. Accessing the “inside” view of autism is one of the most appealing features for readers of such literature, often non-autistic family members, therapists, or educators seeking to better understand the autistic people in their lives.

Sean’s ability to speak and write about his feelings in the candid way he does in the book, developed in his later teen years (though could speak and write before then, he struggled to clearly communicate his thoughts and feelings), enables him to share his insight into previously incomprehensible behaviors and shed light on the experiences Judy writes about with such frustration. According to Judy’s descriptions in the book’s preface and afterword, at age twenty-five Sean suggested writing a book about the family’s experiences while he was growing up, “to try and explain what autism is really like from the inside” (ix). Throughout the four-year process, Judy and Sean wrote and compared their accounts and, Judy comments, through reading Sean’s sections she “discovered much of the real story for the first time” (258). I will discuss the relationship between Sean’s and Judy’s written portions and the implications for narratives of autism and autistic individuals later in this chapter, but what is important to note here is that Sean does in fact make a significant contribution in this book to telling the story of his
life and explaining his experience from his own perspective, at various times in response to, in corroboration of, and in resistance to the narrative told by his mother.

_Carly’s Voice_, which lists Arthur Fleischmann as its author, “with” Carly Fleischmann, is somewhat different from _There’s a Boy in Here_ in its makeup, structure, and type of collaboration. Like Judy Barron, Arthur Fleischmann dictates the structure of the text, which is based on the timeline of Carly’s life; also like her, he begins with his child’s birth and relates many experiences, such as becoming aware of Carly’s differences and searching for answers and treatment options, which lie outside the boundaries of Carly’s experience or narrative ability. Unlike Sean, however, Carly is not physically able to speak, and until her “breakthrough” when she begins to communicate through writing at age eleven, there is little in the way of direct communication between Carly and the world around her, including her family. Arthur narrates the text until the point when Carly begins to “speak,” and then he starts to incorporate pieces of her writing in the text—selections from email and instant message conversations; letters and “speeches” that she writes for her bat mitzvah and other events; Tweets; and a short story that she is composing. Also, like Paul McDonnell, Carly writes the final chapter of the book; however, unlike in Paul’s case, this is by no means the first time that we have heard from her, though it is the most direct since it is written to the reader for inclusion in the book, rather than having been written for other purposes and audiences and reprinted here.

In comparison to the collaborative work between Judy and Sean Barron, the Fleischmanns’ book is far less balanced—there is a great deal more of Arthur’s voice than Carly’s (despite the title). However, this may be largely due to the slowness of
Carly’s physical writing process, along with the fact that she is still a teenager (attending a mainstream high school) at the time of writing, and is not at leisure to devote intensive time to writing for this purpose. Carly’s communication abilities were developed much later than Sean’s and are still continuing to develop; in this sense, this book has even more significance as a collaborative text, because it helps amplify an autistic voice that otherwise would have been unlikely to have been heard in quite this way. Even more significant, juxtaposing Carly’s voice with her father’s narrative enables her to express her experience in ways that help establish and legitimate her as an individual, for the people in her life and for readers.

Auto/biographical works which incorporate the voices of more than one person, as both of these collaborative texts do, not only demonstrate the relationality and interdependence of the two lives and life stories, but also entail the interaction between and often conflicting narratives of the two voices. Such double-voiced, or dialogical, collaborative texts have the potential not only to share multiple, intersecting versions of the involved parties’ life stories with a reader; they also have the potential to reciprocally affect the tellers of these life stories. Through the interaction of the two voices, the writers may influence one another’s understandings of each other’s, and their own, life stories and identities. Mikhail Bakhtin, in *The Dialogic Imagination: Four Essays*, describes the interaction of voices and social languages, identifying it as a defining feature of the genre of the novel. In the essay “Discourse in the Novel,” Bakhtin defines the concept of heteroglossia, the “social diversity of speech types…and the differing

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30 I should note, however, that in addition to the book, Carly has made her voice heard through television appearances, her Facebook page, and a Twitter account. While not the only venue for her voice and story, the published book is both more thorough and more formal (and as a published work, more formally legitimated by a form of cultural authority) than these other sites and offers the opportunity to place her perspective alongside that of her non-autistic father who tells his own version of the family’s story.
individual voices” that are gathered together in a novel by an author (263), arguing that “[t]hese distinctive links and interrelationships between utterances and languages, this movement of the theme through different languages and speech types, its dispersion into the rivulets and droplets of social heteroglossia, its dialogization…is the basic distinguishing feature of the stylistics of the novel” (263). For Bakhtin, “dialogized heteroglossia” (272) is a variety of forms and genres of language that are in dialogue with the “official languages of [a] given time” (273), directly or indirectly opposing or challenging such languages. In this way, the presence of multiple voices makes possible dialogue and friction between perspectives and ways of speaking. While Bakhtin uses the concepts of dialogism and heteroglossia to legitimize the novel as a valid literary style, he also urges further study of such “intra-language dialogue” (273) in text. This sort of dialogue is by no means limited to novelistic discourse but is clearly recognizable in collaborative auto/biography as well.

In her book Mirror Talk, Susanna Egan discusses the presence of double voicing in autobiographical texts. Her own definition of dialogism helps shed light on its potential not only in novelistic but in auto/biographical discourse:

Interactions among people and among genres are not simply dialogues because they involve pluralities but are often also dialogic—in terms of their dynamic and reciprocal relations between text and context; their relation of the difference between self and other; the contestatory nature of many of these relationships; the frequent recognition and destabilizing of power relations; the common move toward decentered heterogeneity; the omnivorous use of genres to subvert or destabilize each other; and,
perhaps most important, the recognition that human beings exist within a hierarchy of languages of ideological discourse. (23, emphasis original)

Like Bakhtin, Egan emphasizes the ways in which dialogue between voices, genres, and languages can help to destabilize dominant ways of speaking and knowing, as well as highlight the relationships and differences between those whose voices are speaking with and against one another. Additionally, Bakhtin observes, “The importance of struggling with another’s discourse, its influence in the history of an individual’s coming to ideological consciousness, is enormous. One’s own discourse and one’s own voice, although born of another or dynamically stimulated by another, will sooner or later begin to liberate themselves from the authority of the other’s discourse” (348). For autistic writers in particular, double-voiced collaborative texts can provide an opportunity for liberation from another’s authority and the development and assertion of one’s own narrative consciousness and identity.

Voices in a dialogic auto/biographical text stimulate one another and challenge one another’s authority, calling the other’s narrative into question but also developing the combined narrative through their multiple, related perspectives. Describing the possible effect of inserting another character’s perspective into a single-author memoir, Egan writes, “One result, surely, would be an increased degree of apparent authenticity established, paradoxically, by the very instability that such externalized doubling would create. Precisely because no single ‘authorial I’ would control perception, the ironic reader would be more fully implicated in the text than before. Because the perceptions being established would destabilize each other, they would also confirm each other” (2-3). One potential result of adding an additional perspective to a text is that one person’s
narrative can contribute to the “correction” of the other; that is, the limitations of a single perspective might be mitigated by adding an additional, possibly divergent, perspective. Because the two narrators in each of the collaborative texts I will examine are parent and child, and their lives closely overlap with one another, they are telling elements of the same story from different vantage points. As Egan explains, “Parallels between text and life become even closer when both subjects are involved in the preparation of the text. Narration then takes the form of dialogue; it becomes interactive, and (auto)biographical identification becomes reciprocal, adaptive, corrective, affirmative, as is also common in life among people who are close to each other…. These autobiographies, in other words, do not reflect life so much as they reflect (upon) their own processes of making meaning out of life” (7-8), a process similar to Eakin’s “story of the story” (“Relational Selves” 70). Collaborative auto/biographical texts consist of two voices constructing their own versions of their life stories while also offering reflection, whether implicit or explicit, upon the process of constructing these converging and diverging stories. Through the juxtaposition of two stories and perspectives that may in fact challenge, complicate, and contradict one another, the dialogic nature of these double-voiced collaborative texts contributes greatly to their potential both for mediating rhetorical and narrative ability for people with limited communication as well as for expanding preexisting notions about personhood and selfhood for people with autism. In particular, the interposition of the autistic narrator’s voice has the potential to destabilize the dominance of the nondisabled parent’s perspective, serving to validate the personhood and unique life narrative of the autistic individual.
Narrative Construction of Recovery

Auto/biographical narratives of illness and disability frequently center around a pattern of recovery—healing from illness and returning to normalcy, prevailing over the disabling aspects of impairment, or erasing impairment altogether. In his discussion of narratives of illness, Arthur Frank calls this pattern a restitution narrative, one in which the ill person is cured or healed and returns to health. Frank identifies restitution narratives as the type of stories that both ill people want to tell and listeners want to hear; “the ill person’s own desire for restitution is compounded by the expectation that other people want to hear restitution stories” (77). G. Thomas Couser refers to this sort of structure alternately as a recovery narrative and as a comic plot, one in which “the protagonist is better off at the end than at the beginning” (Recovering Bodies 16). He, too, emphasizes the cultural pressures on life writers to tell this kind of story, since “[a]utobiographical narratives, almost by definition, involve comic plots” (16); it is the expected trajectory of a life story that audiences will want to read. However, Couser also notes that this movement of the protagonist’s life story from worse to better is often challenging for people with disabilities that “do not admit of cure or complete recovery” (183); indeed, most disabilities fall into this category.

However, such a contradictory reality does not prevent the teller of a life story from seeking to make use of this traditional structure of the autobiographical narrative. In life narratives of disability, this often takes the form of “overcoming” disability in a variety of ways, including by rising above obstacles presented by disability to achieve things previously considered impossible. “Overcoming” is a fraught and usually malign concept in the field of disability studies, imbricated as it is with limiting and
ableist stereotypes about what it means to have a disability. In life stories of autism specifically, the narrative frequently takes the form of the person with autism “recovering,” “emerging” or “breaking through” autism. Such narratives suggest that autism is not a permanent disability or aspect of one’s identity but rather an eradicable impairment which, with the correct effort, therapy, or resistance, can be broken through (by family, doctors, or therapists) or recovered/emerged from (by the autistic person him- or herself). While, as I have discussed in Chapter 2, the understanding of autism by both professionals and those directly affected by it has changed significantly over the seventy years since the diagnosis was established, current views of autism recognize it as a “lifetime condition” (Park, *Exiting Nirvana* 199), not something from which one can actually “recover.” According to current conceptions, an autistic person cannot become non-autistic (and, likewise, does not “become” autistic at a certain point, but has been so from birth). Still, the recovery narrative persists in a variety of forms, and life writers frequently describe autistic subjects as having emerged from autism’s “prison,” “fortress,” or “bonds.” Learning to interact socially with others, control compulsive behaviors, and communicate effectively through speech or writing are some ways in which autistic subjects might be described as having “overcome” autism’s limitations and therefore achieved some level of triumph over their disability. However, such examples of growth, while often exciting, need not be seen as somehow breaking out of the realm of autistic experience; on the contrary, they are evidence that autism is, in fact, a developmental disorder, and people with autism continue to grow and develop throughout their lives, albeit sometimes at a different pace than those without autism. As Oliver Sacks has observed, “[A]utism, being a developmental disorder, tends to become less
extreme as one grows older, and one may learn to cope with it better” (Anthropologist on Mars 272). Recognizing changes and improvements as possible for autistic people helps to normalize disabled experience and minimize the tendency for the “overcoming” story to promote the idea that only by triumphing over one’s disability can one be successful or happy.

Both Judy Barron and Arthur Fleischmann, in their stories of life as parents of autistic children, make use of narratives of restitution or overcoming in ways that present largely limiting and negative views of autism prior to the communicative breakthroughs that each of their children experiences. The parents’ “outside” view of autism, which often seems to see only the problematic behavior and differences of the autistic child, is, of course, a literary trope that sets the reader up for the miraculous emergence from the autistic “prison” which occurs when the child begins to communicate and prove that there is more to him or her than may have previously been apparent. As Couser points out, this movement from worse to better is common in works of autobiography, and seems to make the story worth telling; were there no “breakthrough” for Sean and Carly, these stories may not have been told, because such a narrative move would not have been possible. A story about a life in which “there was no bottom,” where things only get worse, never better, as Arthur describes the family’s experience at one point before Carly’s breakthrough (74), is one to which few readers would be attracted. In a sense, then, the breakthrough makes possible the restitution narrative; it gives the story a reason to be told. As a motivation to tell a life story that might otherwise remain silent, the posing of triumph at the end of tragedy has positive potential in increasing the number of life stories about autism that are made available to the reading public. However, as many
scholars of disability, and especially autism, life narratives have noted, the dominance of such narratives of disability reinforce the idea that only narratives that follow this pattern are worthy of being told. Mark Osteen comments that Temple Grandin’s and Donna Williams’s autistic autobiographies “may send mixed signals to autistic readers: We are autistic and have written books, so you can too—but only if you present them as a ‘recovery’ or emergence from it” (28-29). While this is a definite danger, and there is a need for narratives that challenge the dominance of the overcoming narrative, I argue that the recovery narratives in these collaborative memoirs offer a chance for the newly “emerged” autistic person to tell his or her story in a way that works to subvert many of the negative stereotypes of autistic subjects that are constructed in the “tragedy” portion of the story. Through the dialogic interaction of voices and related life stories, the recovery narrative is challenged and new possibilities for stories of life with autism are presented.

**Judy**

Judy Barron’s story, which begins by recounting the joyous occasion of Sean’s birth, quickly shifts to the painful reversal of that joy which occurs as she begins to recognize Sean’s difference. Sean’s autistic behaviors—including repetitive, often destructive actions; failure to listen to or follow instructions; and apparent lack of consideration for other people—are framed by Judy as frustrating, embarrassing, and defying explanation. These behaviors become the focus of Judy’s narrative as she builds a case for why Sean’s autism for most of his childhood was unbearable and a breakthrough was needed in order to bring relief to the family and for Sean to achieve the “triumph” of becoming more fully and recognizably human.
Judy’s view of Sean’s autism from the “outside” presents Sean as incomprehensible and as so different from others that he can scarcely be viewed as a “real” child. His obsessive behaviors and his lack of responsiveness to scolding or punishment lead her to wonder what might be wrong with him: “[D]id we have a child with something missing—a conscience, a capacity to understand consequences?” (Barron & Barron 20). As with the concept of Theory of Mind, here the autistic person is constructed as being “missing something” that other human beings have—in this case, a “normal” response to consequences. Sean’s “abnormal” lack of response does not prevent his “normal” parents from responding with anger and frustration to his behavior, or from looking for signs of “normalcy” beneath the autistic veneer. It is when Sean seems to come closer to normalcy that his mother finds hope in the situation; when Sean is sick and his usual behavior “slow[s] down,” Judy reflects that “[h]e was like another child altogether. This is my son, I thought, this sweet, angelic little boy, free of the frenzied behavior that drives him” (33, emphasis original). Although he is ill and therefore not his usual self, Judy sees this version of Sean as more her son than when he is healthy, because he allows her to touch him and read him stories. In this state Sean fits her idea of what a child should be like, in the same way that her second child, Megan, fits that expectation: “She was easy to care for, easily satisfied by being changed, fed, held. So this, I caught myself thinking, is what it’s like to have a baby!” (23). In not meeting such normative, ableist conceptions of personhood, Sean, the autistic child, is figured as somehow not a “real” child. On another occasion, Sean is unusually, if briefly, attentive to Judy’s emotional state—her frustration, resulting in tears, at his inability to complete a therapy activity—and Judy again takes this as evidence that the “real,” “normal” Sean is
hidden behind the barrier of autism: “There’s a real child in there, I thought. He’s trapped and we’ve got to get him out” (61).

Such glimpses of the “normal” child she was expecting, and would like to have, give Judy hope that she will somehow liberate him from the prison of autism, by continuing to try to reach him, by refusing to institutionalize him, and by seeking what professional and educational resources are available to the family. In seeking professional expertise and any books she can find on the subject of autism (including Karin Junker’s *The Child in the Glass Ball*, Bruno Bettelheim’s *The Empty Fortress*, and, eventually, Clara Claiborne Park’s *The Siege*), Judy Barron looks even further “outside” in her attempt to gain insight into what is going on “inside” Sean’s world—not only the recognizable person but also the recognizable self. Judy reports that Junker’s early memoir, which ends with her autistic son’s institutionalization, “scared [her] to death” (68), and the doctors and experts that the Barrons seek out are almost entirely ineffective in reaching Sean or changing his behavior. Several doctors seem to blame Judy, following the tradition of the refrigerator mother; one doctor prescribes drugs that only make Sean’s hyperactivity exponentially worse; another doctor spanks him; and Sean’s stint at a residential school makes him miserable (though this incident does offer an example of the family responding to Sean’s feelings and wishes by eventually bringing him home [e.g., 141]). Ultimately, “outside” resources offer little to help in understanding Sean, and his difference and distance from others are only increasingly highlighted. Comparisons to younger sister Megan consistently leave Sean lacking; while “Megan [was] so easy to care for, to be with—interested, funny, reasonable, responsive[,] Sean…certainly was not fun to be with, and nothing was ever easy for him.
Almost everything he did was ‘wrong,’ and much of the time I couldn’t stand the sight of him” (99). Sean’s lack of normative emotional responses to others jeopardizes his status as a person worthy of human relationship: “How long can a mother continue loving a child who doesn’t love back, ever? A child who overtly rejects her love every time it’s offered, year after year?” (134). Without insight into Sean’s “inside” experience, there is little to convince Judy that Sean has reasons for his behavior, has feelings that are worth considering, and is not intentionally disobeying her and acting inappropriately. The reader of the book, however, who has access to Sean’s retrospective reflections on his thoughts and behaviors as a child, has insight that helps in viewing Sean as a person and not just as a problem or an enigma. As we will see, Judy’s great frustration with the “outside” experience of Sean’s behavior is offset in the book by Sean’s narration of the “inside” experience, which demonstrates both personhood and selfhood that Judy’s narrative undermines. Although retrospective, Judy’s narrative seems to seek to recapture her feelings at the time of the original events, and she does not respond to Sean’s reflections and explanations of his earlier behaviors with any change in her own narrative.

**Arthur**

Like the Barrons’ account, Arthur and Carly Fleischmann’s *Carly’s Voice* begins with the parent’s “outside” view of autism, particularly in the first section of the book and of Carly’s life, when she is unable to directly communicate with others. In this text, the mystery and frustration of Carly’s autistic behavior are exacerbated by the fact that unlike Sean, who learns to speak after some delay, Carly is not able to speak at all, and so cannot communicate through words to her family until her “breakthrough” at the age of
eleven. The book begins with Arthur’s narration, detailing Carly’s early childhood and her parents’ struggle to figure out “what’s wrong with Carly” during the period they referred to as the “Fix Carly years” (Fleischmann & Fleischmann 18). The first anecdote related by Arthur in the book, in which he finds seven-year-old runaway Carly naked at a playground and struggles with the need to explain her to bystanders, offers a clear picture of the family’s view of Carly during this time:

“Carly has autism.” Three short words must suffice to explain a tome of weird behaviors and limitations. It’s shorthand for Carly-is-different-she-acts-in-odd-ways-she-loves-taking-off-her-clothes-especially-if-what-she-is-wearing-has-a-spot-of-water-on-it-she-likes-repetitive-motion-like-that-of-the-swing-she-doesn’t-speak. We didn’t know what Carly knew and what she was incapable of knowing. She made odd movements and sounds and covered her ears when it was noisy. She cried often. And she never, ever stopped moving. Never. (5)

Carly’s inscrutable behavior, and her inability to convey what is going on “inside,” leads to her parents’ frustration with trying to understand and deal with her behavior and explain it to others. The use of the words “weird” and “odd” in the passage above, along with the phrase “we didn’t know,” illustrate the difficulty of interpreting her anomalous behavior; but, on the other hand, the use of “she loves” and “she likes” indicate that some information can be deduced from her behavior even if she cannot verbally express it. They can observe what she reacts to positively or negatively and identify her basic preferences. These preferences, however, are unusual and seemingly unreasonable, and so place her, like Sean, outside the realm of normative personhood. Arthur’s reaction to
this incident further reinforces the frustration of dealing with a child like Carly who does not behave as a child is expected to: after finding Carly and bringing her home, Arthur writes, “I wanted to say, ‘Stop this. Stop scaring the shit out of me. Stop creating havoc every five minutes. Stop being so needy. I love you, but stop’” (5). He expresses love for his daughter, but with the condition that she become more normal, more like other children, and less “needy,” a word that disparagingly suggests relationality and interdependence rather than the individualism and independence so highly valued in Western society.

In a number of other ways, Arthur’s narrative characterizes Carly’s state of being before her communication breakthrough as problematic, broken, and detrimental to the rest of the family. For instance, Part I of the book (the only one which does not incorporate Carly’s words because it takes place before she is able to write) is titled “Chaos Is Born.” Carly here is objectified, in a perhaps playful yet also diminishing way, as “chaos,” a source of “utter confusion and disorder” (“Chaos”), an interruption of normalcy for the rest of the family. The suggestion of absence or emptiness offered by another of the Oxford English Dictionary’s definitions for “chaos”—“the ‘formless void’ of primordial matter”—further implies that Carly’s behavior and her inability to communicate or explain it makes her “void” of personhood and selfhood. Like Judy Barron’s portrayal of Sean, Arthur’s description of Carly as “chaos” suggests that she is missing something that would make her a person. Arthur also makes use of Carly’s name as a pejorative that represents all of her most difficult qualities: “We could find no ailment to cure or person to blame for Carly being so Carly” (Fleischmann & Fleischmann 19, emphasis original). This use of Carly’s name to stand in for something
like “problematic” or “strange” also removes her from the realm of normative
personhood and instead figures her as a collection of challenging behaviors. Instead of
accepting Carly as she is, Arthur and his wife Tammy search for ways to “fix” her, to
make her become human: “‘I feel like there’s a button in her brain we just need to switch
on,’ Tammy said. … In our hearts, we had hoped to find a magic pill that would turn
Carly into someone else, someone who could speak, play, and be with us.  But that folly
had to come to an end” (27). Eventually, though, when Carly begins to communicate
through writing, her parents seem to get their wish; the “button” gets switched on, and the
Carly who is able to express complex thoughts and feelings through writing takes on the
personhood and selfhood that the obscure, uncommunicative Carly does not seem to
merit.

Similarly, Arthur figures autism as a “thief” that steals the “real” Carly from the
rest of the family, implying that if her autism were somehow removed, a “normal” child
would remain, in the same way that Judy Barron believes she sees glimpses of a child
behind the barrier of autism. Arthur admits that unlike some parents who demonstrate
“admiration of their child’s unusual behavior… I saw no beauty in this condition.
Autism was a thief. The opportunities it stole from Carly were obvious: the chance to
participate, to play, to learn, to fit in. It stole a sister from Matthew and Taryn. It stole

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31 This wistful hope that Carly could “be with” the family in the way they want her to be ironically echoes
Barry Kaufman’s memoir *Son-Rise*, which emphasizes “being with” as the family’s philosophical approach
to helping Kaufman’s son Raun, who is autistic. In a condemnation of the behavior modification therapy
approach, Kaufman argues, “When you push someone, there is an almost automatic tendency to push back.
You are saying to the child that he ‘must’ or ‘should’ be with you in a way that you define as acceptable.
Why would anyone want to be with someone who is disapproving of him? How could anyone want to
learn from someone who does not allow him any freedom or prerogative in the process? Why ignore what
the child wants?” (Kaufman 40, emphases added). Although Kaufman’s story and techniques raise their
own questions, his point, quite relevant here, is that acceptance of the autistic person as he or she is, and
recognition of his or her feelings, are key components of living with and loving that person—and of
recognizing him or her as a person and self worthy of consideration.
energy and money and patience. It was stealing our daughter, bit by bit” (83). Autism steals away the hypothetical “normal” daughter that seems preferable to the more complicated reality of Carly. Arthur’s and Tammy’s hopes for Carly are guided by ableist narratives of “real life” and “normalecy,” rather than recognition of the possibilities and potential for Carly as an autistic person who does not match those norms. After recounting his wife’s empathy with a local doctor who had killed herself and her baby—she muses, “‘I can imagine what she was feeling. If not for Taryn and Matthew…. I could never leave them motherless”’ (70)—Arthur watches Carly as she is sleeping and articulates his hopes for her that seem, at this point in her life, unrealizable: “‘Carly, I want you to be calm and happy,’ I whispered. ‘I want you to speak. I want you to play and have friends and go to school. I want you to accomplish something you will feel proud of. I want you to sit at the dinner table and share in the conversation. I want you to have a first boyfriend whom I will regard with skepticism, and then a husband whom I’ll welcome with open arms. I want you to have a life. I want you to know peace” (72). While certainly laudable hopes for a child, this litany also suggests an unwillingness to accept that a disabled person for whom some of these goals are difficult or impossible may still have a “real” or successful life. Though Carly will likely never be able to speak, that certainly does not preclude her potential to be happy, to accomplish something she can be proud of, or to “have a life.” However, the ways in which these goals are accomplished may not look the way the nondisabled parent expects them to, and may be difficult to recognize in the absence of traditional communication.

Arthur’s comparisons of autistic, uncommunicative Carly to her “normal” twin, Taryn, offer an even stronger contrast than Judy’s comparisons of Sean to her daughter
Megan. Since Carly and Taryn are exactly the same age, Carly’s differences in behavior and ability are constantly highlighted. Though Taryn and the twins’ brother Matthew both appear, from Arthur’s narration, to be fairly accepting of Carly, they obviously are able to perform tasks and engage with other people in ways that Carly does not, and so their “normal” lives reinforce, by contrast, Carly’s disabilities. A visit to the playground calls attention to some of these differences: Taryn runs off to play with the other kids, and Arthur watches parents interact affectionately with their children, while Carly prefers to stay on the swings. While Arthur frames this preference as “less than” the more conventional activities, it is obvious that Carly takes great pleasure in swinging: “The motion and the wind in her face seemed to provide a sensory relief we could not replicate elsewhere. She could swing for hours, her eyes closed, hands over her ears, and make a humming sound through her closed lips. Brrrr, brrrr, brrrr. Mmm. Mmm” (84, emphases original). Yet despite her apparent enjoyment, Arthur yearns for this daughter to be like the other: “What if I could take a gram of Taryn and inject it into Carly? I dreamt of what it might be like to have twins who were both normal. Maybe Carly was dreaming the same thing” (84). Since Carly cannot yet articulate her thoughts or even demonstrate clearly that she has them, Arthur imagines that she must be dreaming the same dreams for her that he is: to be normal, to be like Taryn—essentially, to be someone else. In this sense, the relational is used here to the detriment of the recognition of Carly’s self- and personhood, as by comparing her to her neurotypical sibling, Arthur emphasizes just how different she is from the norm, and therefore how far she is from his recognition of her as an individual. As we will see below, however, Carly’s own
narrative helps to counteract this negative application of relationality by its dialogical interaction with her father’s perspective.

Finally, the Fleischmanns, like the Barrons, seek help from professionals who are even further “outside” of Carly’s experience than they are themselves. Arthur incorporates verbatim reports and letters from Carly’s doctors, psychologists, and educators to support and legitimate his narrative, as they provide a professional perspective on Carly that corroborates his more personal account. For instance, a doctor of clinical genetics describes Carly’s developmental status at age three and comments, “The investigations I have done so far have failed to reveal any specific diagnosis. I explained to the parents that I doubt if we will be able to further delineate her condition” (28), validating Carly’s parents’ frustration regarding her complicated diagnosis and symptoms. These reports are most frequent in the first part of the book, when Carly herself cannot yet write; they provide a supplement to Arthur’s perspective on Carly’s autism, but they are far from representing Carly’s own experience. The use of the medical perspective represents an effort at relationality among discourses, but a much less productive one than the interaction with Carly’s voice and narrative. While the doctors’ comments add an additional perspectival layer to the text, Carly’s reports from the “inside” carry much more weight and are far more interesting, in my view, for the reader. While not necessarily more “true” than “outside” accounts, the personal narrative of the individual being represented offers a perspective that cannot be replicated by any other source; and, as noted earlier, the multiple voices of the collaborative memoir help to offer a more complete narrative of the Fleischmanns’ relational life story than either one can alone. As I will discuss in more detail below, Carly also takes issue with some of the
common medical views of autism and its symptoms and behaviors, calling into question the legitimizing power of the “expert” sources Arthur cites.

**Breakthroughs and Transformative Voices**

Up to this point, I have primarily discussed the voice of the parent in each of these collaborative memoirs. In many accounts, this is the only perspective that the reader is offered, and it can be a limited, limiting, and at times strongly negative one. However, as I have noted, the positive aspect of the recovery narrative pattern, which both *There’s a Boy in Here* and *Carly’s Voice* follow to some extent, is that, by definition, it sets up a breakthrough or transformation. In this way, the negativity of the pre-breakthrough narrative is redeemed by the post-breakthrough “triumph.” Contrast is needed to make the breakthrough appear as dramatic as possible to the reader, which seems to permit the parent to depict life with autism as virtually unbearable until the moment of breakthrough.\(^{32}\) This is an intentional storytelling technique, but what I would argue is less calculated, and more transformative, is the power of the autistic individuals’ voices after the breakthroughs in communication that both Sean and Carly experience. In addition to describing life with autism as mostly frustrating and unbearable, both Judy Barron and Arthur Fleischmann present their children as not only less than ideal in their abilities and behavior, but in many ways less than full persons; they are described as

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\(^{32}\) I do want to acknowledge the importance of allowing life stories about disability to represent real experience, even if that experience is negative. Arthur Frank, noting the complaints of a parent of a child with a mental disability that her support group does not let her talk about disappointments and frustrations, explains, “Many if not most North Americans share a cultural reluctance to say that their lives have gone badly in some significant respect and to mourn the loss of what was desired but will never happen. Our contemporary version of stoicism borders on denial. The good story refuses denial, and thus stands against social pressures” (63). Thus, telling stories of pain and difficulty can help resist cultural pressures to tell stories with “happy endings,” such as recovery narratives. There is a fragile line, however, between telling the truth about experience and representing life with disability in entirely damning ways. One person’s experience dealing with the challenges brought on by disability should not result in the denial of the personhood or worth of the disabled individual.
“missing” important components, as having a button that is switched off, and as lacking both qualities and abilities that “normal” people have. Rather than being recognized as individuals, both Sean and Carly are figured as problems in need of fixing. This understanding is in large part a result of both of these children’s inability to express themselves, to explain their behavior, or to demonstrate that they do in fact have thoughts and emotions that would validate each of them as selves.

Sean’s and Carly’s journeys, while occurring in somewhat different ways and on different timelines, lead to each of them gaining the ability to tell their own stories and to be recognized as individuals worthy of recognition as persons and selves. While Couser warns of the risks of collaborative life writing for disabled children, whom he describes as “doubly vulnerable subjects—triply so if their impairment compromises their competence or diminishes their autonomy” (Vulnerable Subjects 57), I argue that the collaborative works I examine here offer the disabled child a voice that increases his or her autonomy by demonstrating evidence of personhood that was previously unattributed to him or her. The parent narrative of each child’s life before communication demonstrates the difficulty of, and resistance to, attributing personhood and selfhood to a nonverbal autistic person with challenging behaviors. As Michael Fischer points out in his discussion of the interaction of autobiographical voices, “The tactic of telling strong alternative stories is a potent device, a far more powerful one than mere complaints against injustice or orthodoxy” (91). Although Sean and Carly’s stories do not overtly or forcefully challenge those of their parents, by offering alternatives to the nondisabled parent narrative they each assert that those with autism are persons and selves with stories worthy of recognition, even if they do not meet normative expectations.
Sean

Sean’s “recovery,” as it is narrated in *There’s a Boy in Here*, occurs when he is a teenager, and is a gradual development of changes in behavior and increased social engagement. Both Judy and Sean describe Sean at various points as “fully recovered” (Barron & Barron v), though both also acknowledge, paradoxically, that he will always be autistic: near the end of the book, Sean reflects, “I know quite well that my autism will always be part of me, that it isn’t something I can expect to be ‘cured’” (254), and Judy’s afterword points out that “[a]utism does not go away” (260). It is difficult to reconcile these acknowledgments with the claim of recovery, but it may be helpful to rework the Barrons’ definition of “recovery” into something more like “growth”—Sean’s learning to cope with his autism in a way that enables him to more fully enter the social world around him—rather than as a “full recovery” resulting in the eradication of his autism. Despite Judy’s assertion that “recovery is so rare” (263), the pattern of growth that Sean’s story reflects is not that uncommon; Paul McDonnell’s story in *News from the Border*, for instance, bears similarities to Sean’s in that Paul learns to interact more effectively with others as he grows up and to cope with his autistic behaviors,33 and Mark Osteen identifies a similar phenomenon in Temple Grandin’s story: “Grandin didn’t emerge from autism so much as *merge with* it, crafting a self from within autism that enabled her to keep one foot on each side of the threshold” (Osteen 26, emphasis original). This description is not one of “recovery” or “emergence” so much as of continuing social and

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33 One illuminating example is when Paul’s father informs him that the reason he is refusing to wear a new pair of boots is because he is autistic, and Paul, taking this in, decides to wear the boots after all. Jane Taylor McDonnell writes, “Hearing this story later, I marveled at it. Paul had just made what Alcoholics Anonymous calls a First Step. He had just accepted the fact of his autism and admitted that he was powerless over it. At the same moment, and in the same paradox recognized by AA, he had gained some power over his autism. By accepting that he was autistic, he was no longer quite so autistic” (306-07).
personal growth—not a miracle, but a long, slow journey; not an overcoming of autism, but an ongoing process of development.

Judy’s preface claims that Sean’s recovery is the result of the family’s ceaseless efforts to draw him into their world: “We used everything we had—our love, our rage, our frustration, patience, inventiveness, violence, ignorance, and humor. … Most of the time we didn’t know what we were doing, just that we had to keep doing something; we were sure that if we gave up and let go, our son would be lost to us forever. Somehow it worked” (Barron & Barron viii–ix, emphasis original). However, Sean’s own narrative does not quite bear out this account, instead suggesting that his “recovery” comes largely from within. Most of his parents’ efforts to get him treatment or therapy take place early in his childhood, while Sean’s “recovery” occurs when he is a teenager. It appears to be his own developing awareness of others, and the pain of his separation from them, that drive his changes in behavior and his efforts to connect with the people around him. Much of this awareness, and motivation to change, seems to come from negative pressure as a result of his difference from others: “I spent an awful lot of time wishing I were a different person. Why couldn’t I be normal? More than anything I wanted to change all my behavior and get rid of every problem I had. I started having ‘corrective’ conversations with myself” (161). Sean becomes his own critic and counselor, engaging in dialogue within himself as he seeks to train himself to be “normal” in order to resemble more closely what he has come to recognize as valid models of personhood and selfhood. Judy appears to have noticed some change in Sean at this time, and his movement closer to conventional selfhood, as she comments, “At fourteen, for the first time in his life, Sean seemed to have a growing sense of himself. It was as if he, too, had
become aware of another child locked within him, a ‘good’ child” (174). While Sean’s
description is of his efforts to improve his behavior and become more like other people in
order to be accepted and included, Judy’s understanding is of the emergence of a more
“normal,” “good” person who has been held captive by Sean’s autism. Sean’s view
suggests a more whole, realistic picture of a person, an individual, who changes and
develops in response to pressures, outside influences, and relationships with others and
with different aspects of himself, of which he becomes increasingly aware as he gets
older; Judy’s suggests that only when the autism is somehow removed or overcome does
the boy underneath become capable or worthy of recognition.

Perhaps the most decisive moment of Sean’s “breakthrough” from autism to more
mainstream social interaction is when he makes the choice to approach his sister Megan
and her friend at school. While Megan has always been supportive of Sean, he has
usually ignored her, and everyone else, when at school. They have recently moved from
Ohio to California and have started at a new high school, and Sean takes this opportunity
to start developing his new persona. This small act of initiating social contact leads to his
becoming part of Megan’s group and making friends, even asking a girl out on a date. In
addition to his growing awareness of other people, Sean’s awareness of himself as
autistic, and of aspects of the world around him to which he has never paid attention,
grows exponentially. Although his parents have not kept his diagnosis a secret, when one
of Sean’s high school teachers discusses autism in class, Sean finally realizes his own
identification with this description: “[I]t was as if she were talking about me, as if
somehow she knew what went on inside my head and was telling the class about it
without using my name!” (227, emphases original). After asking his mother, “‘I’m
autistic too, aren’t I?” (229), he starts to become closer to her, and to feel that “I could ask Mom anything, say anything I wanted, and that it would be all right—she would understand me. Inside me a dam burst open. I knew I could use words like everybody else” (229). As he grows in social awareness, Sean’s use of language to communicate with others—both to share and to seek information—increases significantly. This enables him to ask about aspects of life that he has not previously noticed or had interest in; as Judy describes, “There was so much he didn’t know, a world he had missed and that had to be explained to him slowly, painfully, carefully” (234).

Through their newfound communicative relationship, Judy helps Sean to adapt to the world of which he has become newly aware, and in the process gets to know him as though for the first time. Sean’s development of meaningful communication and social awareness humanizes him for his mother and makes him into someone whom she has not previously recognized:

As I grew to know my son I was taken aback by the kind of person he was. For seventeen years he had appeared to be destructive, negative, self-absorbed, insensitive—heartless. Now I saw a young man whose eyes filled with pain if a remark he made was misunderstood, if he did even the least thing to displease us. … He began reading newspapers and was horrified by the personal and political crime that was everywhere. He grew more and more amazed at the way people behaved with one another. (239)

Judy’s description of Sean’s growing sense of empathy suggests that for her, one way in which Sean “recovers” from autism is by shedding his “mindblindness.” As discussed
earlier, many autism researchers see mindblindness, the inability to intuit the thoughts and feelings of others, as a defining characteristic of autism. As Sean becomes both more socially aware and better able to express his feelings through language, he seems to lose this quality and gain a theory of mind, making him “normal” in a very important sense for this conceptualization of autism. Though neither of the Barrons directly addresses theory of mind, its influence appears to be at work in the claim that Sean has “recovered” from autism or “changed…into a ‘normal’ person” (240) as he is able to more effectively interact with other people and express emotions. As Melanie Yergeau comments, the idea of autistic people as lacking a theory of mind often calls into question whether they are capable of telling their own story: “Can someone who lacks a theory of mind accurately narrate the lives and actions and abuses of others? Can she narrate her own life?” While Yergeau’s own answer is that she and other autistic people are certainly capable of these acts, in opposition to the theory of mind stereotype, she argues that “denying autistic selfhood and…denying autistic rhetoricity reifies systemic abuse and ableism.” Sean, until this point, has been unable to narrate his life or ideas; as he gains the ability to do so, he also gains the right to assert himself as a person and to affect his own representation, overcoming the limitations inherent in the views of autistic people critiqued by Yergeau.

For Judy it is as though Sean is a new person, but as Sean’s narration of his childhood experiences demonstrates, he has always been a person with thoughts, feelings, and a sense of self, even if he was unable to verbally express them or to make his behavior fit his parents’ expectations. As his comment above reveals, it took Sean a long time to realize that he “could use words like everybody else” (Barron & Barron 229); this
does not, however, mean that he did not possess an inner life that might be communicated through language. Much of Sean’s narration throughout the book makes efforts to explain the thought processes behind his atypical behavior. Some of his sections serve to elucidate his autistic behaviors, such as the lack of fear he demonstrated by running out into the street: “At this age I lacked an imagination; I simply could not picture things in my mind. ... I wasn’t afraid of moving cars because I couldn’t imagine that they could hit me” (88). He also comments on seemingly small things that made him angry as a child, like his belief that “a left turn was ‘dumb’ and a right turn was ‘better’” (91), and his love of repetition, which made him fearful of people: “People bothered me. I didn’t know what they were for or what they would do to me. They were not always the same and I had no security with them at all” (20-21). His fear of unpredictability and need for control, as well as his feeling that he “could not talk the way ‘normal’ people talked” (105), contributed to his unusual verbal interactions with people, asking them incessant questions to prove his knowledge of a topic. While some of his explanations of his behaviors may be difficult for a non-autistic person to understand, they offer evidence that he was a thinking, feeling person as a child, even before he could explain himself—but person who differed from the norm.

Sean’s descriptions of the negative feelings he experienced as the result of being different, and being treated as different, surface repeatedly throughout his narrated sections. In his Foreword, added to the 2002 edition of the book, Sean writes about a visit to Iceland to promote the book (which had been translated into Icelandic), and comments on the respectful atmosphere he witnessed toward autistic people there: “[T]he people of Iceland seemed to accept autistic behavior as ‘normal,’ and I left wishing I had
had that kind of acceptance during my childhood” (vii). This sentiment, though written ten years later, echoes the implication of many of Sean’s reflections in the book. He frequently mentions that he knew something was “wrong” with him, or that he was a bad person, based on the way he was treated, including by his family; for instance, “My parents hated me, I knew that—why else would they yell at me so often?” (64); “I did not want to be different because I knew that different was wrong” (80); “Since I was being yelled at all the time, I believed that I was a horrible person” (117); and, upon being sent away to a residential school during the week, “They were telling me that not only was I rotten, I also was no longer worthy of being part of this family” (135). The repetition of these sentiments, while not direct indictments of his family (he does, at times, make allowances for his mother: “‘But you couldn’t have allowed me to just do what I wanted,’ Sean said recently. ‘If you had, I know for sure I would have stayed inside myself forever’” [259]), suggests the damaging effects on Sean of not being treated with the kind of “dignity and respect” he witnesses at the Icelandic school (vii). This respect only comes later, when both Sean and his parents are able to communicate with and understand each other. Sean’s ability to express his feelings post-“recovery” seems to ensure his recognition as a person and self.

In Judy’s afterword to the book, she relates an anecdote about Sean’s development in dealing with his feelings during the four-year process of writing the book together. After beginning to read other people’s writing, he rewrites everything, trying to make it clearer and simpler. He concludes, “‘You know the real reason I was writing that way? It helped me keep a distance between me and my feelings—it was as if I was writing about someone else, and it wasn’t as painful that way. I’ve got to change that—it
has to be painful or it won’t mean anything”’ (258, emphasis original). In accessing the pain and emotion of his life before his breakthrough in communication, Sean works to transmit a full picture of himself to others, particularly non-autistic readers, and to assert himself as a fully human person. In this way, he transforms the recovery narrative from one of tragedy to triumph into one of revelation—through his expanded ability to communicate and narrate his life, he claims the right to be recognized, both currently and retroactively, as a legitimate self.

Carly

Carly’s “breakthrough,” at least on its surface, seems to be much more sudden and momentous than Sean’s. After eleven years of not speaking, and of her family not being able to determine “what Carly knew and what she was incapable of knowing” (Fleischmann & Fleischmann 5), Carly suddenly types a message on a communication device (the first message is “HELP TEETH HURT” [111]), surprising her therapists, who are present at the time, and stunning her parents, who are not. Arthur describes his initial reaction:

Anyone who knew Carly as we did would be incredulous. Spelling independently? Words with meaning? Not Carly. How could she? She was a girl who still had toileting accidents. A child whose only words were garbled sounds, and whose tantrums and destructive acts were her strongest skills. This is not a child who writes, we thought. This is not even a child who understands. Carly is “cognitively impaired.” Isn’t that what all the doctors had been telling us for ten years? (113)
Arthur’s view of Carly before her breakthrough, here as elsewhere, is limited both by her external appearance (the “outside” view), which does not “look” intelligent, and by professional opinions such as those cited here (even further “outside”), which have offered Carly’s parents a dim prognosis of her cognitive capabilities. Arthur recounts his and his wife’s skepticism about whether Carly could actually type; this first seemingly miraculous incident takes place in March 2005, and it is more than six months before they witness her typing, something she does only with her therapists, Barb and Howard, and often only with much coaxing, apparently because of her obsessive-compulsive disorder. After her “second major breakthrough—typing in full sentences” (122), she begins to type, occasionally, in front of her family and to communicate with them via email and instant messages.

Conceiving of Carly as something more than their established, limited picture of her takes some adjustment for Arthur and the rest of the family. Because her behavior is still often difficult, and her facial expression remains unreadable, they must reconcile this autistic exterior with a personality that they had not previously been able to discern with any precision. Arthur asks, “Was it possible there was more to Carly’s personality than we had thought? After all, Carly was autism. Autism, tantrums, and neediness. … [T]here was a wall that couldn’t be breached, locking her in and us out. Bit by bit, now a few stones were beginning to crumble” (116, emphasis original). Describing Carly as autism echoes Arthur’s use, noted earlier, of “Carly” as an adjective, standing for all of her challenging qualities. Without the ability to communicate or express her personality, Carly has been figured as devoid of individuality, rationality, and self-consciousness, instead merely a representative of her disability. Now that Carly has begun to type, the
presence of a personality and of a person who is more than her autism begins to impress itself on her family’s consciousness. Along with excitement about their recognition of her new abilities and now-obvious personhood and selfhood comes a sort of retrospective recognition of her as a perceiving, thinking self prior to this point. The fact that she has been able to observe, understand, and think about what is happening around her means that some of the family’s treatment of her based on previous assumptions was inappropriate: Arthur realizes that “the often-harsh language and brutal honesty that should have been reserved for moments behind closed doors had not been lost on her” (124). The family, therefore, has mixed feelings about her breakthrough, and must make adjustments to acknowledge her personhood and individuality in ways they have never before done.

As Carly begins to “speak” through her writing, her personality begins to take shape for her family members, which changes their perceptions of her significantly. For Arthur, “As she opened up, she became more of a daughter and less of a charge” (134); the evidence that she is a person, and not just a personification of autism, seems to make taking care of Carly (which is still challenging despite her communicative ability) more worth the effort. Arthur is able to begin to figure out who she is as an individual, a process which, in the absence of communication, seems to have been difficult or impossible for him to do. He explains, “…I eagerly collected the tiny random shards

34 Arthur and his wife’s distance from Carly’s therapy seems to exacerbate their limited view of her as a person. It is significant that while her father takes time to process Carly’s newfound ability to communicate and newly-revealed personality, her therapists, particularly a young man named Howard, have recognized and appreciated her personality well before this. A striking example is when Howard accompanies the family on vacation and takes Carly swimming, a skill of which parents are unaware: “‘Carly loves the water,’ [Howard] said matter-of-factly. ‘She’s been swimming like that for a few months now.’ I began to realize that Howard knew Carly far better than I did” (106). Either because of their training as therapists or because of their more intensive time spent with Carly, Barb and Howard are often notably more aware of Carly’s abilities and preferences than are her parents.
that, like a mosaic, began to form a beautiful picture of my daughter” (155). This “beautiful picture” is in sharp contrast to the “rough-hewn…exterior” (209) that had long controlled his perception of her. Even more striking is Carly’s twin sister Taryn’s blunt comment to her mother that “‘Carly is becoming more human’” (172). Such a statement ties Carly’s humanness to her ability to communicate evidence of the abilities that traditionally define her as a person—the abilities to think, to feel substantial emotions, to engage meaningfully with other people. While these requirements for personhood are in many ways problematic, Carly’s breakthrough in communication enables her to subvert others’ misconceptions about her and about other individuals with autism, particularly those who are unable to speak or write. If she can offer evidence that she had thoughts and feelings prior to her ability to communicate them, then others who are unable to communicate can also be accorded recognition, or at least the possibility, of personhood that they have not previously been granted. Holly Robinson Peete, whose autism advocacy organization honors Carly with its Youth Champion award, comments on the book’s dust jacket that “[Carly’s] book…disproves the ridiculous notion that nonverbal people with autism don’t have feelings and thoughts or are unintelligent.” By gaining the ability to prove her own personhood and engage in dialogue with those around her, Carly also opens the door for broader recognition of the personhood, selfhood, and worth of many others. The accordance of personhood in this sense is both claimed by Carly and granted by others; both actions are necessary for Carly’s full recognition as a person. The ability to communicate makes it possible for Carly to assert her personhood in ways that are recognizable to others, including her father and the rest of her family. Those others must then accept her narrative and grant her personhood from their perspective as well.
And, as I have suggested, Carly’s narrative promotes the granting of personhood to nonverbal people with autism who may not be able to assert themselves through language in the way Carly is able to do.

Like Sean’s, Carly’s narration offers evidence that challenges views of herself before her “breakthrough.” As we have seen, Arthur characterizes pre-communication Carly as more of a personification of autism than a distinct self with a personality. As she begins to communicate through writing with her father, he learns that she has interests and preferences that he had never previously been able to detect. In instant messages, she suggests activities to do when she comes home from respite care (where she spends part of each week): “i looked at black creek pioneer village because i want to walk around / it looks like fun / I saw go karting too but you drive to slow and mom wont drive … Can we go to the science center / I want to go with you / Can we see Howards baby” (157-58). In expressing desires to participate in activities and to go places, Carly asserts her personality and desires in ways she has not previously been able to do, changing her father’s view of her: “My daughter likes outings. I never really knew that. Carly has a sense of humor. A sense of irony. And a sense of self-esteem” (158). These are aspects of Carly’s personality that obviously pre-existed her ability to communicate them, but it is only when she can communicate that they become realities for the people around her. In her final chapter, Carly offers explicit evidence that her “voice” did not only come into being when she gained the ability to make it heard: “I always had a voice. It was just inside of me. I would talk to myself and even reply back to people sometimes even though they couldn’t hear me” (360). This evidence from Carly may assist in the recognition of personhood and voice for other nonverbal people with autism while also
highlighting the potential of double-voiced narratives to tell stories of relational lives in ways that a single narrative cannot achieve on its own. Having access to both Carly’s and her father’s narratives, readers are able to synthesize the two conflicting versions of these related stories into a more complex and complete relational life narrative. Her narrative also demonstrates her development of the ability to communicate as less of a sudden, miraculous moment and more, like Sean’s, of a gradual process. Carly explains that she had been using words in combination with symbols on a communication device for several years, and had more recently been learning to spell specific words with Scrabble letters. She explains, “My photographic memory started taking in those images/words. … I already had over two thousand words in my head that I was just processing and [the] program started getting me to understand what to do with those words” (366). With a broader idea of the skills Carly had been working on for years, her ability to type on her own, while still unexpected, is far less shocking.\footnote{Carly also explains the meaning of her message, “HELP TEETH HURT”: she had been feeling sick and did not want to participate in therapy that day, so she tried to communicate that she was feeling nauseated and had thrown up in her mouth. “In my head, I was just trying to think of a word that would describe what had just happened in my mouth. In hindsight, I should have written the word mouth, but I was just a kid” (367, emphasis original). Carly’s explanation assists, again, in seeing her as a person and self with feelings and thought processes, and also adds her side of the story of this key moment, since, she says, “I have never been asked about what was going through my head the first time I spelled” (366).}

Carly’s written communication also provides a way for her to explain herself to others and to advocate for herself, even and especially when she wants something different from what her parents or teachers want. A significant instance is when her parents and school want Carly to take an assessment test so that they can figure out an appropriate educational situation for her, since she appears to be bored or unhappy in her current program. Carly, however, refuses to cooperate with the assessment, and eventually writes a long letter to the school’s program director which Arthur describes as
“a cathartic explosion of pent-up emotion” in which “she continued to refuse assessment, but also gave us a better understanding of why” (298). Arthur’s recognition of both Carly’s emotional state and her ability to offer a rational explanation are evidence of his growing awareness of her as a self. Carly explains not only why she does not want to undergo the assessment process—“You want me to be in a room with three kids and concentrate on playing a game I probably can’t do in the first place and at the same time try to control my behaviors” (299)—but also her frustration at being different and her need to overcome people’s judgments of her: “I wish I could put you in my body just for one day so you can feel what it’s like... I was asked why I like MSN [instant messenger] so much. It’s because I can talk to people without them seeing me hit the table or screaming” (299). Carly’s letter is effective in achieving its object—she does not have to take the assessment and eventually her family and teachers find a way for her to join a mainstream classroom—and reflects her own frustration at being different and at not being accepted. Her ability to influence her educational placement emphasizes the transformative power of her ability to communicate: despite ongoing challenges, she has begun to achieve recognition as a legitimate self, capable of consciousness and feelings about her situation.

Finally, Carly overtly advocates not only for herself but for others with autism, particularly those who cannot speak for themselves. Arthur notes that Carly “was determined not to be seen as the autistic girl without a voice but rather as the voice of autism” (323), a voice which she asserts primarily through online writing such as Facebook and Twitter. While clearly there can be no one voice that speaks for all those with autism, Carly’s ability to speak from a position on the spectrum that is much less
represented in published texts makes a significant contribution both to life writing and to public perceptions of autism, in the way that Ian Hacking has argued. Many of Carly’s messages, a selection of which is included in an appendix to the book, address readers’ questions about their own loved ones with autism, many of whom are nonverbal and not able to answer these questions themselves. She explains stereotypes and professional misconceptions of autism from her own perspective; for example, she writes in a Tweet that “Drs. have the definition of stimming wrong. Stims are when you make or create output to block sensory input or over load” (376). She also works to change social perceptions of autistic personhood: “my moms friend just had a tragic accident happen and she had one of her two autistic sons pass away and people told her its for the best. It’s really sad the way society views the importance of life just because he was different does not mean he did not have any importance or any things to teach us. We all have feelings even if we don’t often show it at times” (372). Carly seems conscious of the influence she is capable of having not only on her own family, but on the public who reads what she writes. Within the collaborative text, her influence on her father’s view of her becomes evident by the end of his narration. As Arthur realizes that Carly “did not see herself as ‘one of them’ [people in need] but as one of us,” he recognizes that “Carly was not looking for sympathy but rather for acceptance” (220). Acceptance comes from recognition of a person’s humanity, despite his or her difference from the norm. This realization on Arthur’s part reflects some degree of convergence of his perspective with Carly’s; her narrative has some perceptible influence on his understanding of her personhood and that of people with autism more generally. Though Arthur and Carly’s narratives have different trajectories, as do Judy and Sean Barron’s, the two come closer
together after the breakthrough that enables the parent to recognize the personhood of the autistic child and to gain some insight into the person she was even before she was able to self-narrate.

**Conclusion**

In each of the collaborative works of auto/biography that I have examined here, the presence of both the parent’s and the child’s voices serves to create a dialogic text with two narratives that tell the same story from different perspectives, thereby both complementing and contradicting one another. To apply Susanna Egan’s descriptors, the parent and child narratives are “reciprocal, adaptive, corrective, [and] affirmative” (7). While each of the relational narratives tells the story of the autistic individual’s “breakthrough,” of a process of development and growth beyond some of the communicative limitations of autism, each does so from a different perspective. Both Judy and Arthur’s parent narratives set up their children’s breakthroughs through a structure of recovery, beginning with dark, tragic days that must be redeemed by the supposedly miraculous triumph of the child emerging from autism and gaining the ability to demonstrate him- or herself as a legitimate person. Sean and Carly’s narratives, on the other hand, while confirming many of the factual details of their parents’ accounts, offer “strong alternative stories” (Fischer 91) that transform the narrative of recovery into one of personal growth and revelation of personhood and selfhood through relationship with others. By narrating personal histories that had previously been undetected, Sean and Carly demonstrate that they are persons and selves not only *after* their moments of communicative breakthrough, but *prior to* those overemphasized moments. In this way both writers demonstrate that their experiences go far beyond simplistic “recovery,”
therefore both challenging and building upon their parents’ and co-authors’ use of this narrative model.

These autistic self life writers’ assertion of their own voices helps to counteract the notion of “autistic voice” as an oxymoron, as cited by Yergeau, while interacting with the non-autistic voices of their parents to both supplement and challenge other versions of their relational life stories. Although no one person can really be the definitive “voice of autism,” as Carly seeks to be, there is a need for those who can make their voices heard to do so, in order, as Hacking suggests, to work toward “a shift…in our conceptions of and relationships to individuals on the spectrum” (1473) and to claim some authority over their own representation. Relationships are central to the process of telling collaborative life stories, and the presence and interaction of multiple voices help to construct more nuanced and complete narratives and identities for those involved, autistic and non-autistic. With the persistent limitation that the recognition of individuals as persons and selves continues to be dependent, to a large extent, on the use of conventional communication strategies to demonstrate evidence of “normal” personhood, Sean and Carly’s use of narrative to offer insight into their nonnormative experience works to re-appropriate traditional communication to assert their right to be recognized as persons, autistic differences and all.
Chapter 4

Expanding Possibilities for Personhood and Narrative:
Parent Memoir about Life with Severe Autism

Introduction

In the previous chapter, I discussed the interplay between parents’ and autistic children’s voices when individuals with autism gain the ability to speak or write to communicate their own experience and assert their subjectivity and personhood. However, for many people with autism, communication through language is not a reality. While communication difficulties of some kind are a hallmark of autism, the extent of those difficulties vary widely among people with different manifestations of autism, and people who are more severely affected by autism may never develop conventional spoken or written communication. This absence or insufficiency of normative language can pose significant difficulties for the transmission of the person’s thoughts and feelings, and ultimately his or her life story and the recognition of his or her personhood and selfhood by others. Cynthia Lewiecki-Wilson observes that language is traditionally privileged to a high degree in the assigning of personhood and the recognition of a life story: “[W]e often demand some verbal response from an Other as proof of their humanness and…[we] have an impoverished language for conveying the rhetoricity inherent in embodied life” (157). As Lewiecki-Wilson suggests, there are other possible modes of rhetoricity, but they are often overlooked by those for whom language is the primary mode. Jane Taylor McDonnell, in her memoir about raising her son Paul, who has autism and struggled with language in his early years, comments on her and her husband’s own prejudice toward language: “I wondered sometimes if we didn’t overvalue language. After all, we were two English teachers. We lived in a world of words” (6). Many other
authors of parent memoirs about autism are also academics with similar language-based training and professions, but the emphasis on language to communicate and demonstrate evidence of one’s mental activity and acuity is common to many in non-autistic mainstream society, not just those in academia. Despite other resources for communication, including nonverbal vocalization, visual indicators, body language, and touch, words tend to be the most commonly chosen option for communicating experience to one another, and in their absence, experience and cognition often fail to be recognized by others.

As Lewiecki-Wilson argues, those of us who place such value on spoken and written language may need to expand our understanding of rhetorical power to include “bodies that ‘speak’ with/out language” (157). Efforts to recognize such acts of embodied communication as “sounds, habits, moods, gestures, likes, and dislikes” (Lewiecki-Wilson 161) require some level of interpretation on the part of the other, particularly the parent who seeks to tell the story of his or her child’s life and to represent the child as a person. Krista Ratcliffe argues for the importance of “rhetorical listening,” which, she claims, “may help us invent, interpret, and ultimately judge differently in that perhaps we can hear things we cannot see” (203, emphases original). While being attentive to embodied rhetoric might, conversely, involve literally seeing rather than hearing, Ratcliffe’s point speaks to the need to look and listen beyond the surface for the ways another person may communicate, which may be a complex and gradual process as non-autistic people seek to understand autistic methods of communication. Rhetorical listening, then, may offer a method of being attentive to alternative forms of

36 Paul Collins, Robert Hughes, Mark Osteen, Valerie Paradiz, Clara Park, and James Wilson are a few examples of other parent memoirists who are also academics.
communicating, since Ratcliffe points out that listeners can “situate themselves openly in relation to all kinds of discourse, whether written, oral, or imagistic” (204). Ratcliffe’s model of rhetorical listening emphasizes both interpretation—recognizing and seeking to understand messages being communicated by others in a variety of forms—as well as invention, in which future communication may be informed by the knowledge gained through attentive and sensitive listening. Parent memoir about life with a mostly nonverbal son or daughter with autism has the potential to be a site both for rhetorical listening to the words, sounds, and body language of the nonverbal person, as well as for mediated representation of the life story and the subjectivity of the nonverbal person.

Completely unbiased, sensitive, and accurate representation of a person who cannot represent him- or herself in language is, of course, a difficult and perhaps impossible goal to achieve. The parent who seeks to write about both his or her own life and that of a nonverbal son or daughter must walk a number of fine lines, including that between the parent’s life story and that of the child; between the particularity of the family’s story and a broader story about autism and its history, causes, manifestations, and treatments (as well as the variety of approaches to each of these issues); and, perhaps most provocatively, between the many challenges that can come along with life with severe autism, on one hand, and the recognition of the value and personhood of the autistic individual, on the other. In the chapter to follow, I will explore the ways that the concepts of rhetorical listening and mediated embodied rhetoricity may be useful in examining the representation of nonverbal subjects with autism in a selection of parent memoirs. I will examine how “listening” to a person with limited conventional modes of communication can impact one’s understanding both of that person’s embodiment and
what I am calling their “enmindedness”—that is, their mental existence. Further, I will consider how the parent writer’s use—or non-use—of these techniques impacts the structure and content of the life story they tell. Stories of life with severe autism, as I will argue, resist positioning within the narratives commonly employed in stories of illness and disability, most notably those established by Arthur Frank in his influential book *The Wounded Storyteller*. Rather than narrating restitution or recovery—i.e., a child overcoming his or her autism—or a “quest” that finds a higher meaning in the suffering and difficulty of life with this disability, these stories emerge in the margins between these more conventional narrative forms as well as what Frank calls the unnarratable “chaos narrative.” In navigating but not resolving the tensions inherent in life with a child with severe autism, these parent narratives highlight the limitations of conventional narratives of recovery and finding closure. Rather than somehow “failing” by not meeting the forms of traditional narratives, and at the same time not creating a clear-cut or singular new narrative form, I argue that these narratives maintain valuable tensions between narrative types because it is in those spaces that the sort of life that severe autism constructs for these families can be represented as what it is—unpredictable, nonnormative, and open-ended. The resistance to traditional narrative,

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37 In using the word “severe,” I am deliberately choosing not to use the term “low-functioning,” one which is often used in conjunction with “high-functioning” to distinguish between people at different ends of the autism spectrum and which Emily and Ralph Savarese characterize as “always demeaning and often quite inaccurate,” in part because levels of ability can vary no matter one’s position on the spectrum (which is itself variable). While “severe” can be a diagnostic gradation (Osteen notes that it is “one step up from ‘profound,’ in official classifications” [*One of Us* 216]), I am using it to indicate the extent to which autism affects the child’s life and the resulting difference from what are considered normative ways of being and behaving. I am also keeping in mind Robert McRuer’s argument for the use of the term “severe” as a point of pride for people with disabilities, along the lines of the word “fabulous” for queer culture; McRuer sees “severely disabled” as “a critically disabled position” which “would call attention to the ways in which the disability rights movement and disability studies have resisted the demands of compulsory able-bodiedness and have demanded access to a newly imagined and newly configured public sphere where full participation is not contingent on an able body” (305). While I do not use the term in quite the same way McRuer does, I find his argument for the reclamation of “severe” to be intriguing, and it influences my willingness to make use of the term here.
rather than being a failure, reflects the instability and conditional, relational nature of autism and of disability and difference more broadly. In telling stories that do not follow conventional patterns of life writing, these parent authors present challenging narratives with unresolved tensions that make room for lives and people, such as those affected by autism, that also do not fit conventional patterns. As these life stories challenge narrative norms, people with severe autism challenge norms of humanness and personhood, and in creating narrative space for the nonnormative life story, parent memoirs about severe autism also create sociocultural space for the nonnormative, autistic human life. In other words, the narratives developed through the relationship between non-autistic parent and severely autistic child reflect the often challenging differences that autism makes in life experience and narrative construction, and work to make space in both text and culture for lives and stories that do not fit the norm.

**Rhetorical Listening, Relationality, and the Recognition of Personhood**

The act of writing a memoir about life with a nonverbal child with autism raises a number of ethical and theoretical questions about the right of the parent to tell their child’s story as well as the way in which the person with autism is represented. G. Thomas Couser expresses particular concerns about issues of representation for children with disabilities, whom he refers to as “doubly vulnerable subjects—triply so if their impairment compromises their competence or diminishes their autonomy” (*Vulnerable Subjects* 57). Couser points out that parents have almost exclusive access to their children’s lives, and that children whose age or disabilities compromise their ability to consent may be taken advantage of by their parents’ narratives. His warning is valid, but the concern that the children might later find their parents’ writing to be “violations of
their autonomy, acts of appropriation or even of betrayal" (57) appears to be less applicable in cases of writing about children with severe autism, who likely will not be able to read—and therefore to object to—their parents’ accounts. Some parent writers in fact use this inability as a motivating factor in writing their account: Kim Stagliano, for instance, declares in her memoir *All I Can Handle*, “The day my kids can read my writing and complain to me that I hurt their feelings will be the proudest day of my life. I will apologize to them and hope they understand that I was fighting for them through my words” (184). This approach excuses the potential embarrassment or exposure of the child in the parent’s text with the fact that the child cannot read it anyway, and if he or she could, perhaps then the text would have served its purpose. In Stagliano’s case, her statement helps to support her search for a treatment or cure for her daughters’ autism— their recovering and being able to read her text as the result of such a cure would make the writing of it worthwhile. Such an approach does not solve—or resolve—the potential problem of violating or appropriating children’s life stories, but it does weigh that problem against another, perhaps more fundamental reality, that the children cannot tell or even read their life stories on their own.

Other parent memoirists point out, rightly in my view, that if they do not tell the stories of their children with disabilities, it is likely that no one will; they have an opportunity, and perhaps a responsibility, to fill Smith’s “silence in need of a story” (233). Mark Osteen comments near the end of his memoir, *One of Us*, “I’ve told Cam’s story from my own viewpoint, yet I’ve also tried to speak for my son, who can’t speak for himself—to convey what I believe he felt, desired, and thought. But I can’t really know how it feels to be Cam. In that sense, his story may never be told” (262). Indeed,
the children represented in the memoirs I will discuss here will likely never produce autobiographies in the traditional sense of written narratives of their life experience. They may communicate about their experience in other ways—through alternative forms of verbal or auditory expression; through their gestures, behavior, and other body language; or through the use of printed or electronic words or images—but as far as producing a life story that can be read in the traditional format of narrative written language, parent memoirs may be the best and only option available. I acknowledge that the desire of the person with severe autism to share his or her story may be difficult to ascertain; objections, for instance, might be raised in response to a statement like Clara Claiborne Park’s in *Exiting Nirvana* that her daughter, Jessy, “cannot tell her story for herself. … I know too that she’d never read such a story even if she could, or understand why it might be worth the telling. So I can tell it freely…” (208). If Jessy does not find interest or value in the telling of her life story, one might ask whether her mother should be sharing it with others. Although Park’s claim to be able to tell Jessy’s story “freely” might be overstating the case, I do argue that the relational aspect of auto/biography implies the right, even the necessity, to tell the stories of those whose lives are intimately connected with one’s own, albeit in ways that are sensitive to how those others may respond or be affected. Park, for instance, changes Jessy’s name to Elly in her first auto/biographical text out of concern for how Jessy might feel about being in the book; in the later book Park uses Jessy’s real name, taking into consideration her knowledge of Jessy’s feelings toward the story.

While Couser’s warnings about the possible exploitation of disabled others in auto/biographical texts are important to consider, and I will address some of these
hazards in my examination of the texts below, on the whole I see parent memoirs as opportunities for the communication of the relational, intertwining life stories of the parent author, his or her child(ren) with autism, and the family and community who are involved and interacting with those individuals. Such texts cannot replace the personal testimony of the person with autism, but in the absence of that more direct and traditional form, they can be a valuable alternative. Bruce Mills observes that although in parent memoirs “[t]he dilemma of any nonfiction author writing about family, the reality that others do not ask to be represented in print, gets magnified,” these texts still “participate in cultural ‘stories’ of disability—whether intentionally or not—and thus may reinforce and/or undercut dominant paradigms.” Similarly, Alison Piepmeier argues that parent memoirs can and should “participate in the process of rewriting the cultural meanings associated with disability.” While they may not be entirely lacking in bias or distortion, such memoirs can only participate in the rewriting of cultural meanings if they are written and made available to others, even as the complicated and imperfect narratives they are. More importantly, such memoirs have the potential to present people with autism as individuals through narratives that result from and encourage attentive listening and sensitive personal relationships.

As narratives of the relational lives of parents and children with autism, these texts may be considered auto/biographies, which tell the parent’s story, the child’s story, and the story of their relationship (see Eakin, “Relational Selves,” as well as my discussion of this concept in Chapter 2). This is not to say that all parent memoirs successfully achieve all of this, nor that all of them go about it in the same way; on the contrary, these memoirs negotiate in varying ways the terrain of tensions associated with
narrating life affected by severe autism. In fact, the broad spectrum of manifestations of autism, and the variation among individuals and families affected by it, necessitates a variety of approaches and stories, including “communal stories that give voice to the wide array of lived experiences, joyful and stressful” (Mills). It is my contention that these memoirs play an important and perhaps indispensable role in making life narratives of autism, in all of its manifestations, available to a wider audience, and in communicating the ongoing processes of negotiation between people, and life stories, in complicated relationships of care, difference, and interdependence.

Given the explosion of parent memoirs about raising children with disabilities, particularly autism, in recent years, it is clear that the obstacles inherent in producing a narrative and representation of a nonverbal person do not prevent many parents from seeking to tell their children’s stories, at least in relation to their own. Rayna Rapp and Faye Ginsburg argue that “such public storytelling…is crucial to expanding what we call the social fund of knowledge about disability. In opening up the experiential epistemology of disability, as shaped by and shaping the intimate world of nonnormative family life, such forms of public culture widen the space of possibility in which relationships can be imagined and resources claimed” (181). It is important, then, to consider the ways that such memoirs do expand the social fund of knowledge about disability, and how they go about doing so. Parent memoirs can help disseminate examples of “nonnormative family life” and make them real to others through narrative, in part because parents often have the closest relationships with autistic individuals and may be best situated to mediate between them and the rest of the world. The challenge to all concerned—writers, subjects, and audiences—arises in the question of how that
mediation happens and the degree to which the parent is willing and able not only to narrate the child’s life from an external perspective, but also to “listen” attentively to the child’s nonverbal communication and narrate that which the child cannot convey in language.

It has become prevalent, both in theory about autobiography and ethnography as well as in the field of disability studies, to speak of the importance of “making one’s voice heard.” Populations that have traditionally been illiterate, disenfranchised, or otherwise prevented from participating in their self-representation, such as women, those under colonial rule, racial minorities, and people with disabilities, have in recent decades made great strides in representing themselves in writing and countering harmful or limiting misrepresentations by others, whether intentional or inadvertent. Such empowerment of previously “silent” people to tell their own stories is a significant development for the field of life writing; indeed, in my previous chapter I show how “finding a voice,” whether literally or functionally, empowers two writers with autism to represent themselves and demonstrate their personhood in interrelation with and opposition to the narratives of their parents, which represent them in sometimes conflicting ways. However, those who have not yet found a “voice,” or cannot make theirs heard in the ways others are accustomed to hearing, are left out of this revolution. Despite the general trend and perhaps preference toward self-representation, in these cases representation by others may be the only option. As Rachel Adams comments, “The claim that speaking for [another] is inherently unethical belies an ableist assumption that, given the means, the subaltern is capable of representing herself” (8); since many nonverbal people with autism are not capable of representing themselves through
language, the caution against speaking for others must be reconsidered. Similarly, James Wilson and Cynthia Lewiecki-Wilson point out in the introduction to their edited volume *Embodied Rhetorics* that “not all disabled people can become rhetors…nor is a culture necessarily open to more than a few carefully restricted types of narrative about the disabled” (12). As they go on to argue, the lack of language necessitates the expansion of understandings of “rhetoric” beyond the verbal to various possibilities of embodied communication, which may, in turn, expand the realm of narratives about disability.

Lewiecki-Wilson extends this claim in her essay “Rethinking Rhetoric through Mental Disabilities,” in which she argues for the importance of “mediated rhetoricity,” efforts to create or magnify rhetorical power for those with disabilities that prevent their verbal communication but who may have other ways of using their embodiment to make their preferences and individuality known.

Building upon Ratcliffe’s concept of rhetorical listening and Lewiecki-Wilson’s work on mediated rhetoricity, I argue that the relationship between a non-autistic parent and a largely or entirely nonverbal son or daughter with autism can translate productively into the textual practice of careful rhetorical listening, interpretation, and mediated storytelling in relational parent memoir. By mediating the communication of the nonverbal autistic person’s individuality, emotions, and preferences, often translating from embodied modes to verbal ones, the parent memoir can contend with stereotypes about the enmindedness and personhood of people with severe autism. The parent memoirist’s use of rhetorical listening can help to negotiate the complicated relationships between parent and child, between autistic and non-autistic experience, and between normative and nonnormative forms of personhood and narrative.
Embodiment, Enmindedness, and Nonnormative Personhood

The concept of embodiment has received a great deal of attention in scholarly work in recent years, including in the field of disability studies, which is often concerned with the rights and representation of people with nonnormative kinds of embodiment. Rosemarie Garland Thomson, for instance, in her seminal book *Extraordinary Bodies*, defines disability as “the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do” (6). Her definition reflects the social model of disability, which holds that “corporeal deviance”—nonnormative embodiment—is transformed into disability by social stigmatization based on normative ideas about embodiment. The body is clearly important to consider, not only for physical disabilities, but also for a disability like autism which is primarily neurological and cognitive, because people with autism frequently experience and use their bodies in nonnormative ways. For instance, many people with autism experience sensory differences; their auditory, visual, or tactile input may be intensified, and many stereotypical behaviors (such as “stimming,” humming, covering their ears, not looking people in the eye) may be attributed to sensory overstimulation. In addition, since current theories about autism maintain that it is a result of differences in brain structure and of some (as yet unknown) combination of genetic material, the condition is clearly seated in the body. Autism, then, is at least in part nonnormative embodiment, although this difference may not be visible to others at first glance. It is autistic behavior, enacted through the body, that creates bodily difference and social recognition of disability, rather than bodies that themselves are different in appearance. In this sense the autistic body may not be quite the “vividly embodied, stigmatized other” (7) on which Thomson
focuses; the “deviance” of the body may only become visible when the body engages in what are seen as deviant behaviors. As anecdotes in many parent memoirs demonstrate, such deviant behaviors, when enacted in public, engender a considerable amount of social stigma toward autistic people and their families, often inappropriately directed at parents for a perceived lack of discipline due to the absence of visible bodily difference that might otherwise explain the child’s behavior.

However, for nonverbal people with autism, embodiment may have significance besides that which marks them as different or deviant. It may, alternatively, provide them with a means of connecting with non-autistic people. Embodiment, as Wilson and Lewiecki-Wilson indicate, can serve as a means of communication in the absence or scarcity of language. Lewiecki-Wilson’s identification of “bodies that ‘speak’ with/out language” (‘Rethinking’ 157) calls attention to the potential rhetorical power of the body—indeed, the role of the body not only in expressing feelings but also in establishing and developing relationships, particularly between disabled and nondisabled individuals. In conventional relationships, communication through language aids people in learning to understand one another, in order to build trust or love as well as to make one’s needs, desires, and preferences known to others. In relationships involving nonverbal persons with autism, these communicative functions may be more complex, but they are certainly not impossible. Rhetorical listening not just to words but to embodied communication—sounds, behavior, body language—shifts focus beyond bodily difference to bodily expression. Ratcliffe describes rhetorical listening as “a performance that occurs when listeners invoke both their capacity and their willingness,” in part, “to locate identification in discursive spaces of both commonalities and differences” (204, emphases
original). Despite what may be pronounced differences between the autistic person and his or her non-autistic parent, there are also commonalities to be found. Fostering recognition of autistic others through relationality does not necessarily mean enforcing normativity; instead, relationality can provide a space in which the nonnormative as well as those aspects of experience that autistic and non-autistic people have in common can be narrated and shared. “Listening” attentively to communication beyond standard verbal language can help the parent to identify points of similarity and to seek to represent the autistic person in a sensitive way.

Of course, embodied communication must be interpreted if it is to be incorporated into the parent’s auto/biographical narrative. Listening only goes so far on its own; it must be put into language in order to be productive or to have an effect on others’ understandings of the autistic embodied communicator. Ratcliffe stresses that rhetorical listening is “a trope of interpretive invention”—a practice which “turns hearing (a reception process) into invention (a production process), thus complicating the reception/production opposition and inviting rhetorical listening into the time-honored tradition of rhetorical invention” (220). In the case of life writing, listening attentively to nonverbal communication must be followed by interpretation of that communication, which leads to the invention process of writing the life narrative of the parent and/or child. Interpretation is naturally open to error, and should always be understood as interpretation rather than direct translation, but it can both inform the parent author and provide opportunities for the reader to engage with and better understand the autistic person being represented. Ratcliffe advocates for what she calls “strategic idealism” in rhetorical listening, which “implies a conscious identification among people that is based
on a desire for an intersubjective receptivity, not mastery, and on a simultaneous recognition of similarities and differences, not just one or the other” (205). According to this approach, the listener must be open to understanding but not suppose that he or she has arrived at a total comprehension of the other person. Even while Ratcliffe acknowledges “the difficulty and dangers inherent in such a project,” she advises “proceed[ing] knowingly” (205), a suggestion which I endorse. Even if rhetorical listening and invention cannot result in exact translation of the autistic person’s thoughts, feelings, or preferences, the effort of listening is worthwhile and reflects respectful relationship with that person and the desire to understand as much as possible about his or her experience.

Ann Jurecic makes use of Stanley Cavell’s concept of “acknowledgment” in a way that is helpful to consider here. In Jurecic’s characterization, acknowledgment is a way of listening to others and of validating another person’s difference from oneself. It is, she explains, “a social response that situates the listener in relationship to the speaker…. Practicing acknowledgment entails recognizing the complexity of living among others, where one is always performing acts of social reading and interpretation. In contrast to knowing or judging, acknowledging also entails recognizing one’s own ignorance and vulnerability, as well as the unpredictability of social encounters and relationships” (63). Jurecic, who uses the concept of acknowledgment in the context of

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38 Cavell discusses the distinction between knowledge and acknowledgment in many areas of his work; in *The Claim of Reason*, he encapsulates some of his analysis: “I [have] said that acknowledgment ‘goes beyond’ knowledge, not in the order, or as a feat, of cognition, but in the call upon me to express the knowledge at its core, to recognize what I know, to do something in the light of it, apart from which this knowledge remains without expression, hence perhaps without possession. … In ‘The Avoidance of Love’ I said that acknowledgment of another calls for recognition of the other’s specific relation to oneself, and that this entails the revelation of oneself as having denied or distorted that relation’ (428). While Cavell’s discussion of this topic goes much further, I am most interested in the application Jurecic makes of the concept of acknowledgment to communication and narrative.
recognizing other people’s pain, points out that “acknowledgment, compassion, and love, like all acts of interpretation, are vulnerable to error, ignorance, and indeterminacy” but that “they are also fundamentally necessary in embodied and social life” (65).

Acknowledgment of the experiences of others, even if the listener cannot understand them completely, is vital to building social relationships, and difficulty in hearing, understanding, or interpreting correctly is not a problem isolated to communicating with nonverbal people with autism. The latter is, instead, a particularly pointed example of the importance of acknowledgment in communication with others. When a parent engages in the practice of rhetorical listening, with the goal of interpreting the autistic person’s embodied communication and ultimately inventing in the form of composing a relational life narrative, the parent is not professing complete knowledge of the other person, in the same way that even with the benefit of linguistic communication one cannot claim such a thing. Rather, rhetorical listening and attempts at mediated rhetoricity through auto/biographical writing serve to express acknowledgment of the existence of the autistic person’s inner subjective reality and recognition of that reality’s independence, and difference, from the parent’s own.

Attention to embodied rhetoric can, then, be a pathway to recognition of inner subjective realities and mental activity, a quality I am calling “enmindedness.” In the same way that recognition of embodiment calls attention to the body and the ways that it influences one’s identity and interactions with the surrounding environment, recognition of enmindedness calls attention to one’s possession of a mental existence. Mental presence is a much less recognized, and much less freely assigned, characteristic than embodiment. Every living thing is recognized as having a body, but humans are often
reluctant to extend enmindedness to those who do not meet certain qualifications. Generally speaking, anything which is not human is not granted possession of a mind, and those humans who do not meet normative standards of mind are placed in a sort of liminal space between the human and the non-human. Michael Blastland struggles with this perspective in his memoir *The Only Boy in the World*; he delves into philosophical writings on the topic of what makes people “human” and finds answers such as self-consciousness, structured language, and elaborate culture and history—and in each category, it seems that his autistic son, Joe, is lacking. He concedes, “If I accept the arguments of philosophers that we define ourselves as humans not in the Linnaean fashion by our appearance [another problem in terms of nonnormative embodiment] but rather by what goes on in our heads, then I’m forced to a grim conclusion: Joe, my son, does not qualify” (183). While Blastland resists this conclusion, seeking “to reconcile [his] head and heart,” which disagree on the matter of whether or not Joe should be considered human, the standards by which the measuring is done remain largely unquestioned. There are, of course, those who argue for the enminded potential of non-human animals, particularly those that appear to be most intelligent and most similar to humans (Cavalieri and Singer’s *The Great Ape Project* is a notable example); some plant scientists have also made arguments for a form of plant consciousness (see Pollan). The ancient philosophical view of panpsychism, with roots in ancient Greece and in the work of philosophers such as Spinoza, Leibniz, and Schopenhauer, holds that “everything is ‘enminded.’ … Everything that is physical also possesses an interior mental aspect” (Koch). While I will not debate the validity of this wide-sweeping view, I do want to point out that it begins from the opposite perspective of the common modern assumption
that only normative humans have minds, with the goal of inquiry being to identify what makes humans different from or superior to other organisms. A better starting point might be that all people, at least, are both embodied and enminded, and might be so in diverse ways without individuals’ differences disqualifying them from inclusion in the category of “human.”

Theorizing about difference in disability studies scholarship has largely focused on embodiment, with little attention to, and often outright disregard of, mental difference. In a discussion of contemporary adolescent literature, Abbye Meyer demonstrates the trend toward recognizing nonnormative embodiment as acceptable while continuing to resist acceptance of nonnormative enmindedness; Meyer argues that “while disability…is treated like other politically marginalized identities (such as race, gender, sexuality, and class) in schools, at camps, and among peers in the texts, intellectual disability remains the ‘other,’ as characters with nonintellectual disabilities work to separate themselves from their intellectually disabled peers” (269). Mark Osteen, in *Autism and Representation*, also accuses disability studies of “almost entirely neglect[ing] cognitive and intellectual disabilities” (4); he suggests that in their near-exclusive focus on the social model of disability, many disability studies scholars have failed to thoroughly consider not only the differences between disabled and nondisabled people, but also the vast array of differences that can fall under the heading of “disability.” I find very compelling Osteen’s critique that “although disability scholars and advocates seek to celebrate disabilities as differences and redress the social and cultural conditions that render disability disabling, in so doing they work to eliminate the terms under which these differences become worthy of discussion” (2-3). Attention to and acceptance of
differences is as important as breaking down the barriers that make such differences into disabilities. Acknowledging differences in both embodiment and enmindedness that constitute the broad range of people who are considered disabled will not only allow the field of disability studies to develop in a positive way toward greater inclusion and deeper reflection on the meaning of disability, but will also allow life writing about people with disabilities of all kinds to have a greater impact both on those being represented in these texts and on the community who will read them.

Attentive listening to embodied rhetoric can help to make connections, in life and in text, between embodiment and enmindedness for those who seek to understand those who are different from themselves. Because people with autism are seen as having mental processes that are significantly different from those of non-autistic people, they seem to “trouble the belief in humanist selfhood” (Smith 233), as we have seen briefly in Blastland’s struggle with whether to classify his son as human. However, in place of seeking to categorize people in broad terms, rhetorical listening may enable acknowledgment of the enmindedness, and humanness—and thereby the selfhood and personhood—of the autistic person on an individual level. Stephanie Kerschbaum discusses the importance of negotiating difference on personal and individual terms, rather than categorically, in order to avoid “fixing” difference; she stresses that “differences are always shifting…because difference is relational. No two individuals have the same relation to one another, and difference cannot be considered in isolation; it inherently implies a comparison” (625). The comparison, in this case, is between the two people in a relationship, instead of holding up one individual against a broad, generalizing category (i.e., “How does this individual measure up to the category of
Kerschbaum’s argument for the identification of nuanced “markers of difference” helps participants in a “communicative encounter” to relate to one another based on a particular interaction and rhetorical context (628). While always “framed by and interpreted within broader sociopolitical contexts” (634), markers of difference can be attended to in the process of listening rhetorically and can help the listener recognize the individual, not just the “autistic person” with stereotyped differences from the norm.

Through the use of rhetorical listening, parent memoirs can navigate the complicated relationship between non-autistic parents and their sons or daughters with autism and in so doing acknowledge the individuality and humanity of the autistic persons through their textual representation of themselves, their family members, and their relational life stories. As I will explore in the following section, in his memoir One of Us, Mark Osteen makes significant, and often successful, efforts to listen to and interpret the embodied rhetoric of his son Cameron and to acknowledge and recognize Cam as a person through these efforts. Osteen’s efforts to focus on Cam as an individual are particularly powerful in imbuing him with enmindedness in addition to his obvious embodiment, making progress toward the recognition of someone with severe autism, like Cam, as fully human if nonnormative. While such recognition through the textual representation of rhetorical listening is an imperfect, ongoing effort, Osteen’s text makes progress toward the representation of a nonverbal person with autism as a person and self, demonstrating the potential of this technique in auto/biographical writing. Parent memoirs that do not engage in this sort of rhetorical listening, such as those by Josh Greenfeld and Kim Stagliano, have greater difficulty navigating the tensions between the nondisabled social norm and the nonnormative life and person affected by severe autism,
and therefore struggle to establish meaningful relationships in their texts between autistic and non-autistic people both within families and in communities.

**Rhetorical Listening and Relationship in Action: One of Us**

In *One of Us: A Family’s Life with Autism*, Osteen makes compelling efforts to engage in rhetorical listening to his son Cameron, with the objective of acknowledging Cam as an individual and, further, of demonstrating Cam’s membership not only in his own family but in the broader human family, as indicated by both the title and subtitle. “One of us” is a variable motif throughout the text; Osteen repeatedly raises issues of inclusion and exclusion, considering the ways that Cam is and is not included in normative mainstream society, as well as the ways that Osteen and his wife Leslie are drawn into the world of the disabled through their son. Similarly, the subtitle indicates the involvement of the family as a whole in living “life with autism,” rather than maintaining a separation of the child with autism from his non-autistic parents. Osteen emphasizes the relationality of the family’s experience as well as the interrelatedness of the life stories he is telling. In integrating disabled and nondisabled lives, despite differences in embodiment, enmindedness, and experience, Osteen’s narrative addresses and maintains the tensions between these categories. In his formulation, the disabled and nondisabled are neither clearly distinct nor quite united; instead, he seeks to negotiate the differences between them through his own experience and, to the extent possible, through Cam’s expressions of body language, behavior, sounds, and limited spoken language. Efforts at interpretation of Cam’s embodied rhetoric aid Osteen, and the reader, in being sensitive to Cam’s nonnormative embodiment and enmindedness, and in granting him a place, with his differences, in mainstream society. This is not always an easy
proposition, even for Osteen as Cam’s father, because understanding and living with Cam’s differences is often complicated, but Osteen’s narrative suggests that despite the difficulties of recognizing nonnormativity as human and valuable, it is a goal worth pursuing.

Osteen’s narration of his practice of rhetorical listening includes many examples of attentiveness to Cam’s nonverbal modes of communication, which aid in the portrayal of Cam as a self, in spite of his overall lack of language and his behavioral difficulties. Osteen offers his own translations of some of Cam’s limited words, nonverbal sounds, and movements, noting that life with Cam is far from the “deep silence” that some might assume “hangs over people with autism” (173). By contrast, Osteen argues that Cam “speaks” in many ways, “most volubly with his body, and over the years we’ve learned to interpret this language: the gleeful scissor-kicking jumps; the contented or angry rocking; the myriad wordless shouts; the fine gradations in a face that to the uninitiated seems blank; an entire lexicon of claps” (174). Osteen emphasizes that experience and attention are necessary to interpret the body language that would be indecipherable to “the uninitiated”; in other words, the kind of “listening” that enables one to notice, and hear, the meaning of these nonverbal communications. He also includes a “glossary” of sounds Cam frequently uses and what his family has interpreted them to mean. Each of these explanations demonstrates efforts to recognize and interpret Cam’s enmindedness, as expressed through observable embodied signals. A particularly sensitive example, in my view, is Cam’s expression, “Hey, hooah, huuh,” which Osteen translates as “I’m deep in thought” (174). While many, including Blastland, resist the idea that people with severe autism could have thoughts and reflections that resemble those of non-autistic
people, Osteen validates the idea that Cam can be “deep in thought,” whether or not his thoughts are similar to those of others. At times Osteen tries to imagine Cam’s mental and emotional states, particularly, as is frequently the case, when he seems distressed without a clear (to those around him) explanation. In one striking scene, Cam is screaming and thrashing while his mother tries to bathe him, and suddenly cries out clearly, “Trapped!” (67). Osteen has never heard his son say the word before, and it seems to bring Cam’s behavior into focus. While this one word does not offer any detailed insight into Cam’s experience, it leads Osteen to reflect on the possibilities for what Cam is experiencing—to consider the markers of difference between himself and Cam, to listen to the intent behind Cam’s word and behavior, and to attempt to put himself in Cam’s place: “I tried to envision living inside Cam’s head. I imagined myself inside a body that wouldn’t obey my commands. … I was constantly bombarded by chaotic sensations but unable to voice my frustration and fear except by screaming or slapping. … I knew I was different, but was helpless to do anything about it” (67).

Osteen’s reflections are, of course, deductions based on his observations of Cam and his speculative knowledge of autism’s effects. However, by seeking to hear his son’s communication, and to understand Cam’s experience as far as is possible for him through relationship, Osteen’s narrative works to legitimate his son’s enminded difference.

In addition to such personal interpretations of his son’s embodied rhetoric, Osteen also seeks to mediate Cam’s rhetoricty to others, particularly those who work with Cam. For example, he laments the lack of rhetorical listening on the part of a teacher, who sends a note home asking, “Does anyone in Cam’s family speak French? He sings ‘Frere Jacques’ and says ‘Louie, Louie’ all the time…” (38). Osteen comments in frustration
that “anybody who has worked with Cam for half an hour should know that ‘looie’ is his happy sound. It simply means ‘I feel good.’ Was she even listening?” (38). Perhaps not, at least not with the intent to understand and acknowledge Cam as an individual based on his nonverbal communication. While it is obviously difficult for teachers to be closely attentive to every one of their students, the classroom is exactly the context for which Kerschbaum recommends communication through attention to markers of difference, as only through such attention can teachers effectively reach individual students with their variety of differences. In a separate instance, Osteen’s wife Leslie writes to another of Cam’s teachers to try to explain what she perceives as his motivations for behaving in a certain (and frustrating) way: “He desperately wants to sing songs and do circle activities. I’m guessing that he feels the other kids are preventing this and he is striking out” (64). By advocating on Cam’s behalf to the professionals who work with him, his parents seek to extend their perception of his individuality to others, in order to help those people better serve him, but also to help Cam himself become a part of these interactions and a participant in his own education and care. This is what Lewiecki-Wilson sees as the key to the practice of mediated rhetoricity, for parents or other advocates “to carefully and ethically co-construct narratives and arguments from the perspective of the disabled person for the purpose of enhancing his or her daily life” (162). Rhetorical listening, then, can also make possible the practice of mediated rhetoricity between the autistic person and others—those directly involved in the lives of nonverbal people with autism, as well as those who read life narratives written by parents such as Osteen—with the potential outcome of enacting “social and persuasive acts that help constitute the disabled person’s subjectivity and agency” (Lewiecki-Wilson 162), or of acknowledging and
demonstrating the individual’s enmindedness and, thereby, his or her personhood and selfhood.

Narrating evidence of Cam’s personhood helps Osteen to make a place for Cam in the nondisabled world—to claim him as “one of us.” Osteen, like many parents, especially those who are also academics, struggles to reconcile Cam’s differences with what he has been taught to value:

Was my whole philosophy of life—that hard work conquers all—a fantasy? And what about my other prized faith, the one I’d clung to tenaciously throughout my life, the belief that intelligence is the truest measure of human value? If my beloved son was retarded, then either he was worthless or my life had been based on a lie. To admit that Cam would never be normal was to accept fallibility—my fallibility. It was to admit that I was, in some sense, disabled. (80, emphasis original)

As Osteen reflects here, the persistent cultural valuing of principles like hard work (followed by a particular type of success) and high intelligence, manifested in conventional and measurable ways, is difficult to put aside, and can stand in the way of efforts to countenance Cam’s nonnormative communication and experience. Meyer notes that even in texts that seek to value differences in embodiment, “many…narratives struggle to permit normalization, pride, and empowerment for people with intellectual disabilities by explicitly valuing and emphasizing intelligence” (269). Recognizing Cam’s enminded difference and helping to communicate it to others through the text represents progress on Osteen’s part toward accepting that his previously held beliefs about what defines human value are wrong, or at least limited. Similarly, his recognition
of his own fallibility seems to blur the lines, for him, of able and disabled, and to call into question traditional definitions of these terms. When Osteen compares his son to another child whose physical disabilities are much more visible than Cam’s cognitive and neurological ones, he asks, “[W]hat was my adorable kid doing here among these desperate people with their terrible disorders? Was he lucky after all? Was he really disabled?” before concluding, “[W]e were here because Cameron was, though in a less visible way, just as impaired. He was one of them. And so was I” (95). Through his relationship with Cam, Osteen becomes “one of them”—a part of the nonnormative other. Even as Osteen seeks to draw Cam into mainstream society through recognition both of his son’s difference and of his value, Osteen is drawn into Cam’s “disabled” world, which may include all manner of differences from the norm. Osteen’s realizations about disability and difference here are heavily colored by the social model of disability, as the label “disabled” becomes less a mark of inherent impairment and more of a mark of difference from normative expectations. Despite James Wilson’s criticism that Osteen’s book does not “explore the notion of autism as neurodiversity that has become prominent in the autism community” (Rev. of One of Us), I would argue that Osteen seeks to explore and assert human value for Cam in a different way. Through his attention to Cam’s embodied rhetoric and acknowledgment of the tension between acceptance of Cam as he is and normative cultural values, Osteen represents his own journey toward embracing Cam, with his embodied and enminded differences, as “one of us.” He also identifies the ways that he and his wife, ostensibly normative in mind and body, have become part of the community of disability and difference, their relationship with Cam having a profound effect on both their lives and identities.
The power of relationship is also evident here in Osteen’s emphasis on the connection between disabled and nondisabled members of the family. Osteen often pointedly refers to Cam as “my son,” as in this passage where he explains the school staff’s overreaction to Cam’s resistance to wearing shoes: “In that year’s class photo, five neatly dressed boys sit in a row, and three actually face the camera. Next to the little sign—Timberland Elementary School, Mrs. DeMazio, 1994-1995—a pair of bare feet dangles in plain sight. They’re attached to my son” (37). Such references underscore in a subtle yet important way the relationship between Osteen and Cam, and even the pride he feels in his son, despite the many differences between them. This element is notably missing in many parent memoirs, including Josh Greenfeld’s *A Child Called Noah*, an early memoir first published in 1972. While Greenfeld makes clear his desire to be honest about the emotions brought on by raising a child with severe autism, his bluntness tends to preclude any understanding of his son Noah as an individual, instead seeing him as a “type,” as a personified representation of autism. In one particularly candid passage, Greenfeld reflects, “[I]t is easy to sentimentalize: how having a Noah gives meaning and definition to one’s life. How people without Noahs are constantly searching for humanistic dedications. How a Noah teaches one the values of all the old verities. Bullshit! Without Noah we’d be freer to explore the boundaries of our own lives instead of constantly trying to pierce his perimeters” (169). Along with refuting the platitudes that seek to give meaning to life with severe autism, Greenfeld reduces Noah to a representative of all autistic children—“Noahs”—who complicate their families’ lives by preventing them from being “normal.” Rather than seeing his son as an enminded individual who is a part of the family even in his difference, Greenfeld figures Noah as a
“problem” that takes the family away from an idealized normative life. By contrast with Greenfeld’s approach, Osteen’s inclusion of Cam in the family and community seems even more significant. Osteen’s use of rhetorical listening to recognize and interpret his son’s emindedness and personhood and to strengthen the relationships between nondisabled and disabled family and community members works to expand possibilities for different kinds of people and, likewise, different kinds of narratives for expressing the life stories for those people and those in relationship with them.

*Separating Autism and Personhood: All I Can Handle*

Perhaps the most fraught boundary for parent writers to navigate in narratives about life with severe autism is that between acceptance of the autistic person as he or she is, on one hand, and the desire or hope that the person will improve and become less severely impaired, on the other. While “neurodiversity”—the idea that people with autism are neurologically different but just as valuable a part of society as non-autistic, or neurotypical, people—has become an influential concept in the autism community in recent years, this sort of acceptance and recognition of value seems to apply more readily to those with less severe manifestations of autism, such as those diagnosed with Asperger’s syndrome. Parents of children with more severe forms of autism tend not to find the neurodiversity view quite as applicable to their situations. Kim Stagliano, the mother of three daughters in the more severe area of the autism spectrum, is rather dismissive in her characterization of the neurodiversity view, writing, “There are bloggers and advocates within the autism community who preach that autism is a set of

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39 In another revealing passage, Greenfeld makes direct reference to “solving” the “problem” of Noah being part of the family: “Indeed, the more I read about such children, the more I’m convinced, unfortunately, that only money can solve most of the problem of having a child like Noah. That’s the damned truth of it. The more money I have, the less of a problem Noah becomes—I can hire out the problem to others. Have a crazy kid and get to understand the gut meaning of society” (126-27).
nifty special traits, like a Swiss Army knife for life” (79). She sees neurodiversity as “[k]ind of a no-brainer” in its message that people with autism should be accepted (181), but she also fears that it leads people to “advocate against treatment, hope, and recovery” (182). A little less ironically, but perhaps more forcefully, Osteen observes, “Certain advocates try to convince us that autism is not a disability, but merely a different way of being human, no better or worse than any other. It’s good that people on the higher end of the autism spectrum are trying to rid autism of its stigma and celebrating their uniqueness. But my son is not like them, and our world is not theirs. If I were Aladdin and had three wishes, the first would be a no-brainer: ‘Please, genie, take away Cam’s autism and make him a regular boy!’” (One of Us 110). Many would find such a wish offensive; parent memoirist Daniel Mont, for instance, suggests that “when parents say, ‘I wish my child did not have autism,’ what they are really saying is, ‘I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead’” (173).

However, parents’ recognition of the impairments that make it difficult for their children to learn or interact with others, and of their own challenges in reaching or connecting with their children, can make it hard to accept autism as just an alternative way of being. Since these impairments do not fit readily into the “differently abled” model, it can be even more difficult for parents of severely autistic children to give up on the search for new treatments and potential miracles that may help their child adjust to the normative world.

At the same time, most parent memoirists strive to demonstrate in their texts that they care for and accept their children for who they are, which can be difficult to do when one is also framing autism as a severe deficit. Some degree of resolution can be found by
seeking to separate the child from his or her autism, a false if at times helpful dichotomy. Osteen, for instance, attempts to direct negative feelings at autism, rather than at his son; in discussing his wife’s uncharacteristic outburst one day, he writes, “…I also know that her rage wasn’t really directed at Cam: it was aimed at the other passenger in the car, the one who made him bite his aide and throw a tantrum in the bathtub. She was angry at autism itself, which seemed to have an unending supply of ways to torture us” (*One of Us* 72). In this figuration, autism is a separate entity that controls Cam’s behavior and complicates life for the whole family. Since Cam, and other people with autism, will always be autistic, it is at best a mental exercise to separate the person from the condition, but it can serve to direct anger and frustration away from a child who does not deserve it. Osteen’s act of blaming autism for the behavior Cam cannot control does indicate acknowledgment of Cam’s embodied and enminded difference, which causes him to act in ways that may frustrate or hurt those around him without intending to do so. Such a separation of autism’s difficulties from the autistic person seeks to preserve personhood for Cam by seeing him as an individual affected by autism, and not just as a force of difficulty in the family’s life (i.e., “a Noah”). As discussed in the previous section, overall Osteen leans more toward recognition of Cam as a self than as a personification of autistic behaviors, but at times that means attempting the impossible task of separating him from his autism.

In Stagliano’s *All I Can Handle*, the relationship between autism and the individuals affected by it, both directly and indirectly, is even less clear-cut. There is an obvious relational dialectic between Stagliano and her three daughters, Mia, Gianna, and Bella; without them and their autism diagnoses, she would not have this particular
identity or this story to tell. However, she is also, in her book, making a case for finding a cure for autism, thereby seeking to erase her daughters’ difference and the basis of her life narrative. This contentious relationship makes for a complicated sense of relationality between her story and that of her daughters. Her narrative includes some biography of the girls—each of their births, their paths to diagnosis, and the challenges that their autism presents to the family—but this is a much smaller element than that of the mother’s own story. Significantly, there is no attempt made toward mediated rhetoricity, the representation of the girls’ perspectives or their efforts to express themselves through verbal or nonverbal means. To some extent this may be the result of Stagliano having three autistic children, rather than a single subject, to represent; obviously, there cannot be too much space given to any one of them without the book being much longer than its 200 pages. However, Stagliano’s objectives of telling her own story and imparting her own view of autism as an epidemic in need of a cure obscure the girls themselves in favor of the bigger picture about autism. The lack of attention to rhetorical listening or interpretation impedes understanding of the girls’ relationship to the family and to the community, and makes personhood or selfhood for Mia, Gianna, and Bella difficult to discern.

Stagliano refers to herself, in the somewhat polarizing jargon of the autism community, as a “curebie,” and her strong focus on her quest for a cure drives the book. Many of the anecdotes about her daughters are used as evidence for her position that “autism is treatable, that kids can recover, and that some/much/all of it was caused by an environmental insult to a genetically susceptible brain” (59). Yet despite this strong sense of purpose, Stagliano admits feeling conflict between the personal and the political,
and therefore between her goals of narrating her own life dealing with her daughters’ autism, on one hand, and of persuading readers of the need for a cure, on the other. While she is concerned with communicating the unpleasant realities of autism as support for the argument that autism can and should be treated and prevented, she also takes pains to make clear that she loves her daughters as they are and does not want their autism to prevent others from caring for or accepting them. This is a difficult position to maintain, and Stagliano’s narrative does not easily walk the line. Early in the text she identifies her belief that a “cure” for autism is on the horizon, one that will enable kids with autism to “blend in with their peers and…live full, independent lives” (18). However, in the next paragraph she addresses the difficulty of both loving her daughters as they are and working for a cure that aims to “fix” them: “I know that many things are wrong with Mia, my firstborn. But I loathe ever talking about her as if she were broken. Even though she is broken. It’s confusing, isn’t it? I write about the trauma and difficulty of autism every day, and yet I hate to bring my kids into the conversation” (18). While Osteen seeks to separate autism from his son in order to emphasize Cam’s personhood and de-emphasize culpability for his challenging behavior, Stagliano seeks to separate her political advocacy about autism research from her personal relationship with her daughters. Since her daughters are the reason for her fighting this fight, this seems counterintuitive, but because she is arguing that people with autism are “broken” and need to be “fixed,” her reluctance to suggest that her children are not valuable individuals as they are is understandable. Indeed, this tension between accepting and changing her children helps to explain the absence of rhetorical listening and mediated rhetoricity in her text. Attention to her daughters’ embodied rhetoric and other forms of communication would
be a way of seeking to recognize and validate their difference and nonnormative personhood, in the way that we see in Osteen’s narrative. By declining to engage in rhetorical listening to any real extent and thereby keeping her daughters’ individuality out of the text, she avoids the danger of undermining her argument that autism needs to be cured. True acceptance of enminded difference would be inconsistent with Stagliano’s efforts to “sound the alarm bells about the autism epidemic” (78).

Despite her resistance to the brand of neurodiversity which, in her view, translates to “not respecting the needs of parents to treat their children’s autism” (181), ultimately Stagliano wants acceptance for her children, but preferably with the effects of autism removed. She wants the “underbelly of autism” (144) to be publicized, yet she, again like many in the neurodiversity camp, takes issue with statements that “sho[w] a stunning lack of hope and bran[d] our children with autism as nothing more than a burden” (172). She acknowledges the “tightrope” that must be walked, “of wanting the public to understand the good, the bad, and yes, the ugliness of autism, while maintaining respect and dignity for our loved ones” (144). Her narrative is precariously balanced on that tightrope: demonstrating the “good” through declarations of love for her daughters, whom she insists “are not a burden” (172); putting forth the “bad” of her daughters’ behavioral, communication, and learning difficulties, as well as health issues such as allergies and seizures, to help support her view of autism as biomedically-based and potentially treatable; and carefully inserting the “ugliness” through unpleasant episodes from her own experience and others’ to establish the urgency of finding treatments and cures for those affected by autism. Her messy negotiation of these conflicting goals and

40 Stagliano is responding in particular here to the controversial statement made by Alison Singer in the documentary Autism Every Day, released by Autism Speaks, that she had considered driving herself and her autistic daughter Jodie off of the Brooklyn Bridge (Stagliano 172; Autism Every Day).
attitudes demonstrate the complicated reality of being a parent of autistic children, and of the experience of feeling love for and acceptance of the children as they are while simultaneously hoping, praying, and working toward something that will help them improve to not only alleviate the parent’s challenges, but also the child’s. Stagliano holds on, perhaps desperately, to hope for her daughters’ improvement, even transformation, while at the same time expressing her love for them as they are. While Daniel Mont, above, suggests that parents who want their autistic children to improve are actually wishing their children did not exist, I think Stagliano’s position, and that of most parents of children with severe autism, is not quite that simple. The tensions within Stagliano’s text reflect the tensions that she, and other parents, experience in living with severe autism in their families. The tension between loving one’s child and working for a cure is not easily (or perhaps ever) resolvable, but as long as that tension exists in the parent’s experience, it may be reflected in uneasy balancing acts in his or her life narrative.

Stagliano’s narrative makes clear the complicated nature of her relationship both with her daughters’ autism and with autism as a larger, social entity. However, in emphasizing her own experience and her desire for a “cure” over her daughters’ own communication and life stories, Stagliano prevents any clear sense of their individuality or personhood from being demonstrated in her text.

**Competing and Insufficient Narratives: (Dis)ordering Chaos**

As these parents struggle to recognize and represent their children’s nonnormative enmindedness and personhood, they also struggle to fit their nonnormative relational life stories into available narrative models. Constructing a narrative out of life with disability or illness is a complicated task, not least because the very differences that one seeks to
interpret and narrate in his or her life story may be difficult to put into readily-available
models of writing or, conversely, to make understandable or palatable to the reading
audience. In Recovering Bodies, G. Thomas Couser asks, “[H]ow do illness and
disability—which in extreme cases might obstruct or defy narration—get written at all?
How does one make a (coherent) story out of bodily dysfunction?” (14). Such questions
rely on assumptions about what comprises “narration” or “coherence,” assumptions
which may be strongly shaped by social and cultural norms about embodiment and
enmindedness. The question of whether nonverbal people with autism can narrate their
own lives, for instance, is dependent on a particular idea of what “narrative” is and what
it should look or sound like. Some common expectations might be that the narrative is
linear in nature, that it follows a familiar plot pattern, and that it makes use of certain
forms of language, both figurative and literal. As I have indicated in my above
discussion of rhetorical listening and mediated rhetoricity, there are many ways that one
can narrate experience that may be unrecognized or unlegitimated by others. Likewise, I
would argue that the criterion of “coherence” is not a fundamental measure of either
narrative or intrinsic worth, but rather a measure of how well a particular text follows
established, and somewhat arbitrary, requirements.

In The Wounded Storyteller, Arthur Frank discusses the function of illness
narratives both “to restore an order that the interruption [by illness] fragmented” and to
find “a different kind of end—a different purpose” for a story for which “tidy ends” are
no longer suitable (59). Indeed, Frank points out the challenge of telling a story that
resists those patterns that others want to hear. However, throughout his book he
discusses just three forms that illness narratives tend to take, suggesting that for the most
part, these narratives do not expand very far beyond a limited range; that they rarely, in fact, resist the imposition of the tidy patterns. Frank’s identified illness narratives include the restitution or recovery narrative, in which the ill person returns to health and some degree of normalcy (owing, typically, to some type of medical intervention); the quest narrative, in which the ill person seeks to find, or create, some greater meaning out of his or her experience of illness; and the chaos narrative, which is actually, according to Frank, impossible to narrate, though “the voice of chaos can be identified and a story reconstructed” (98-99). However, each of these narrative forms presents challenges and limitations for the story of life with a child with severe autism, leading to a need for stories that lie at or beyond the margins of these defined available narratives.

Parent memoirs about life with severe autism are rarely able to follow the plot of the recovery narrative. The parent-authored texts that do attempt the recovery narrative model typically depict children at the less severe area of the spectrum and espouse a particular treatment approach which has apparently changed the child’s, and parent’s, life; Osteen describes the thrust of such texts as “How I Saved My Child from Autism and Became a Better Person” (Autism and Representation 19). Barry Neil Kaufman’s 1976 text Son-Rise, for instance, tells of a treatment method Kaufman and his wife developed to help their young son Raun “recover” from autism. The so-called “Son-Rise” method continues to be offered today at the Autism Treatment Center in Massachusetts, and the program’s website identifies Raun as a “fully recovered” adult who holds a leadership position in the program. However, often what is described as “recovery” or “emergence” from autism might be understood, alternatively, as development; while all people

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41 I prefer the term “recovery narrative” to “restitution,” particularly in relation to the sorts of expectations such narratives hold out for people with autism to “recover from” or overcome their disabilities. However, the basic plot of the narrative is the same as that described by Frank as restitution.
diagnosed with autism develop throughout their lives, drastic changes are not the typical experience of those with more severe autism (Clara Park concedes that Kaufman’s experience is a “miracle recover[y]” [The Siege 164]). Without “recovery” or a significant change in the status quo, parent memoirs cannot tell such a story. In Chapter 3, I discuss the recovery narrative in relation to auto/biographical works written collaboratively by autistic people and their non-autistic parents. In these collaborative texts, I found that while the parent writers follow a narrative of recovery when describing their child’s autism, identifying the communication breakthrough that each child experiences as a sort of recovery that alleviates the unpleasant or even unbearable nature of life with a child with autism prior to that point, the autistic writers’ perspectives subvert that narrative by dismantling the idea that their growth demonstrates a miraculous “recovery” or any change in their status as persons or selves. The recovery narrative is similar to the “overcoming” narrative often critiqued by disability studies; both imply that life can only be worthwhile once illness or disability is overcome, and that life with disability is not worth living. The story of the “Supercrip,” which Couser explains is “an Inspirational Disabled Person who overcomes impairment through pluck and willpower” (Recovering Bodies 203), is an extreme example of the overcoming narrative. Supercrics frequently appear in the media in the form of people with disabilities who run marathons, climb mountains, or achieve other feats beyond what most people, disabled or nondisabled, are able to do; in other words, the Supercrip is not typical and does not offer an authentic representation of disabled experience to nondisabled audiences. In the same way, narratives that focus on recovery from autism can offer limited views of autistic life to readers, implying that the only acceptable narrative about autism is one in which it is
overcome or eradicated. As parent memoirists make use of rhetorical listening and interpretation in order to recognize and call attention to the nonnormative enmindedness of their severely autistic children, the presence of such nonnormative lives and identities leads to a disruption of common narrative models. Pushing against the boundaries of normative narrative structures in life writing is not only useful but indispensable for representing those who do not overcome their disabilities or achieve extraordinary feats, but instead live meaningful yet uninspiring everyday lives with nonnormative embodiment or enmindedness.

The quest narrative would seem more applicable than the recovery narrative to the experience of many of the writers of parent memoirs about life with severe autism. As Frank defines them, “Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience” (115, emphasis original). Certainly an attempt to find meaning is present to some extent in most autobiographical narratives; people want to make sense of their life experiences, particularly an experience that has been challenging, such as illness or disability for oneself or a loved one. However, the meaning of an experience might be difficult to clearly identify, and in the absence of what Couser terms the “comic plot,” in which “the protagonist is better off at the end than at the beginning” (Recovering Bodies 16), it might be impossible to achieve any sense of closure to the writer’s search. Frank acknowledges this difficulty somewhat in his description of the genre of the memoir, which he describes as “the gentlest style of quest story,” one in which “no special insight is claimed at the end; the insight is rather the
incorporation—a good pun in this case—of illness into the writer’s life” (120). I would argue, however, that parent memoirs about raising children with severe autism differ somewhat from this characterization. While such parent memoirs are, as I have suggested, relational, relying upon and interacting with the children’s lives and life stories, illness or disability often is not, or cannot be, quite “incorporated” into the writer’s life. The disability of a child is always outside of the parent’s self, and therefore the efforts to understand, acknowledge, and incorporate it are more complicated. The search for meaning in another’s life is, if anything, more complex than the search for meaning in one’s own, and the difficulty for many non-autistic people to recognize fully the meaning of autistic life makes closure to the quest-type narrative—even without the claiming of a particular insight—very challenging. For this reason, many parent memoirs about autism do not reach a “satisfying” ending of the sort that the quest narrative might lead a reader to expect. Some, including Osteen’s One of Us and Kate Rankin’s Growing Up Severely Autistic, end with the autistic child moving out of the family home and into a residential school; the child leaving home is not a resolution of autism’s challenges, but rather the next step in a still uncertain and ongoing journey for these families. Others, like Stagliano’s, simply end in medias res, looking toward the future, perhaps with a particular stance, but with no real climax, resolution, or insight to relay. The story of life with autism has not yet ended, nor has it changed dramatically, though there might be some prediction or hope for what the future may hold.

In this sense, life with autism most closely resembles chaos, a type of narrative Frank describes as unnarratable because the experience of chaos is inconsistent with the structure of narrative. He explains that chaos is an “anti-narrative of time without
sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself. … [T]hese stories cannot literally be told but can only be lived” (98, emphasis original). To some degree, of course, what Frank describes is the case for all life narrative—life as narrated is always re-constructed from memory and after reflection; in Park’s words about her own life writing, “Experience as analyzed is no longer experience as lived” (The Siege 87). However, life experience that is nonnormative and does not fit conventional patterns of storytelling might be particularly challenging to translate into the form of a traditionally accepted narrative. As Osteen characterizes Frank’s view, “As soon as chaos or interruption becomes a narrative, it is no longer chaos or interruption” (Autism and Representation 17). Osteen also acknowledges that “autism equals ‘living with perpetual interruption,’” which he argues results in “a tension between narrative order and narrative disruption—whether figured as endless repetition or as outbreaks of chaos—[that] runs through virtually all family autism stories” (17). I think Osteen is right that life with autism often presents a sort of chaos that defies narrative convention, but I also argue that a major reason for this incompatibility is the limited range of narrative patterns that are available and that others find acceptable. As opposed to the happy-ending recovery narrative, the narration of chaos does not necessarily have an ending at all, and likely does not follow the comic plot of progress or improvement. Frank claims that “[c]haos is the opposite of restitution: its plot imagines life never getting better” (97), a statement which presumes that life has to “get better” in order to correspond to some sort of norm, and that chaos, in whatever form it manifests itself, is unacceptable. Ann Jurecic identifies a similar normative pressure in her discussion of “narratives of risk,” which often fail to achieve the sort of closure that readers seek:
"Narratives demand closure, and this demand is always at odds with the vast quantities of information that could be taken into account and the indeterminacy at the core of individual accounts of risk" (33). Narratives of life with severe autism are full of indeterminacy regarding issues such as autism’s causes and manifestations, the future of the person with autism, and the meaning of autism in personal and sociocultural contexts. Because these narratives, too, frequently lack closure, they challenge narrative norms and may prove “unsatisfying” to readers who seek the kind of meaning and reliability found in traditional narratives.

I argue, however, that indeterminacy, lack of closure, and departure from convention should not disqualify a life story from being considered as “narrative.” That is, while Frank may define chaos as “unnarratable,” stories of life with severe autism, along with other life stories that are not easily fitted into available models, are narratable, and should be recognized as representing lives that may themselves not fit into available models of life or personhood. While some of the types of chaos to which Frank refers, such as Holocaust experiences, are indeed “horrible” (Frank 112), this is not quite the same type of chaos as that in autism narratives. The unpredictability of life with autism is a kind of chaos that is ongoing and even lifelong, and rather than ending in misery, usually leads to adaptation and a new, if nonnormative, pattern of life. Rather than being a “condition of horror” (Frank 109), chaos might simply be life that refuses to adhere to conventional principles of order. As such, it can and should be narrated in unconventional ways. Such unconventional narratives of nonnormative lives have the potential both to communicate life stories that reflect real experience and disrupt narrative constraints, and to make space for different sorts of personhood and subjective
reality to which conventional narrative is poorly suited. Frank’s description of the chaos narrative as embodied helps to illustrate this point: Frank points out that “the chaos narrative is probably the most embodied form of story. If chaos stories are told on the edges of a wound, they are also told on the edges of speech. Ultimately, chaos is told in the silences that speech cannot penetrate or illuminate” (101). Because nonverbal people cannot tell their stories through speech, those stories might inevitably be seen as chaos narratives; if speech “cannot penetrate or illuminate” their silence, their stories cannot be told, or heard, using traditional narrative devices. Parents who seek through rhetorical listening to hear and mediate their children’s stories can move toward better recognition and acknowledgment of their stories, and by extension the children themselves; however, attempting to fit those embodied, chaotic stories into conventional narrative forms will result either in a story that is not true to lived experience, or in a story that falls somewhere in the liminal spaces between conventional narrative forms.

In the face of narrative models that are not able to accurately or fully represent the life experience of those living with severe autism, one might expect a new, more suitable narrative form to emerge. Couser looks for such innovation in his examination of disability memoirs, but finds that what he identifies as “new disability memoirs” are actually “not innovative, much less experimental” but have a “disability consciousness” which is what makes them different from other life writing about disability (Signifying Bodies 165). I am less interested in whether these parent memoirs about autism establish any sort of unified new form of narrative than in the ways in which their resistance to available models reflects the reality of forms of life and personhood that fall outside the norm. In this way these pieces of life writing engage with what might be termed “autism
consciousness” in important and revealing ways. While their lack of conformity to traditional narrative forms could be seen as a kind of failure, as Osteen suggests when he writes that Robert Hughes, in his parent memoir *Running with Walker*, “does not fully succeed in turning this compelling material into a compact story: because Walker’s improvements are not dramatic enough to call him ‘cured,’ the book remains a series of episodes leading to an anticlimactic conclusion” (*Autism and Representation* 21), I am inclined to see it as a success in its progress toward dismantling the more traditional, and more limited, forms of life narrative, in favor of something that represents more accurately the life experiences being narrated. These stories’ refusal to “fit” expresses and maintains the existence of difference: different life trajectories as well as the embodied and enminded differences of the autistic people who are represented in these life narratives.

**The Impossible Quest: Autism as Mystery in The Only Boy in the World**

Michael Blastland’s memoir *The Only Boy in the World* might at first glance look like a “quest” narrative. Blastland sets out, as the book’s subtitle suggests, to “explore the mysteries of autism,” using his son Joe as a case study. Arthur Frank distinguishes between “mysteries,” which must be lived with, and “puzzles,” which may be solved, commenting that “[m]odernity seeks to turn mysteries into puzzles” (81), or to resolve the unresolvable. If a condition like autism is seen, in Frank’s terms, as a puzzle to which there is some answer to be found, then the quest might make sense as a narrative device, particularly if the writer believes he or she has found answers to questions about how to understand autism’s meaning in a personal or social context. If, on the other hand, autism is seen more as a mystery, which does not have an answer or key that can resolve
questions and difficulties, the quest is a less useful narrative trope, and, if it is employed, will likely appear to be unsuccessful in achieving its aim. Indeed, Blastland’s text does not arrive at any neat conclusions in his exploration of autism’s “mysteries,” though he admits, “I make no secret of my desire for meaning” (186). That is, the book represents a quest for higher meaning without any real discovery of such a higher meaning, because of autism’s, and Joe’s, inherent resistance to being deciphered. Blastland’s particular interest is in examining definitions of what it means to be human, holding them up to his son, and determining whether or not Joe, and other severely autistic people, can or should be seen as fitting that category. This is ultimately an impossible task, though Blastland’s efforts do help him make progress toward acknowledging his son’s value even with his enminded difference. There is, however, no resolution as to the meaning of that difference, at least not in the terms Blastland looks for it. Because of this, the narrative is not a quest; it also does not resemble a recovery narrative since there is no drastic improvement in Joe’s status, nor, in my view, does the text the present the sort of unnarratable chaos that Frank identifies. The text does indeed narrate life with Joe’s autism, and the chaos of that life appears to be both bearable and ongoing. Instead, Blastland’s text falls into a liminal space between narrative models, in which Blastland seeks to resolve the mystery of autism and finds that it cannot ultimately be resolved, causing his quest to be unfulfilled (though not entirely unfulfilling). Blastland’s narrative does, however, explore the nonnormative aspects of Joe as a person with autism and the complex relationality between Joe and both non-autistic people and mainstream society. While Blastland fails to achieve a resolution to his quest for meaning, his narrative demonstrates efforts to understand nonnormative personhood and reflects an ongoing
negotiation of experience that refutes the notion of autism as a puzzle with an artificially tidy resolution.

Beginning with nine-year-old Joe’s placement in a residential school, Blastland’s text provides an early indication to readers that this story is not one of “recovery” from autism. By revealing up front that Joe’s autism is severe enough that his family deems it better for him to be cared for by others most of the time, Blastland is clearly not promoting a miracle cure or even telling a story of dramatic improvement. Indeed, Blastland presents Joe as being very resistant to improvement, explaining, “The fact is that in general he doesn’t learn, or at least does so inch by painful inch” (5). Though he is only ten years old at the book’s end, Joe is depicted as having developed about as far as he is capable toward “normal” human behavior and mental experience. In this way Blastland discounts the recovery narrative as a possibility, and rather than holding out for a cure for Joe’s enminded difference, instead makes this difference the focus of his quest toward understanding. In the first chapter, titled “Fascination,” Blastland declares that “of course Joe is one of the most fascinating among us. Quirky, maddening, hilarious, adorable, hateful, sensitive, dangerous, and exposed; he goes through his life’s repertoire on a Tilt-A-Whirl. Of course he deserves our attention, and when we give it, what things he tells us, what questions he asks” (4, emphasis original). According to Blastland, Joe’s difference provides an opportunity of learning not only about how autistic people work, but, perhaps (for Blastland) more importantly, how non-autistic people work. In a sense, Blastland seeks to find order beneath the apparent chaos of life with autism.

Finding meaning behind chaos forms a significant part of the impossible quest Blastland sets out on in his text. Textually and intellectually, chaos is analyzed and to an
extent dismantled through the sort of philosophical inquiry the book carries out.

Literally, it seems the only way to order the chaos that Joe presents is to largely remove him from the family’s everyday lives. Blastland explains everyday life with his son:

“For sheer apprehension, life with Joe when he was at home sometimes felt as I imagine a midnight stroll through an inner-city no-go area, wondering when the blade will flash in the moonlight” (61-62). Moving Joe to a residential school during the week takes away this chaotic feeling of apprehension, and seems to give Blastland space to engage in the more intellectual process of sorting through autism’s mysteries and its meaning for non-autistic people. Yet if ordering chaos is a personal issue, it is also a societal one in that social structures and practices are not prepared to accommodate someone like Joe.

Blastland’s defense of the decision to move Joe to the residential school hints at this reality: “After nearly ten years of looking after Joe, we were running out of steam, at the point of accepting that we could no longer customize his future. Our problem was not controlling him—we managed that passably well—it was controlling the world” (23).

The distinction here as to the object of the control that Blastland and his ex-wife are able to exert is a telling one: while Joe himself is a source of fascination for Blastland, the problem with the chaos he creates in their lives is that he does not fit easily into the normative world around him. In a notable scene, Blastland describes how Joe once punched a baby in a stroller while they were out shopping; Blastland uses this incident as an example of Joe’s apparent inability to empathize with others, since his reaction to the baby’s crying is not to try to understand or comfort, but to strike. However, Blastland’s

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42 Blastland and Joe’s mother are divorced, a fairly rare element in parent memoirs about autism, though some claim that divorce rates for parents of autistic children are significantly higher than for other married couples; see Hartley et al. Interestingly, their separation receives no attention in the text beyond their living in separate homes and Blastland’s reference to her always as “Joe’s mother.”
own difficulty in responding appropriately to the baby’s mother—“for what does etiquette demand following unprovoked toddler atrocity?” (149)—indicates that social norms, such as etiquette, provide some of the primary obstacles to the inclusion of people like Joe. People are not supposed to punch babies; when a person (even a small child) with autism commits such a prohibited act, he undermines the norms of social behavior and seems unassimilable in mainstream society. Blastland acknowledges that Joe likely did not intend to do the baby harm, reflecting, “A court wouldn’t find him criminally responsible and the interesting question is what peculiarity in Joe allows us to say that the court would be right” (149). While Joe may not be held responsible for his actions, for Blastland this seems to underscore Joe’s nonnormativity even more. Joe’s presence in Blastland’s life means a constant need to deal with the chaos caused by his nonnormative behavior.

In addition to the chaos it imparts to everyday life, autism imposes chaos on efforts to create normative forms of narrative as well. Blastland remarks on the common desire for recognizable narrative patterns, and the problems that Joe, and autism more generally, present to conventional ideas of narrative. In a chapter titled “Storytelling,” Blastland examines the impact of narrative and the implications of autistic people’s apparent deficit in imaginative ability. He comments that “Joe…in common with most autistic children has little sense for narrative, seems uncertain about the borders of the fictional, and performs almost no socio-dramatic play,” and he asks, “Are the chambers of his imagination unbuilt, unstretched, his boundaries of the acceptable unformed in part because stories make no sense to him?” (132-33). The answer that Blastland inclines toward would be “yes,” since he hypothesizes that Joe’s inability to imagine or to narrate
in normative terms means he is limited in other capabilities, such as reacting to unexpected situations (137). However, another aspect of a solution to the “narrative problem” for people with autism would be to recognize that other, equally valuable if less commonly recognized, types of narration may be available. Blastland mentions Christopher Booker’s *The Seven Basic Plots*, which argues that stories “work as archetypes because of some deep resonance in the unconscious, in the way our psyche organizes experience, perhaps…because narrative patterns, experienced from childhood, have priority over conscious thought” (Blastland 135-36). This notion suggests that certain plot structures are influential because social experience gets codified into psychological impact (to both of which autistic people might be less receptive due to differences in social interaction and cognitive approach). As a journalist, Blastland recognizes the tendency for writers to funnel stories into familiar narratives: “‘the betrayal,’ the feud,’ ‘the pledge,’ ‘the bungle.’ Though we’re all taught to avoid clichés, the fact seems to be that newspapers in particular (and perhaps readers) are happier once a story can be nailed down in terms of one or another stock theme” (136). Although Blastland laments Joe’s lack of ability to create, recognize, or appreciate such familiar narratives, I want to call attention to the perception that newspapers and readers are both “happier” when a stock narrative can be used. This recalls Frank’s observation that restitution narratives are the ones writers want to write and that readers want to read; this does not mean, however, that these stories most accurately or productively portray experience. Readers might be “happier” when narratives follow familiar patterns, but not all narratives can or should fit those patterns. Blastland’s own narrative, I argue, tries to fit itself into the quest narrative form (also one of the stock plots identified by Booker).
but the reality of life with autism resists the end result that such a quest anticipates and forces the narrative out of that traditional narrative form.

Toward the end of the book, Blastland appears to recognize that his narrative is incapable of having a conventional ending, which implicitly disqualifies it from inclusion in the common narrative patterns he discusses above. He acknowledges that this story does not progress in the ways stories are expected to do, because there are no drastic changes in the status quo (i.e., recovery) or dramatic discoveries of meaning (quest). In terms of Joe’s development, Blastland comments, “[T]here is no ending, happy or otherwise, but certain fears have receded and new ones emerged. … I tend not to see Joe’s future as a steady march to the sunlit uplands; his life doesn’t await maturity, change being so slow that I’ve thought of him for a long time now as of no age in particular. The future is here, it will be as it already is” (197-98). Joe’s story does not fit into any stereotypical narrative model because it does not reflect the kind of progress, improvement, or closure that those patterns require. Even the least progressive (i.e., showing improvement or forward movement) of Booker’s plot structures, “Tragedy,” still has a decisive end. However, real life—life in Jurecic’s “risk society”—does not always, or even often, fit into such plot structures, and life with severe autism is real life, sometimes overwhelmingly so. Despite its lack of neatness, I would argue that real life, particularly life with autism, can still be narrated; in fact, its narration is imperative to expanding recognition of what life stories can look like—often lacking in clear progress; challenging and confusing; clouded in unresolvable mystery; and requiring efforts to interpret and attempt to understand others’ experience. In their refusal to settle into established narrative forms, stories of life with severe autism can help expand
opportunities for other sorts of life writing to escape the limitations of conventional narrative structures. Although Blastland’s narrative is styled as a quest, its ultimate failure to find the answers it seeks places it in the liminal space outside of conventional narrative models and therefore pushes against the restrictions placed upon life narratives.

Blastland’s “quest,” then, does not fulfill its goal of resolving questions about autism, such as exactly how different Joe is from other people, or what the value of someone like Joe is for the rest of the world. The chaos of autism’s instability as a category or as an experience, along with the chaos which comes from Joe’s nonnormative enmindedness, subvert the path of the quest and disqualify the text from identification with that more conventional narrative form. Far from being a failure, however, this text’s resistance to narrative models manifests the insufficiency of such models to capture real life experience, particularly nonnormative experience like that of life with severe autism, as well as other forms of different embodiment and enmindedness. And though the mysteries of autism go unresolved, the text’s unresolvability opens the door to a better understanding of the importance of relationality—of relationships between people as different as autistic and non-autistic—in broadening definitions of personhood and accepting those with different enminded experience as persons. In Blastland’s pursuit of answers he is ultimately unable to find, he explores the meaning of relationships between non-autistic people like himself and autistic people like his son, working toward better recognition of the legitimacy of Joe’s nonnormative experience. Texts such as Blastland’s demonstrate, albeit unintentionally, the need to look beyond conventional narratives to the ways real experience might narrate itself.
Accepting the Nonnormative: Growing Up Severely Autistic

Kate Rankin’s memoir *Growing Up Severely Autistic: They Call Me Gabriel* strays even further from a conventional narrative model than does Blastland’s text. Rankin’s son Gabriel is, as the title indicates, at the severe end of the autism spectrum and, like Cam Osteen and Joe Blastland, eventually moves out of the family home and into a residential school. As Osteen notes in *Autism and Representation*, Gabriel “may be the most seriously impaired [autistic] child depicted in any parent memoir: at age seventeen, he is not toilet-trained, doesn’t speak at all, has almost no ordinary play, social or academic skills, climbs compulsively, runs away, destroys furniture” (21). Life with Gabriel’s autism is even more obviously chaotic than some of the other examples we have seen, particularly because he is completely nonverbal, communicating directly only through one sign (touching his lips, indicating “yes” or “please”), and his behavior is both nonnormative and hyperactive. Like Osteen’s, Stagliano’s, and Blastland’s texts, there is no possibility of Rankin’s story being a recovery narrative; Gabriel is able to learn very little academically, and he does not in any way “emerge” from his autism. Nor is there a tendency toward a quest in Rankin’s narrative as there is in Blastland’s; while there are certainly insights gained as life with Gabriel proceeds, Rankin is not searching for answers or a higher meaning as to why Gabriel is the way he is or what this signifies for non-autistic people. Instead, she seems to have accepted Gabriel himself as well as the chaotic but, ultimately, tolerable way of life that Gabriel brings. Rankin makes clear that the process of “coming to terms with” life with autism is a long and difficult one (63); it is a necessary stage for parents with autistic children, but it passes, and although the chaos does not go away, life goes on and becomes “normal.” After going through this
stage, Rankin reflects, “I was faintly perplexed to find myself quite contented and happy with my life, despite the fact that Gabriel was not getting any easier” (63). This life never ceases to be challenging, and Rankin is honest about those challenges, acknowledging that when Gabriel goes away to school, “however much I may miss him—and of course I will—for myself, I cannot deny that the vision of a life unfettered by the demands he imposes on me…being able to socialise in the evenings and at weekends and pursue my own interests, is a prospect that fills me with pleasure” (193, emphasis original). Still, despite the difficulties of caring for Gabriel and the real relief that respite can bring, Rankin suggests that this does not need to be a story of complete chaos or of misery, but one of life with difference, a nonnormative narrative about life with a nonnormative but still valuable person. While Osteen claims that Rankin’s “narrative never gains momentum” (Autism and Representation 21), I find this evaluation to be a relic of normative models of narrative that presuppose a certain type of narrative trajectory, including “momentum,” a climax, and resolution. I find instead that Rankin’s text refutes such presuppositions about life writing through its willingness to tell its story of life with severe autism without bowing to the pressures of narrative convention.

Rankin’s unconventional narrative first makes room for the unconventional personhood of her son Gabriel, in Rankin’s own efforts at attention to and interpretation of difference. There are many ways in which Rankin emphasizes Gabriel’s differences from other people; for instance, in her foreword, she acknowledges that in a previous article she has used the word “idiot” to describe her son, a word that is usually considered offensive and dehumanizing. She explains, “I used the word not as an insult but to convey just how handicapped and utterly helpless he was” (5), urging readers to “bear in
mind that the original meaning of ‘idiot’ was a person who was unique in a way that others are not—and Gabriel is certainly that” (7). In addition, at times Rankin compares Gabriel to animals in order to express how unnatural some human behavior is to him: for instance, she says that he is able to hand money to a cashier in exchange for a pastry, but “he does [this] without apparently having the remotest idea why; he does it rather like a performing animal, simply because that is what he is required to do to get the reward” (10). Again, many readers might find this comparison degrading in its suggestion that Gabriel is somehow less than human; however, I would argue that Rankin uses these terms to help give readers a better sense of how different Gabriel’s experience and behavior may be from their own. Rankin is certainly not the only writer to make comparisons between autistic people and animals; autistic animal scientist Temple Grandin has used such comparisons extensively in her work, arguing that at least some autistic people, including herself, engage in “visual thinking patterns [that] probably resemble animal thinking more closely than those of verbal thinkers” (Thinking in Pictures 187). Grandin’s comparison of autistic thinking to animal thinking stems from an effort to better understand how autistic people are different from non-autistic people, and for her this difference is not dehumanizing but advantageous. Although Gabriel is more severely impaired than Grandin, I contend that Rankin’s comparisons of him to animals are similarly aimed at understanding markers of difference between Gabriel and herself or the reader. Rather than discounting Gabriel as a person, Rankin acknowledges both his humanity and his enminded and embodied difference. As she asserts shortly after explaining her use of the word “idiot,” “Above all it is necessary to remember that we are talking about individuals. … They are people in their own right who, most
Importantly, show us there are many ways of being human” (6). Rankin’s descriptions of Gabriel that extend beyond the normative may be jarring on the surface, but they also make space for the kind of “ways of being human” that Gabriel personifies.

Rankin makes clear that the relational story she tells of Gabriel and his family cannot end with the closure that conventional narrative requires. Real life is disruptive, not only because of Gabriel’s autism, but because of many other uncontrollable factors, such as the sudden death of Rankin’s husband Neil, which throws the family into disarray and hastens Gabriel’s move to a residential facility. Like Osteen, Rankin blurs the lines between able and disabled, describing the family as disabled by life with Gabriel’s severe autism: “One got used to it like one might get used to having only one arm—learning to make do in all sorts of ways, even forgetting about it a great deal of the time, yet wistfully aware one was never going to become a concert pianist” (83-84). This statement suggests that not only Gabriel but those in his life are affected—disabled—by his difference; however, it also acknowledges the fact that challenges, of which disability is one example, are realities of life that must be dealt with not only personally but in family and social relationships. Neil’s death is another of these realities. In both cases, Rankin must face the difficulties that come along with each challenge, move through it and accept that life is different than it might have been, and may not meet normative expectations, but it is a life story nonetheless, and worthy of narration that is faithful to its difference. In her final chapter Rankin writes, “[T]he reader would be forgiven for hoping perhaps, as I also once did, for some unexpected turn of events—a wonder drug or a new therapy and therefore a new Gabriel. It hasn’t happened, but is that to say his is a meaningless life and not worth the telling?” (205). I echo Rankin’s insistence that real
life is worth the telling, whether or not it fits the norm. Narratives such as hers open the
door to more narratives with alternative trajectories that reflect real experience,
indeterminacy, and nonnormative personhood.

**Conclusion**

In this chapter, I have sought to demonstrate how parent memoirists approach
some of the difficulties of narrating the life stories of their children with severe autism,
and to explore the potential for such stories to expand understandings of communication,
personhood, and narrative. As they seek to represent sons and daughters with autism who
are largely nonverbal, many parent writers make use of rhetorical listening in their efforts
to interpret and mediate their children’s nonverbal modes of communication, or
embodied rhetoric. Parents such as Mark Osteen make efforts to use rhetorical listening
in a way that helps to acknowledge the personhood and nonnormative enmindedness of
the autistic child; others, such as Kim Stagliano, show less attention in their narratives to
the individuality of their children with autism, emphasizing instead the need for a cure to
normalize people with autism so that an idealized relationship between the individual and
normative society can be restored. The potential of rhetorical listening in parent memoir
is to create a sense of relationality, both in life and in text, that encourages recognition of
the personhood and selfhood of those who do not meet standard conceptions of what it
means to be human.

As parent writers seek to attend to and interpret their autistic children’s alternative
modes of communication, they also seek to shape their story in a way that reflects
nonnormative experience, embodiment, and enmindedness. Stories of life with severe
autism seldom fit into traditional narrative models, including Frank’s recovery, quest, or
chaos narratives of illness and disability. Instead, such parent narratives reflect the chaos, or rather the disorderliness, of life with autism that itself does not fit ideals of home or family life. Unlike Frank’s “chaos,” however, life with autism is neither unlivable nor unnarratable, but instead requires different, and less restrictive, narrative forms. These narratives, then, tend to fall outside the boundaries of traditional narratives, but just as rhetorical listening can help make space for autistic people with nonnormative forms of communication and enmindedness, unconventional narratives about autism can help make room for stories of nonnormative individuals and families. While Michael Blastland’s text seeks to follow the quest model, its inability to do so suggests that such models are insufficient and in fact inappropriate for narrating life with autism. Kate Rankin’s narrative moves even further away from conventional narrative into indeterminacy, and in so doing works to make room for lives and persons affected by severe autism who, with all of their challenges and differences, are still worthy of inclusion in both narrative and personhood. In seeking to tell stories that reflect their own and their children’s relational experiences, these parent memoirs have the potential to forge new possibilities for stories of life with autism, unhindered by narrative convention.
Chapter 5
Autistic Autoethnography: Articulating Self, Locating Culture

Introduction

In Oliver Sacks’s profile of Temple Grandin in the title chapter of his 1995 book *An Anthropologist on Mars*, he quotes Grandin as follows:

> She said that she could understand “simple, strong, universal” emotions but was stumped by more complex emotions and the games people play. “Much of the time,” she said, “I feel like an anthropologist on Mars.”

(Sacks 259)

Grandin’s comment suggests that she feels herself to be so different from the majority of people around her that it seems as though they are part of a different culture, one that she has spent much of her life studying and learning to understand. Sacks emphasizes this observation, just one of many Grandin makes throughout the several days he spends following and interviewing her, likely because of his own view of himself as a sort of “neuroanthropologist, in the field” (xx), as he describes himself in his preface to the volume—a neurologist studying the lives and experiences of people with various neurological disabilities. Sacks stresses the limitations of the “observation of behavior, from the outside” and seeks instead to use an “intersubjective approach” (xx) to better understand neurologically diverse individuals like Grandin. While his intersubjective approach is a constructive one, highlighting relationality to an extent, and he hopes that

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43 When I discussed this essay with an undergraduate literature class, the students surprised me by interpreting the idea of “an anthropologist on Mars” somewhat differently. Since there are no people on Mars, they said, one cannot effectively be an anthropologist there; it would be a futile endeavor. I had not thought about the phrase in that way, nor do I think this is the sense in which Grandin or Sacks uses it. The suggestion of futility, however, is an interesting one to consider in terms of the attempts (or resistance) of people with autism to learn to understand, or fully join, non-autistic culture.
Grandin can see him as “an anthropologist of autism, of her” (292), he still frames Grandin and the other subjects of his book as patients, and their differences as deficits. His account, then, is not a neutral ethnography of Grandin as a person, but a neurologist’s analysis of a patient with autism. Grandin’s own writings, including her autobiographical texts published in 1986 and 1995, provide different, and more complex, insights into her own experience and her relationship to the world around her than can Sacks’s medically-based account. Rather than being anthropologists of others, seeking to understand the ways of mainstream, non-autistic society, Grandin and other autistic life writers might better be seen as autoethnographers—amateur anthropologists studying and explaining themselves and their own sense of culture and identity.

Because people with autism are seen as significantly different from the norm, narratives and writing styles by autistic writers that are recognizable to nondisabled readers have often been viewed with suspicion. General consensus is that Temple Grandin’s 1986 Emergence: Labeled Autistic (coauthored with writer Margaret Scariano) was the first published account of life with autism. Sacks expresses the consternation with which this and other early texts were received: “When I first read [Grandin’s] 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” (253, emphasis original). Similarly, autism researcher Bernard Rimland’s foreword to Emergence shows his own reluctance to accept Grandin’s story: “In recent years autism has become fashionable, and the term is vastly overused. Only about one-fourth of the people who tell me that they are recovered autistics seem to
me to be probably correct. In Temple’s case, her voice and her unusually direct manner persuaded me that she was a recovered (or recovering) autistic, but the content of her message made me skeptical” (Rimland, “Foreword” 1). Rimland is “persuaded” that Grandin is genuinely autistic by the nonnormative aspects of her speech and behavior, but the apparently normative aspects of her story provoke his suspicion, either that she is not autistic or that she did not actually write the book. He obviously overcomes his skepticism to endorse Grandin’s book, but his suspicion, from the perspective of a professional, might raise doubts and reinforce preconceptions about autistic ability and nonnormativity for readers as well. Dominant conceptions of autism prior to the publication of Emergence did not allow for the type of self-consciousness and self-representation that Grandin demonstrates in her text; for example, Uta Frith and Simon Baron-Cohen’s arguments about autistic people’s lack of a “theory of mind” that would allow them to delineate clearly between themselves and other people would call into question the sort of social awareness and self-analysis in which Grandin engages. Critics such as John Duffy, Rebecca Dorner, and Melanie Yergeau have pointed out the ways that the theory of mind approach works to push autistic experience outside the realm of the normative. As Duffy and Dorner comment, for Baron-Cohen, “[t]he autistic mind…is so radically alienated from ‘normal’ modes of thought and communication that only through acts of great imagination can we, ‘normal’ people, begin to understand it” (208). Like Duffy, Dorner, and Yergeau, I argue that while in many ways unique and interesting, autistic experience does not need to be made alien to non-autistic experience, and that the use of relationality, either through collaborative writing or through the construction of narratives and identities that are built upon relationships with others,
allows for recognition of the common, “human” aspects of autistic life stories and identities, along with the recognition of the qualities that make autistic individuals unique.

As I will argue in this chapter, autobiography and self-advocacy by autistic people have the potential to contribute significantly to conceptions of autism and of individuals labeled as autistic by calling attention to the role of relationships in the construction both of life stories and of the personal and cultural identities of people with autism. Autistic life writers can potentially subvert expectations and preconceptions of themselves and their abilities not only by the stories they tell, but also by the ways that they present those stories and demonstrate their existence in relationship with other people, often challenging common narratives of people with autism as isolated, uncommunicative, and unable or uninterested in connecting with the social world around them. In making use of relationality in the telling of their life stories, autistic life writers create a space in which the normative and nonnormative aspects of their identities can coexist, calling attention to the commonalities between autistic and non-autistic people as well as the differences in ability and experience that set people with autism apart. I will examine here several autobiographical texts by writers with autism which I see as autoethnographic. While I do not claim that these texts explicitly use anthropological methods of ethnography, I do maintain that they perform important work by providing valuable insight into the identities and cultural relationships of individuals with autism. Information about autism from “outside” sources, including the medical establishment and advocacy and research organizations (such as Autism Speaks, currently the most influential), have their own kinds of value and are accorded a certain level of sociocultural legitimacy. However, the
texts generated by autistic people themselves, in response to others’ views and treatment of them, are invaluable in establishing these subjects’ abilities and rights to speak for themselves and in challenging misconceptions about those with autism and other disabilities, particularly developmental disabilities that may complicate communication and self-representation. In addition to communicating autistic individuals’ understanding of themselves to others, the autoethnographic accounts of people with autism open the door to recognizing them as members of culture(s)—the culture of people with autism; the culture of their family, friends, and community; the broader culture and society of which they are a part—in opposition to the conventional view of autistic people as isolated from others, what Douglas Biklen calls “the myth of the person alone.” As Kamran Nazeer observes in his autoethnographic work Send in the Idiots, which I will discuss further below, “The term ‘autism’ derives from the Greek autos, meaning self. What joins all of the preconceptions…which have recurred throughout the stories of my former classmates, is that they derive from the same belief—that autistic people are themselves only, self-enclosed and sealed off to the world” (228). In contrast with this notion, the autoethnographic texts which I will examine here demonstrate from an “inside” perspective that many autistic people, far from being “self-enclosed and sealed off,” are connected, and interested in developing connections, with other people, autistic and non-autistic. Autistic people are in relationship with others in perhaps nonnormative ways, but they are, and often desire to be, part of the culture and community around them, and the type of writing that I see as autoethnographic enables a recognition of this sort of cultural presence. More broadly, autoethnographic writing about autism also
expands the possibilities for life writing about autism and disability, and expands both literary and anthropological understandings of what autoethnography can be and do.

Autoethnographic Writing: What Is It and What Can It Do?

I approach the concept of “autoethnography” from a literary background, not a strict anthropological one. However, both literary notions of self-representation and anthropological ideas about culture are at play in my classification of these autistic autobiographical texts as autoethnographic. Scholars of both literary autobiography and anthropology have made use of this term in a variety of ways to describe a type of autobiographical writing that explores the experience of a particular cultural or social group from an insider’s perspective. G. Thomas Couser, in particular, has applied the term autoethnography to disability autobiography, explaining that “disability autobiography is often in effect a post-colonial, indeed an anti-colonial, phenomenon, a form of autoethnography…” (“Disability” 401). Some scholars of postcolonialism and anthropology have used the term autoethnography to examine how oppressed populations, such as women of color in the former colony of Mauritius (Françoise Lionnet), or members of the Pan-Mayan movement of Guatemala (Kay B. Warren), have narrated their experiences of colonization and oppression in liberatory ways. Although disabled people do not literally constitute a separate cultural or ethnic group from the nondisabled majority, in many situations both historical and contemporary, people with disabilities occupy a similar position to that of oppressed cultural minorities. Couser offers several pertinent examples of the “colonization” of the disabled: “[C]onsider the leper colony. … Disabled people have been subjected to the same genocidal practices—sterilization and execution—as the ethnically and racially different, and the
institutionalization of people who are mentally retarded or mentally ill amounts to a kind of internal colonization” (*Signifying Bodies* 90). In addition to these dramatic examples, there are many more subtle ways in which those with disabilities, particularly those with autism, are set apart from mainstream society and classified not only as different from the norm but at times, either implicitly or explicitly, seemingly less than human.44 Autoethnographic writing carries the potential for marginalized and underrepresented populations, which undoubtedly includes people with autism, to gain recognition as human persons and unique selves by affirming that they have stories to tell (and that they are capable of telling them), and to resist repressive treatment and misrepresentation by others.

Broadly speaking, autoethnography can be understood as ethnographic writing with some degree of self-reference. However, the term has been applied in a number of specific ways, so I want to situate my own definition in the context of prior uses. In Mary Louise Pratt’s literary discussion of a seventeenth-century letter by a native Peruvian to the King of Spain, she defines an autoethnographic text as one “in which people undertake to describe themselves in ways that engage with representations others have made of them. … [A]utoethnographic texts are representations that the so-defined others construct *in response* to or in dialogue with those texts” (35, emphasis original). Although Pratt’s discussion deals specifically with cultural others, South American natives conquered by Europeans, this description fits quite well with what I consider

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44 Michael Blastland, whose memoir *The Only Boy in the World* I discuss in Chapter 4, engages with these sorts of questions in examining his autistic son Joe: “What we see when peering into his mental machinery is a child possibly lacking almost all the philosopher’s traditional definitions of what it is to be human. … How different can you be, how many fundamentals can you lack, and still be human?” (7). It can be difficult or impossible for others to recognize or accurately represent a person with autism when that person’s very humanity is called into question.
many autistic autobiographers to be doing: engaging with and resisting stereotypical, inaccurate, or harmful representations of people with autism, and constructing their own representations of themselves in response. Whether explicitly or implicitly, autoethnographers demonstrate awareness of the ways in which they, or those with whom they identify, have been represented by others, and consciously write in response to those representations. Françoise Lionnet’s use of autoethnography in her study of race and gender in women’s autobiography is slightly different; using Zora Neale Hurston’s Dust Tracks on a Road as her model, Lionnet describes autoethnography as “the defining of one’s subjective ethnicity as mediated through language, history, and ethnographical analysis; in short,…a kind of ‘figural anthropology’ of the self” (99). Lionnet’s definition places more emphasis than does Pratt’s on the anthropological method of cultural analysis; this definition extends beyond representation to analysis of oneself and one’s culture.

Anthropologist Deborah Reed-Danahay, in the introduction to her edited collection Auto/Ethnography, provides a useful summary of three similar yet discrete senses in which autoethnography has been used:

Autoethnography stands at the intersection of three genres of writing which are becoming increasingly visible: (1) “native anthropology,” in which people who were formerly the subjects of ethnography become the authors of studies of their own group; (2) “ethnic autobiography,” personal narratives written by members of ethnic minority groups; and (3) “autobiographical ethnography,” in which anthropologists inject personal experience into ethnographic writing. (2)
In the first two autoethnographic genres named here, the “native” or traditional subject of the ethnographic study becomes the narrator of the text, a reversal of, or challenge to, the traditional ethnographer-subject dynamic. The first definition, “native anthropology,” is probably the most literal sense of autoethnography, since it involves the writer doing actual ethnographic study of the group to which he or she belongs; this is consistent with what Lionnet sees Hurston as doing in her text. Donna J. Young makes use of this sense of the term for her anthropological work with a society and culture of which she herself is a part (“Writing Against the Native Point of View”). The second definition, “ethnic autobiography” (or, as Couser adapts it, “ethnographic autobiography” [Signifying Bodies 95]), suggests a more literary and less strictly anthropological text which focuses on the personal experience of the individual, while still providing insight into a cultural group that has ethnographic value; Pratt’s definition is comparable to this one. Finally, the third definition places the emphasis of the “auto” (self) upon the anthropologist, still an outsider to the group being studied and described, who incorporates his or her own personal experience into the ethnography of the “other.” Carolyn Ellis, Tony Adams, and Arthur Bochner describe the trend toward this approach by anthropologists who “wan[t] to concentrate on ways of producing meaningful, accessible, and evocative research grounded in personal experience, research that would sensitize readers to issues of identity politics, to experiences shrouded in silence, and to forms of representation that deepen our capacity to empathize with people who are different from us.” While this last is a valuable development in the understanding of the anthropological research method of ethnography, here I am most interested in the first two definitions, which emphasize the autobiographical and autoethnographic voice of the marginalized subject him- or herself.
For the purposes of her text, Reed-Danahay settles upon a definition of autoethnography as “a form of self-narrative that places the self within a social context,” allowing that it may be performed by an anthropologist, by another non-professional ethnographer, or by “an autobiographer who places the story of his or her life within a story of the social context in which it occurs” (9). It is this last iteration that I find most useful for my own discussion of autoethnography in the context of autistic autobiographical writing.

In my analysis, I am interested in autoethnography primarily as autobiographical writing that engages with the social and cultural context of the writer’s life, and responds to representations of the writer and his or her identified social and cultural settings through self-representation. While a strict anthropological approach might privilege, as does Heewon Chang, “autoethnographies that handle autobiographical data with ethnographic methodology and intent” (56), I find autobiographical writing that engages in representation and analysis of the self and the self’s positioning within culture(s), and that consciously seeks to respond to others’ representations of the self and cultural group, accomplishes the goals at the heart of autoethnography. Identification as a literary autobiography or memoir should not disqualify a text from being considered autoethnographic; Reed-Danahay’s explanation, cited above, as well as Ellis, Adams, and Bochner’s recognition of the literary elements and potential of autoethnographic writing, make space for the non-expert, literary autoethnographic text. While anthropological ethnography may be considered more “objective” in that it has an outside researcher recording the perspectives of many members of a given community, the sort of autoethnographic writing I am interested in here offers a more direct, more detailed, and, potentially, more nuanced insight into the experience of the writer through a first-person
perspective and representation that is not often made available through traditional ethnography. I call the works of autism autobiography that I will examine here “literary autoethnography” or merely “autoethnographic” to acknowledge the difference between these and what might be considered autoethnographies in a methodological sense. With or without anthropological method or training, these texts can perform important work in representing the writer’s self and cultural location in response to, and in conversation with, existing representations of themselves and of autism produced by others.

As one might suspect, a large number of autism autobiographies engage at least somewhat with others’ representations of them or of people with autism more generally, and therefore many—though certainly not all—works of autism autobiography can be considered autoethnographic to some extent. Life writing by people on the autism spectrum almost invariably seeks to tell one’s story from the “inside,” though the extent to which “inside” meets “outside”—the space in which autoethnography occurs—varies. Some texts, such as Donna Williams’ *Nobody Nowhere*, focus primarily on narrating one’s own experience, rather than drawing connections between self and others, or engaging with outside representations of the self or of autism (this may be in part because Williams seems not to have received an autism diagnosis until she was largely finished writing the book). So there is likely some level of autoethnographic quality in most autistic life writing, but I argue that the texts that I examine in this chapter are examples that place particular emphasis upon relationships and identity and are more explicit about their engagement with existing representations. The autistic writers of these texts position themselves within social and cultural settings, they recognize and respond to others’ representations of them, and they demonstrate ways in which they relate to other
people, both autistic and non-autistic. While some texts are more clearly identifiable as autoethnographic than others, I would argue for the recognition of autoethnographic moves wherever they arise, and would call attention to the effects of these moves for understandings of the life stories of individuals with autism.

It is important to note that no individual’s life story or autoethnographic text is fully representative of an entire group; this is true in regard to both traditional cultural ethnography and to the kind of autoethnographic texts about autism that I identify here. Certainly all people with autism are not the same; not only is there a wide variation in the ways in which autism is manifested and experienced, but all people with autism are individuals with unique personalities and characteristics, and each person may interpret his or her autism and its meaning in different ways. Mark Osteen, discussing issues of representation, writes that “no one—neither autistic or [sic] non-autistic—speaks for everyone in the autism community. Therefore, it is essential to attend to a range of voices, not just the loudest ones…. In so doing, we may come to understand…that autism isn’t one thing but many things, that there is no ‘autism,’ per se, but autisms” (298). There is certainly no individual within any community who “speaks for everyone”; however, it is important that someone—and, preferably, many—within that group speaks from personal experience so that those outside the group may develop a better understanding of its members, its group identity, and how that group does connect, and might connect more effectively, with the broader social and cultural community. By focusing on the three autoethnographic texts in this chapter, I do not mean to suggest that these authors represent all people or writers with autism, or that their accounts are more important or in some way better than others. Rather, I see these as three valuable
examples of autistic autoethnographic writing that have significant differences from one another, demonstrating the variety of experience represented within autistic life writing and the diverse ways in which relationality is used to make space for both normative and nonnormative aspects of experience.

**Autism and Culture**

While autoethnographic writing can be important and productive for any marginalized social or cultural group—just as ethnographic research and writing is used to study a broad variety of groups in anthropological work—\(^45\) it is particularly useful for autistic self-representation, which is frequently complicated by difficulties with communication and social interaction with others. Public perceptions of autism since its diagnostic beginnings have been largely controlled by professional, “expert” opinions of one kind or another. In the early days of autism’s history, Leo Kanner and Bruno Bettelheim were the most influential of these experts, disseminating the psychogenic hypothesis of autism—that is, that autism was a disorder caused by psychological trauma, most often attributed to parental neglect. As I discuss in Chapter 2 in relation to Clara Claiborne Park’s parent memoir *The Siege*, this approach silenced both autistic people and their families and offered little in the way of educational or treatment options for those living with autism. As the psychogenic explanation gradually gave way to a recognition that autism is a product of neurological differences and, most likely, genetics, some of the blame of families by professionals fell away, but the main source of knowledge about what autism is and how it should be viewed has continued to lie with the “experts.” These experts include medical professionals and researchers, therapists,

\(^{45}\) Philippe Bourgois’s ethnographic work on drug use, drug dealing, and homelessness in East Harlem provide one fascinating and somewhat unconventional example of the broad range of populations deemed worthy of study (see *In Search of Respect: Selling Crack in El Barrio*).
and educational professionals who determine and enact the “rules” identifying and defining autism. Many scholars, most notably Majia Holmer Nadesan and Douglas Biklen, have pointed out the great extent to which autism as a condition is socially and culturally constructed, and the ways in which perceptions and treatment of autistic people are shaped by such constructed ideas about autism. As Nadesan explains,

To make the claim that the idea of autism is socially constructed is not necessarily to reject a biological basis for the conditions or symptoms that come to be labeled as “autistic.” Rather, I use the phrase “socially constructed” to point to the social conditions of possibility for the naming of autism as a distinct disorder and to the social conditions of possibility for our methods of interpreting the disorder, representing it, remediating it, and even for performing it. (2)

Nadesan’s application of “socially constructed” here makes an important point about the ways that the diagnosis and label of autism have developed as the result of a particular confluence of social, historical, and cultural factors, and therefore, that “there is no fixed, universal biological truth to be located” about autism (Nadesan 7). Similarly, Biklen points out that characterizations such as “autism” or “autistic” are labels, and not necessarily descriptions of an inherent reality; he describes his “recognition that autism is a concept developed and applied, not discovered” (12, emphases original). This is not to undermine the reality of the physical, mental, or social experiences of people with autism; however, it is valuable to recognize the speculative and often unverifiable nature
of the available ways of understanding autism, and to see these ways “not as natural, but as social constructions” (Biklen 13, emphases original).\footnote{In addition, Biklen describes many of the theories of autism, including mental retardation, “mindblindness,” lack of central coherence, and difficulty with executive function, as “metaphorical.” For instance, he writes that “the metaphorical nature of the mindblindness representation goes unacknowledged. [Uta] Frith and other researchers have not actually located a physical mechanism. Thus reference to a mechanism, a ‘component of the mind’” (p. 19), or to what another person ‘thinks’…can only be metaphorical. That it is easy to consider other possibilities should give readers pause about the explanatory power of mindblindness theory” (38). In other words, the lack of biological verifiability of most of the theories that seek to explain autism make them far less definite than they are generally accepted as being.}

The evolution of autism’s description in the \textit{Diagnostic and Statistical Manual of Mental Disorders} (DSM), published by the American Psychiatric Association (APA), exemplifies the unstable nature of even “expert” understandings of autism. Despite its “discovery” by Kanner in the 1940s, autism did not appear in the APA’s official diagnostic manual until 1980, in the DSM-III, and Asperger’s syndrome was not added until the DSM-IV, published in 1994. The most recent iteration of the manual, known as DSM-5 (2013), has removed Asperger’s syndrome as well as childhood disintegrative disorder and PDD-NOS (persistent developmental disorder, not otherwise specified) as separate diagnostic categories, instead using the term Autism Spectrum Disorder (ASD) as an “umbrella disorder” for all areas of the spectrum. In its fact sheet on the ASD updates in the DSM-5, the APA suggests that there will be little change as to who receives a diagnosis of autism under the revised system, citing an October 2012 study in the \textit{American Journal of Psychiatry} which found that “DSM-5 criteria identified 91 percent of children with DSM-IV PDD diagnoses, suggesting that most children with DSM-IV PDD diagnoses will retain their diagnosis of ASD using the new criteria.” However, other studies, including one released by the Centers for Disease Control and Prevention (CDC) in January 2014 (Maenner \textit{et al.}), suggest that “as many as 20 percent
of people found to be on the autism spectrum using previous criteria would lose this designation with the DSM-5” (Wright), and an article in the American Academy of Child and Adolescent Psychiatry predicts that many of these people may receive a new diagnosis of social communication disorder (SCD) (Kim et al.). The effects of the new system of diagnosis for people with autism and their families remains to be seen, and this uncertainty emphasizes how much—from diagnosis to the ability to procure services—is dependent upon constructed and evolving diagnostic criteria. The evolution of the DSM’s definition of autism reinforces Biklen’s recognition of autism as a developing concept that is applied in varying ways to particular individuals, rather than an inherent reality that has been discovered.

Because of the unstable nature of autism as a diagnosis and as a label that is applied to certain individuals, it is important to consider the social and cultural implications of autoethnographic writing about life with the autism label. I do not necessarily wish to claim that autism is a culture of its own, in some way entirely separate from non-autistic culture. In traditional anthropological definitions of ethnography, the ethnographer seeks to understand and interpret the culture of the subjects of his or her ethnographic study; often those subjects’ culture is figured as different and other. Young characterizes this earlier attitude as follows: “Like Conrad’s Marlowe, whose journey up the Congo River ‘was like travelling back to the beginnings of the world’…the anthropologists’ journey to other places was cast in metaphors and tropes that implied a radical otherness somehow lost in time” (207). There have certainly been shifts in approaches to ethnography over the past few decades, particularly a growing sensitivity to the perspective of the ethnographic subject and greater attention to
groups and individuals who are not (or are not approached as) “radically other.” As Couser observes, “In the last several decades…the nature and authority of ethnography has been called into question…. To a large extent, this is a function of concern among professional anthropologists about the complicity of ethnography in Western imperialism” (Signifying Bodies 89). This rethinking of the implications of the treatment of ethnographic subjects is a significant factor in the growing attention to the forms of autoethnography described above, and approaches to studying and writing about social and cultural others continues to develop. Luke Lassiter identifies two ongoing goals of contemporary ethnography: “[F]irst, the call to illustrate cultural diversity and the power of culture in people’s lives and, second, the call to teach us something about ourselves—as individuals, as groups, and as societies (wherever they may be situated)” (91).

Understanding self and others, as well as social and cultural relationships between individuals and groups, remains at the heart of the ethnographic—and autoethnographic—project.

So what is culture, and how might it be defined for the purposes of autoethnographic texts about life with autism? Heewon Chang, in navigating the meaning of autoethnography, offers the following definition: “[C]ulture is a group-oriented concept by which self is always connected with others” (13). She acknowledges the difficulty of answering the question “Where is culture located?”, observing that “[t]his question has been entertained since the beginning of anthropology as an academic discipline, and answers are divided into two groups: one argues that culture is located outside of individuals, and the other that culture is located inside people’s minds” (17). Chang resists the idea that culture is individualistic or somehow separate from a group
identity; however, she notes that cognitive anthropologists, such as Ward Hunt Goodenough, “assert that culture consists of cognitive schemas or standards that shape and define people’s social experiences and interactions with others” (Chang 21). While I agree with Chang’s point that how individuals form groups and relate to one another is an essential component of culture, I also find the cognitive approach compelling, particularly in regard to the sorts of differences in experience, communicative ability, and social interaction that often characterize people living with autism. People with autism are certainly members of a variety of cultural groups, but they also frequently have different ways of understanding or relating to others than do non-autistic people. It is important to recognize, then, the potential influence of autism (including differences in physical, mental, and social experience, as well as the effects of the autism label and others’ notions of what it means to be autistic) on autistic individuals’ understandings of themselves, understandings of others, and relationships to their own and other cultural groups.

At the same time, individuals with autism are by no means entirely separate from other cultural groups; it is likely most productive to see them as both/and—in some ways different or nonnormative as a result of their autistic characteristics, but also part of larger social and cultural groups that include many non-autistic people. It is not necessary, or even possible, in my view, to identify “autistic culture” as a distinct or unified group. For a variety of reasons, including misdiagnosis, lack of diagnosis, lack of educational or social support, or difficulties with communication, many people with autism may not have opportunities to be part of communities with others with the autism label. When autistic people do form communities with one another, this can be potentially
transformative, both for themselves as individuals with particular identities, and in terms of their ability to convey their own experiences and views of autism to others, in much the way that the autoethnographic texts I examine here do. Nancy Bagatell has done thought-provoking ethnographic research with local and internet-based autistic self-advocacy communities (see “From Cure to Community: Transforming Notions of Autism”). Autistic self-advocacy groups such as Autism Network International (ANI) and the Autism Self Advocacy Network (ASAN) have grown in their ability to speak to and be heard by those in power, advocating for autistic people through public policy work, communicating with federal and state governments, and working with other disability advocacy organizations. However, even within autistic self-advocacy groups, conflicts and differences of opinion arise about autistic experience and identity, problematizing the idea of a unified culture or community. In addition, and perhaps more significantly, the manifestations of autism can be so different as to seem like entirely different disabilities, leading to problems with applying a single label of “autism” or even “Autism Spectrum Disorder” to such a broad range of experience. My point is that I do not wish to paint all people labeled autistic with the same brush, and so I am not inclined to denote one particular group or experiential category as “autistic.” Instead, what I am interested in here is how autistic writers of autoethnographic texts speak for themselves in response to others’ representations of them and locate their own identities and cultural relationships with others. In addition to figuring out what it means to be autistic and how their experiences compare to others with the autism label, these writers seek to elucidate

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47 A recent example is ASAN President Ari Ne’eman’s testimony to the Neurological Devices Panel of the Medical Devices Advisory Committee of the Food and Drug Administration, urging the FDA to prohibit the use of aversive conditioning devices with people who have behavioral disabilities (see Ne’eman).
how they are connected to other cultural groups, including familial, national, ethnic, religious, school, and work communities.

While I am not interested in singling out an “autistic culture” per se, I do want to emphasize the importance of autoethnography in representing people with autism in ways that counteract potentially inaccurate and restrictive representations by “experts” and others. In representing themselves as individuals labeled autistic, autoethnographic writers have the potential to make their own presence as autistic people known, and to make this presence part of the ongoing conversation about and public awareness of autism. Stuart Murray, in his thoughtful book *Representing Autism*, argues for the need to consider “autistic presence” in the representation of individuals labeled autistic.\(^{48}\)

Autistic presence is a valuable concept, particularly because, as I have discussed in Chapter 3, “autistic voice” is sometimes viewed as an oxymoron due to the communicative disabilities of many people with autism (Yergeau). As Murray proposes, “The material nature of [autistic] presence, the excess it creates when confronted with any idea of what “normal” human activity or behaviour might be, stubbornly refuses to be reduced to any narrative—medical, social, or cultural—that might seek to contain it without reference to its own terms” (xviii). Autistic presence might be seen as the “realness” of autism as experienced and represented by people with autism themselves. Autoethnographic writing is certainly one mode of establishing and conveying autistic presence to others and, while autistic presence is not the same as an autistic culture, the experience of people labeled as autistic contributes to the way they understand themselves and others and relate to and take on cultural identities. Ultimately, then, I will argue that the following texts can be read as autoethnographic works in productive ways

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\(^{48}\) See Chapter 1 for further discussion of autistic presence.
that offer self-representations of autistic presence and help further the project of “understanding autism on its own terms” (Murray 12). Such a project is a complicated one, since autistic experience does not fit neatly into normative categories, and because the diversity of autistic experience may lead to inconsistencies among self-representations. However, it is in these complications and inconsistencies that the “realness” of experience, of autistic presence, may be found. As Young notes, there is no “all-encompassing native point of view” (206) to be found in any group of ethnographic subjects. Autoethnographic writing about autism does, however, offer unique points of view that cannot be found in “outside” or “expert” perspectives on autism and autistic experience and so supplement such perspectives in essential ways.

I will discuss three example autoethnographic texts here: Dawn Prince-Hughes’s *Songs of the Gorilla Nation*, Kamran Nazeer’s *Send in the Idiots*, and Ido Kedar’s *Ido in Autismland*. These texts address the writers’ perspectives on their own experience and positioning as individuals with autism in a sociocultural setting; they respond to others’ representations of themselves, thereby defining life with autism from their own points of view; and they make cultural connections by relating, in a variety of ways, to others with autism, while also seeking to better understand, communicate with, and forge relationships with non-autistic people. Through these accounts, non-autistic readers may gain new insight into the experiences of those labeled as autistic, both the aspects that are recognizable to non-autistic experience and those that may diverge significantly from the norm. The construction of the writer’s identity in relationship with others in these autoethnographic texts allows each writer to demonstrate the hybridity of life with autism, not entirely normative or entirely other, but a blending of the two.
Dawn Prince-Hughes’s lifelong interest and formal education in anthropology helps situate her memoir, *Songs of the Gorilla Nation: My Journey through Autism*, quite squarely within the category of autoethnographic writing. Although she does not use the word “autoethnographic” within this text, she does apply it to several other subsequently written articles, suggesting her own recognition of the suitability of this label for the type of writing she and other autistic writers are doing. In this sense, her writing is more explicitly autoethnographic than that of many other autistic writers. Prince-Hughes writes of her interest as a child in early human civilizations, and her practice of interviewing other children about their thought processes and behavior. In a way very reminiscent of Temple Grandin’s self-characterization as an “anthropologist on Mars,” Prince-Hughes reflects, “After all, anthropologists lived among those whose ways of being were totally foreign to them in order to learn more about their culture. Though most of my fellow children couldn’t answer my questions, some gave me thoughtful answers and helped me begin to understand some facets of human behavior” (Prince-Hughes 46). Clearly Prince-Hughes is interested from an early age in understanding behavior, taking a pseudo-anthropological approach both to her own experience and that of the people around her. Prince-Hughes goes on to study anthropology in college and graduate school, earning a Ph.D. after completing a dissertation about “ancestral memory as a physical phenomenon…the possibility that our minds and memories are not specific to us as individuals but are part of a resonant fabric that informs our psychology and

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morphology” (183). Prince-Hughes is obviously quite interested in meanings of culture, individual and group identities, as well as the relationship between humans and non-human species such as gorillas, who play an important role in her journey, in her own life, and in her academic work.

Prince-Hughes explains that her story is one of finding “context,” which helps position her text within Reed-Danahay’s definition of autoethnography as autobiographical writing that “places the story of [the writer’s] life within a story of the social context in which it occurs” (Reed-Danahay 9). Prince-Hughes writes that her book “is about how I moved full circle from being a wild thing out of context as a child, to being a wild thing in context with a family of gorillas, who taught me how to be civilized. They taught me the beauty of being wild and gentle together and as one” (1). Prince-Hughes’s lesson of fostering the coexistence of wildness and civilization echoes the larger theme I find in autistic autoethnographic writing, of creating a space for the coexistence of nonnormative and normative aspects of experience and identity.

Finding “context” manifests itself in several ways in the text. First, Prince-Hughes tells the story of discovering that she is autistic, which does not happen until she is an adult. Getting a diagnosis of autism, specifically Asperger’s syndrome, in adulthood helps Prince-Hughes to put her own experience in the context of autism and to construct a better understanding of herself, both for herself and for those around her. Second, working with and getting to know the gorillas at Seattle’s Woodland Park Zoo helps her to develop a better understanding of social relationships, which have been a challenge for her throughout her life. Observing the gorillas and how they interact with one another and with the world around them helps Prince-Hughes to overcome some of
her social anxiety and to learn lessons that she can then apply to her relationships with other humans as well. By placing herself in a sociocultural context through a diagnosis of autism, and learning to develop social relationships with others, first gorillas and then, increasingly, other humans, Prince-Hughes negotiates and comes to define her own individual and group sociocultural identity. She finds commonalities between herself and non-autistic people—ways in which her experience is recognizable to others—while also identifying the qualities that mark her as autistic and “other.” In doing so, as her subtitle suggests, she journeys “through” autism—not, as in some descriptions, “out of” it and into “normalcy,” but perhaps the opposite. She explains,

When I speak of emerging from the darkness of autism, I do not mean that I offer a success story neatly wrapped and finished with a “cure”; I and the others who are autistic do not want to be cured. What I mean when I say “emergence” is that my soul was lifted from the context of my earlier autism and became autistic in another context, one filled with wonder and discovery and full of the feelings that so poetically inform each human life. When I emerged, I had learned—from the gorillas—far better how I could achieve these things. (2-3)

On Prince-Hughes’s journey, far from leaving autism behind, she instead better learns how to be autistic by placing herself in a new social and cultural context. This includes both a better understanding of how to be herself, taking on and applying the label of autism to her own experience, and a growing understanding of how to be in relationship with those around her. In finding context for herself, Prince-Hughes demonstrates her identification both with normative human society and with the nonnormative “other,”
which for her includes both autistic people and the gorillas who facilitate her emergence into autism and her own identity.

As she seeks to present herself and her positioning within context to readers, Prince-Hughes emphasizes the broadness of the category of “autism,” and seeks to validate the uniqueness of varied individual experiences—her own and those of others. She aligns herself, as in the passage above, with “others who are autistic” (3), emphasizing that individuals’ real stories may differ from dominant medical or popular portrayals, remarking that “[s]ome authors have been criticized because their stories do not adhere strictly to known patterns of autism” (7). This acknowledgment anticipates possible criticisms of her own text, and story, for not fitting readers’ expectations of what a person with autism looks or sounds like. Like critics of Grandin’s Emergence, readers of Prince-Hughes’s text may find her too educated, too well-spoken, or too successful to fit their preconceptions of autistic people. Drawing from her own experience, Prince-Hughes explains, “One of the reasons it took me so long to get a diagnosis is that beliefs about what autism is and what it looks like are often very narrow and, as a result, inaccurate. This, it can be argued, is the result of media portrayals of autistic people, which come off as one dimensional and made from a single template mold” (27). Many see Dustin Hoffman’s performance as autistic savant Raymond Babbitt in the 1988 film Rain Man as the epitome of such monolithic media portrayals, though autistic people’s responses to the film vary widely. While on one hand Prince-Hughes implies that all autistic people think the same way she does in not wanting to be cured, she also acknowledges that manifestations of autism are wide-ranging and that there is no “single template mold” into which all autistic people fit. Though resistance to a “cure” is a
prominent view among autistic people, certainly not everyone shares it, and both
Nazeer’s and Kedar’s accounts display notably different attitudes from Prince-Hughes’s.

Prince-Hughes, though she acknowledges that her own experience of autism “is
both like and unlike other people’s autism” (1), primarily focuses her account on her own
process of finding context and locating her personal and cultural identity. She is
particularly concerned with the subset of autistic people whose experiences are similar to
her own—Asperger’s syndrome, diagnosed later in life—and the ways public perceptions
may eclipse people like her who have developed skills enabling them to function fairly
successfully in mainstream society. Expectations that people with autism should not be
able “to interact socially, go to college, hold a job, [or] have a relationship” suggest that
people like her who have been able to accomplish these things “can’t possibly be autistic”
(31). Prince-Hughes’s story of how she developed these skills and accomplished these
tasks—often through long, difficult processes—demonstrates that she and others with
similar experiences may undergo “silent desperation and psychological struggles” (31) as
they seek to appear “normal.” For instance, Prince-Hughes explains her journey to
receiving a Ph.D. in anthropology, from struggling in school from a young age, suffering
both teachers’ and students’ abuse and rejection, and dropping out at the age of sixteen,
to becoming homeless for several years and working as an exotic dancer to support
herself. Like many autistic people, her lack of skills and abilities made it difficult for her
find employment; as she recounts, “I had no life skills and no clue how to survive. I had
no idea how to go about getting a job, and even if I had, I couldn’t read maps well, I got
lost easily, and I was terrified of talking to interviewers face to face, not to mention the
fact that I had no work experience” (64). It is not until she happens across the gorillas on
a trip alone to the zoo that Prince-Hughes finds motivation and, gradually, a way to continue her education and find a vocation for herself—studying the behavior of the gorillas, who come to teach her about relating to other people.

One of the preconceptions that Prince-Hughes directly engages with is the notion that autistic people do not experience emotion in ways that are recognizable to normative human experience. Prince-Hughes observes that “[m]any people…lay and professional alike, believe that all people with autism are by definition incapable of communicating, that they do not experience emotions, and that they cannot care about other people or the world around them,” quickly countering, “My experience, both personally and with others like me, is that in many cases quite the opposite is true” (31). She supports her careful claim with explanations of why she and other autistic people behave the way they do, often keeping their feelings to themselves or only expressing them in personal writing; her text makes the case for the positive potential of this sort of personal writing being made available to help educate others. As she gets to know the gorillas, for instance, getting a job working with them and eventually embarking on a research project studying their behavior, she demonstrates her ability to care deeply about them, to care increasingly about other human beings as she learns to better understand and interact with them, and to be attentive to the world around her and her own part in it. Her emotional connections with the gorillas and her response to the death of one gorilla, Congo, in particular, is very striking: “I stood there frozen. Some part of me believed that if I didn’t move, I could just hold my place, like a bookmark, so that someone could open time and move back to the pages he had missed, perhaps to put the book down again and forget to go on to the part where the world shattered” (158). Prince-Hughes communicates quite
clearly and poetically here, evoking the feelings many people have upon learning of a loved one’s death, and expressing her own emotional connection with another being. In telling this story and sharing her reaction to the death of someone she loved, Prince-Hughes implicitly challenges the presumption that autistic people do not feel emotions or make connections with other beings; her poetic writing also refutes the related notion that autistic people are not able to think or write imaginatively.

As she challenges common preconceptions about people with autism, Prince-Hughes traces her own process of coming to identify as autistic—of finding the “context” that enables her to understand who she is and to come to terms with her place in her social and cultural setting. Although she was different from others and often difficult as a child, she did not receive a diagnosis, and her family does not seem to have sought one; Prince-Hughes explains, “I come from a working-class family descended from coal miners, and working-class people more often than not don’t have the money to spend on expensive diagnoses, which they often see as having little practical value. … [I]t is no surprise that my behavior was simply tolerated” (168). In other words, there was no perceived need for a diagnosis in the context of the culture in which she was raised; however, as an adult, Prince-Hughes feels the need for a diagnosis to help her explain her difference to herself and to others. She tells about a younger relative who has been diagnosed with Asperger’s syndrome, which leads to Prince-Hughes’s frustration that he now receives understanding from others that she does not: “His intelligence was focused on as a great strength and the thing that could save him. He was loved and understood. Although I experienced a vicarious joy at his new window of knowledge and understanding, another part of me was angry that I had not had the same window” (171).
Her own suspicion that she, too, has Asperger’s makes her envious of the label that helps explain her relative both to himself and to others. Eventually she seeks and receives a diagnosis, which helps her learn to cope with her autism and its manifestations. For her, the label of “autistic,” far from being a stigma, is freeing. She recommends that others look past the stigmatizing aspect of diagnostic labels, and urges parents to share their children’s diagnoses with them, explaining, “While they try to come to understand themselves without having a name for their condition, other people definitely are labeling them—and usually without the compassion that a real education would bring” (174, emphasis original). For her, being “labeled autistic” enables her to better understand and explain the nonnormative qualities of herself, and creates a sort of cultural connection to other people with autism—even if only through common labeling—that helps give her a place, community, or sociocultural group, to which to belong.

Importantly, through her emphasis on connections with others, both ape and human, Prince-Hughes works to undermine the belief that autistic people want to be isolated from others or are locked within their own world. Instead, she stresses that though social interaction and connection may be more difficult for people with autism, it is something that they, like most people, desire and need. The gorillas ease the way toward connection because, for her, they are more understandable and approachable than are most humans. She explains,

The restoration of spirit that I achieved through belonging—first with the gorillas, and then to a group of people like myself at long last—is no different for autistic people than it is for all other people who need companionship. It is this sense of companionship that validates one’s
experience from afar. It is crucial for our sense of well-being and the awakening of our potential. But it is also, after this kind of healing, essential for our emergence as individuals. (33)

Prince-Hughes plays again here on the term “emergence,” so often used to suggest one’s “cure” or “recovery” from autism. Alternatively, she uses it to show growth, particularly her movement from the isolation of being different, not understanding why, and not being able to connect with others, to the “restoration of spirit…through belonging” that she finds through the context of understanding herself and connecting with others in some kind of community. This includes connecting with the gorillas through her extended work with them; connecting with people who share her interest in the gorillas as well as in anthropology; connecting with other people with autism through an online support group; and eventually, connecting with her partner, Tara, and building a family with her.

The gorillas offer Prince-Hughes a pathway into connection with others, in part because they, like autistic people, are different and misunderstood by many humans. Prince-Hughes watches zoo visitors jeering at the captive gorillas, whom they see as uncomprehending and savage, which she aligns with how autistic people are often viewed: “The gorillas don’t speak human language, look the way humans look, move the way humans move. They are stupid” (95). As she observes the gorillas, she sees many of her own traits in them, such as engaging in ritual activities (25), needing space between themselves and others (57), and perseverating on a particular task (148). However, she also sees traits in the gorillas that are more like other humans, and from which she can learn. She explains, “Because gorillas are subtle and unthreatening, I was able to look at them, to watch them, in ways I had never been able to do with human
people. Through this process I learned that persons are more than chaotic knots of random actions; I learned that they have feelings, needs for one another, and valuable perspectives, and that as people we are reflected in *one another*” (3, emphasis original).

Being able to watch the gorillas without feeling threatened enables her to build on her awareness of the feelings and behavior of others and to respond more appropriately to other people. She recounts, “By applying the bodily and verbal language components I had learned from the gorillas, I was beginning to have more social success; this led to less tension for me when I was in social situations, and that in turn enabled me to relax and read people better” (137). By becoming part of the sociocultural group of the gorillas, she also becomes a more integral part of human groups, including the academic world, where she successfully completes her doctoral degree, as well as the social world, in which she makes friends and begins a partnership that leads to a family and child.

Prince-Hughes’s identification with the characteristics of the gorillas that would be considered nonnormative in a human context helps her to better recognize and understand the qualities they, and she, share with normative human beings. Through her relationship with the gorillas, she begins to transcend the boundaries between normative and nonnormative, autistic and non-autistic, and even between human and animal, and to find her own unique positioning among those identities. Prince-Hughes’s autoethnographic account makes space for herself and others with autism to be both nonnormative individuals *and* members of normative communities.

*Send in the Idiots: Relationality, Normativity, and “Getting Better”*

Kamran Nazeer’s *Send in the Idiots: Stories from the Other Side of Autism* is in many ways a very different text from Dawn Prince-Hughes’s *Songs of the Gorilla Nation.*
While Prince-Hughes did not receive her diagnosis of Asperger’s syndrome until adulthood, Nazeer was diagnosed with autism as a young child and grew up with the context of this aspect of his identity. His autoethnography, then, is more focused on what autism comes to mean as one progresses through childhood and becomes an adult, and how relationships with others influence one’s sense of autism, culture, and identity. The two works also differ in the ways each might be classified as autoethnographic. While Prince-Hughes’s text might be seen as a sort of blend between Reed-Danahay’s categories of ethnic/ethnographic autobiography and autobiographical ethnography, especially because she is actually an anthropologist studying and reporting on her own life, Nazeer’s text would best fit into the category of “native anthropology” (Reed-Danahay 2), because it is primarily an ethnography of a group of which Nazeer himself is a part: adults who attended a particular school for autistic children in New York City in the early 1980s. Nazeer is one of the subjects on whom he reports, but his ostensible focus is on his former classmates. The book is a revisiting of this group of autistic people, most of whom Nazeer has not had contact with since early childhood, from Nazeer’s point of view as he seeks to discover “how they have emerged into adulthood” (Nazeer 6).

Here again the term “emerge” appears, though with yet another nuance. While Prince-Hughes’s use of this term suggests a greater recognition and acceptance of oneself as autistic, for Nazeer, “emerged” does not quite equal “recovered,” but it does indicate movement toward normalcy or normativity. Like Prince-Hughes, Nazeer is interested in tracing these individuals’ (and his own) “journeys through autism”: what having autism has meant for their lives and their understandings of themselves, as well as what kinds of
improvement they have experienced, and how it has come about. Although Nazeer was
diagnosed with autism as a child, he often, particularly early in the text, speaks of autistic
people as “they,” rather than “we,” and uses a rather distant tone; for instance, he writes,
“Autistic individuals find it difficult to develop intuition or empathy. In meeting my
classmates again and writing about their lives, I want to understand how a life is different
when it lacks these elements or when they’re not fully formed” (7). Speaking about the
challenges to “autistic individuals” and stating his intention to “understand how a life is
different” when intuition and empathy are impaired sounds like the work of a non-autistic
researcher seeking to understand autism. In some ways, Nazeer aligns himself with the
“expert” perspective on autism, accepting many of the dominant theories about autism’s
causes and manifestations, and setting out to study his former classmates from a
professional, almost clinical position, as though he is not actually one of them. The
reader senses Nazeer’s desire to establish himself as an authority, as someone who has
progressed far enough beyond autism and into normativity that he can view it from a
critical distance. This sort of legitimating impulse echoes the “expert” forewords to early
autism memoirs like Grandin’s Emergence, verifying that the writer is authentically
autistic and worthy of readerly attention; in this case Nazeer straddles the line between
wanting to show that he is autistic, with the nonnormative valences that come with the
label, but also that he is now “normal” enough to write about it. He also appears to want
to assert himself as a professional—not exactly an anthropologist, but an ethnographer
with the authority and ability to carry out this informal study of a group of people and to
tell their story from a unique perspective.
As the book progresses, however, this professional distance breaks down somewhat, and details of Nazeer’s own experience, progress, and insecurities emerge to help align him more clearly with the nonnormative range of the autism spectrum. He at times appears troubled by the collapse of his ethnographer’s distance; for instance, he expresses discomfort when his subjects become emotional, complaining, “I wanted to pass through the lives of my former classmates without tampering, without changing anything, not even accidentally trampling on a butterfly—just making a few notes, having a few conversations, and then leaving” (88). When this proves to be impossible (and ultimately, undesirable), he acknowledges that his “conception of this book had itself been an autistic one and it couldn’t be sustained” (88). The recognition that he cannot interact with these individuals without becoming involved with other elements and other people in their lives foreshadows one of the book’s eventual conclusions: that for autistic people to “get better” (Nazeer’s term of choice), they need to interact with and enter into relationships with the people around them. Nazeer’s autoethnography, his study of both himself and this small group of other autistic adults, makes a case for the value of relationality—of mutually beneficial relationships with others—for autistic people to come as close as possible to normativity. His text complicates the focus on “self” suggested both literally and figuratively by the term “autism,” and through his study of the lives of his autistic peers, Nazeer emphasizes the potential of reaching outside the self in order for autistic people to develop and grow—or “get better.” Nazeer’s account acknowledges that the nonnormative can never be entirely eradicated from autistic experience, but he suggests that through relationships, autistic people can move much closer to normativity than many people might expect. He draws these conclusions
through a text that literally enacts relationality by tracing Nazeer’s own relationships with his autistic autoethnographic subjects, people with whom he identifies in many ways. In his exploration and inhabiting of both lived and written relationships, Nazeer responds to common representations of autism with his own evolving understanding of what autism means him, for other people with the diagnosis, and for those around them.

Along with Nazeer’s own experiences, which are scattered throughout the book, *Send in the Idiots* tells the stories of his one-time classmates André, Randall, Craig, and Elizabeth, each of whom is given his or her own chapter. There is also a chapter dedicated to Nazeer’s reunion with two of his former teachers, Rebecca and Ira, from the school that he and the other subjects attended. Despite the somewhat off-putting title of the book, which is taken from the echolalic phrase, “Send in the idiots,” that Craig repeated often and enigmatically as a child, no one actually suggests that the people represented here are idiots; on the whole, as Nazeer has acknowledged in an interview, this group is largely “an unrepresentative sample” of the autistic population, with most of the subjects situated “towards the middle or higher end of the autism spectrum” (“Memoir”). André is a computer scientist, Randall is a bicycle courier and poet, Craig is a political speechwriter, and Nazeer, who has a law degree and a Ph.D. in the philosophy of legal theory, works in the U.K. civil service. Only Elizabeth, as I will discuss further below, experienced something less than academic or professional success. Indeed, Nazeer is often more concerned with people having overly high expectations for individuals with autism; he cautions against seeing autistic people as “geniuses” and tells with some amusement of how he, André, and Craig all seem to have had an advantage in the college admission process because of “other people’s hopes about how intelligent we
might be” (*Send in the Idiots* 224). But Nazeer is also focused on how he and his former classmates have become “less idiotic”—and therefore more normative—than they were as children, as well as the fact that “we became this way through exposure to the world that lay beyond the horizon of our own selves” (228); in other words, that they had social and cultural interactions with one another as well as with non-autistic people. In Nazeer’s terminology, he, and all of his classmates to one extent or another, “got better.” This does not mean that he or his classmates are no longer autistic, but that they have grown and “didn’t display as many of the symptoms” and “no longer had all the same limitations” as they did as children (227). They have developed ways of adapting to the normative world around them through exposure to and interaction with others.

In his investigation of how he and his classmates have “gotten better,” Nazeer addresses some of the dominant modes of thinking about autism, and responds to them based on his own experience and what he observes in his fellow autistic adults. In this way Nazeer assesses outside representations of autistic experience from a position that his subtitle refers to as “the other side of autism.” For instance, he takes on the prominent idea that people with autism are lacking in a “theory of mind,” incapable of recognizing or intuiting other people’s mental states, popularized by researchers such as Uta Frith and Simon Baron-Cohen.50 Rather than accepting that “theory of mind” is an inherent incapability for people with autism, Nazeer posits that “Everyone lacks a theory of mind to begin with; theory of mind is not something innate. … Everyone needs to learn how to read other minds. And autistic children—because they develop language later, more slowly; because their own minds are so difficult to manage—don’t learn as quickly or as well as others, and need more help in doing so” (72, emphasis original). In

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50 See Chapter 2 for a brief description of the “Sally-Anne” experiment, originally developed by Frith.
making such a claim, Nazeer contests the binary opposition between nonnormative, autistic experience and normative, non-autistic ability. Nazeer reflects that his school operated on the premise that the autistic children could learn skills such as theory of mind, and that his own class’s learned skills of sitting with and playing together, as well as the success of some autistic people, such as Randall, in having romantic relationships, provide convincing evidence that awareness of and empathy for others can be developed. Indeed, Nazeer is impressed by Randall’s ability to interpret his partner’s attitude toward Randall’s poems: “‘I don’t think Mike can be objective about them.’ Randall smiled. ‘His own writing isn’t going well, so he thinks that mine is brilliant.’ … I was distracted by the quality of Randall’s insight. I realized that Randall and I weren’t supposed to be able to understand others’ attitudes with such clarity” (79). Of course, Nazeer himself demonstrates his ability to interpret others’ attitudes throughout his book, which is an extended exercise in listening to, interpreting, and relating to the subjects of his study. In his response to the hegemonic “theory of mind” theory, Nazeer uses his own and his classmates’ experiences as autistic children and adults to challenge one of the most influential theories about autism by the “experts” and to move the realm of autistic experience a bit closer to the non-autistic norm.

Another dominant theory of autism, that of weak central coherence, proves to be more useful for Nazeer, and he largely embraces it as a heuristic for explaining some of his and his classmates’ behaviors. Originally proposed by Uta Frith in 1989, the weak central coherence model proposes that autistic people are capable of perceiving minute details but are often unable to put those details together into a coherent bigger picture. In Frith’s view, “autistic detachment…results from a lack of coherence” (Autism:
Explaining the Enigma 160); that is, behaviors that tend to isolate autistic individuals from others are a result of the difficulty of recognizing connections between fragmented details. In his account, Nazeer focuses on the techniques that he and his autistic subjects use to achieve what he refers to as local coherence; as he explains it, “This is the preference that autistic people frequently demonstrate for a limited, though immediate, form of order as protection against complexity or confusion” (4). Nazeer attributes some of the most stereotypical autistic behaviors—rocking, flapping, putting objects in a particular order, and other repetitive or obsessive actions—to the struggle for local coherence. Nazeer uses his own action of playing with a crocodile clip in his pocket as an example: “I play with the clip for something to focus on while I try to do something harder, like explain to a friend why I didn’t return her call” (37-38). André’s use of puppets, which he builds himself and often uses in his conversations with others, is an even more vivid illustration. Nazeer hypothesizes that “the puppets came out when he couldn’t find local coherence. André tried for that first. But when he couldn’t get it, he substituted one of the puppets for his own self. He escaped instead of standing there without local coherence. This was what the puppets gave him, a powerful backup to the more conventional resources of the autistic individual” (41-42). Although Nazeer prefers this explanation, André’s puppets clearly mean more to him than only an escape when local coherence is difficult to obtain. They are also artistic creations that he builds out of wood, and a source of creative expression, as André indicates when he puts on a play for friends using two of the puppets. However, Nazeer uses the desire for local coherence as a controlling metaphor, and this use limits other possibilities for behaviors that he sees as efforts to achieve coherence. Nazeer concludes that “the puppets, rather than a means of
emancipation, are a further defense against the breach of [André’s] local coherence” (51). While the puppets may be a way of “getting better” in that they enable André, much of the time, to participate in normative conversation and mainstream society, Nazeer still sees them as a crutch, an artifact of nonnormativity that he would prefer to see give way to more normative behaviors and ways of coping through interaction with others.

In Douglas Biklen’s terms, local coherence is Nazeer’s preferred metaphor of autism (Biklen 38), an interpretation without a concrete biological “mechanism” behind it and therefore no verifiable foundation. As Biklen remarks, “The outsider is always in the position of having to ask, ‘What am I seeing here? What does this mean?’”, whereas an insider may be able to use his or her own experience to explain behavioral differences (46). Biklen points out the focus on deficit in the “outside” approach, in which “the outsider develops hypotheses or theories…from a normate\(^{51}\) perspective and applies them to and tests them on people defined as disabled, in effect saying: What does the person labeled autistic lack that the ‘normal’ person possesses?” (46). In place of this deficit-based model, Biklen’s preferred approach lies more along the lines of the neurodiversity model, which acknowledges the differences and difficulties of autistic experience but does not necessarily frame these as deficits. Despite a lack of biological evidence, the local coherence theory appears to be consistent with Nazeer’s own experience and what he observes in others, making it more than just a metaphor proposed by an “outside” researcher. While Nazeer’s autoethnographic account certainly offers perspectives from “the other” (nonnormative) “side of autism,” as opposed to that of the “outside”

\(^{51}\) Biklen borrows the term “normate” from Rosemarie Garland Thomson; as Thomson defines it in Extraordinary Bodies, “the term normate usefully designates the social figure through which people can represent themselves as definitive human beings. Normate, then, is the constructed identity of those who, by way of the bodily configuration and cultural capital they assume, can step into a position of authority and wield the power it grants them” (8).
(normative) researcher, Nazeer is inclined toward a deficit model, perhaps because of his own success in “getting better” and becoming a participant in normative society. His focus on normalizing autistic behavior to the extent possible makes his view of autism largely incompatible with the idea of neurodiversity. Nazeer recounts his classmate Craig’s experience attending a meeting of a group that held that “[p]eople who were autistic suffered no lack; their symptoms were not shortcomings, but simply the characteristics of the autistic individual, and the way of life and the style of thought of the autistic individual were as valid as what clinicians defined as ‘normal’” (209). Both Craig and Nazeer disagree with this view, seeing it as essentializing and as potentially damaging, preventing autistic children from improving by insisting that there is no need for them to improve. Nazeer reflects, “The view that autism has to be defended as a distinctive way of being originates, I think, from the same core belief that autistic people don’t really get better. And so instead of trying to measure up to societal norms, autistic people should be permitted to maintain their own” (227). He acknowledges that the Deaf community, which seeks to be viewed not as disabled but as having their own legitimate form of communication, may be able to be viewed in this way, but that autism is somewhat different. He points out that because “there’s no autistic equivalent of sign language, some level of intervention is necessary, and it doesn’t often fail” (227). Nazeer here diverges significantly from Prince-Hughes’s and others’ resistance to the idea of autism as something to be “cured”; he places great value on the potential of intervention by non-autistic others to help move autistic people as far as possible toward the norm. For Nazeer, the deficit model is necessary to seeing the potential for autistic people to improve from the impairments caused by autism, and neurodiversity is a misdirection that
can actually prevent improvement from happening. At the same time, Nazeer argues against the idea of an autistic culture or community, instead placing emphasis on the inclusion of people with autism in the larger social and cultural community, a sort of contextualizing that is a bit closer to Prince-Hughes’s conclusions about the value of her journey through autism.

The main thrust of Nazeer’s autoethnographic account, enacted through the revisiting and narration of relationships, is that ultimately, “getting better” is achieved through interaction and relationship between autistic people and non-autistic others, particularly in educational settings. Nazeer is very positive overall in his descriptions of the education he received as a young child at the unnamed school, which has since closed. He describes how his teachers helped the children learn to better interact with others by, for example, practicing recognition of others’ emotional states by listening to conversation tapes (177) and constantly practicing making eye contact and shaking hands (182-83). These sorts of lessons, he maintains, helped him and his classmates to develop the ability to behave and function in normative ways. Most of the adult subjects of the book are able to hold jobs; Craig and Nazeer each live on their own, André lives with his sister, and Randall lives with his partner. Although each of them still displays some of the nonnormative, disabling aspects of autism—André uses the puppets to communicate and runs away if his system of local coherence is interrupted; Randall has difficulty reading other people’s intentions on the job and so is taken advantage of by some clients; Craig can write brilliant speeches for others but cannot deliver them effectively, in part because of his flat affect and tone of voice—they are in many ways able to function quite well in mainstream society. Nazeer himself seems to be the most successful of the group,
so improved as to be barely recognizable anymore as autistic. When he meets with Ira, the former head of the school, and Rebecca, his classroom teacher, he is anxious to get their reactions not only to the book he is writing but to himself as an adult, twenty years since they worked with him as a much more impaired child. Their response to him is somewhat cryptic, and they comment repeatedly throughout their conversation that he seems to no longer be autistic. For example:

“Do you think that I’m autistic anymore?” I asked Rebecca. The question tumbled out. I hadn’t meant to ask it. “She doesn’t.” I nodded toward Ira.

“She does not,” confirmed Ira.

Rebecca smiled and took my hand. “I agree,” she replied. “I was thinking about it just a moment ago. You ran this conversation from start to finish. More or less. So, yes, I agree. Is it important?”

I shook my head. It couldn’t be important. Or I couldn’t admit to them that it was important, but perhaps I’d think about it again later. (216-17)

Perhaps because of his emphasis throughout his autoethnographic text on the process of getting better, Nazeer seems to need confirmation here that he has in fact gotten better, so much better that he is no longer autistic. And the proof of this transformation needs to come from his former teachers, a form of authority that still means something to him, in particular because he gives them a good deal of the credit for his and his classmates’ improvement. When he first meets with Ira, he is nervous that “I might not have come far enough. … Might she have expected me to do better than I had?” (183). This
expectation is rather hard to imagine, and both Ira and Rebecca are obviously pleased
with and proud of the adult Nazeer has become. He later acknowledges that “Ira and
Rebecca were teasing me when they told me that I wasn’t autistic anymore” (227), since
he, like most people, recognizes that autism does not really go away, but he still clings to
the idea that they recognize the improvement in him. In a sense, then, his desire to
recognize that others with autism have “gotten better” might also serve as validation,
corroborating his own experience.

Still, Nazeer acknowledges that the experience of most of the subjects in the book
is not exactly typical of people with autism. He admits, “It’s unusual for autistic
individuals to become top-rank speechwriters or computer scientists, like Craig and
André” but insists that “progress is legion” (228). Perhaps the most difficult case to be
made for progress is that of Elizabeth, the only female subject of the book (not surprising
given that autism affects significantly more males than females), and the only one who is
not present to tell her own story, having committed suicide several years earlier. When
Nazeer contacts former classmates about being involved in his book, Elizabeth’s parents
agree to participate, and Nazeer wants this story to be told, despite its apparent
contradiction of the theme of “getting better.” He reflects, “Elizabeth’s story was
important. I was in danger of turning her into an emblem of autistic misery, of making
her stand for all those whom I didn’t get to talk to and whose troubles I had to imagine
(whose triumphs, though there must be some, I didn’t dare to imagine)…. I wanted to
avoid this fate by learning more about her” (143). Elizabeth’s depression is separate
from her autism; her parents make clear that depression runs in the family but that it is
likely made more challenging by her autism. Depression and suicide are unfortunately
not uncommon among autistic individuals, and it is significant that Nazeer chooses to include her story alongside those of the other, more obviously successful individuals in his book. However, Elizabeth’s story, despite its end, is still presented as one of progress, a representative of those individuals with autism whose improvement is more modest.

When Nazeer first meets Elizabeth’s father, Henry asks him two questions: “‘Why did you get better?’” (141) and “‘Did everyone get better?’” (142). The questions suggest the conclusion Nazeer immediately draws: that “his daughter, Elizabeth, didn’t get better” (143). Comparing Elizabeth’s trajectory to Nazeer’s might be painful for Elizabeth’s parents, and her father seems to be asking why the educational intervention that apparently helped Nazeer progress toward normativity did not have the same results for Elizabeth. Of course, the broad spectrum of autistic experience means that nearly everyone with an autism diagnosis has a different manifestation of it (many people point out, “If you’ve met one person with autism, you’ve met one person with autism” [e.g., Finland 21]), and Nazeer describes Elizabeth as being on “the harsher end of the autism spectrum” (151), while he would seem to be on the “milder” end. Unlike the book’s other subjects, Elizabeth was not able to have a career (in part due to her depression and epilepsy), and she lived with her parents. But later in the chapter, Nazeer reveals a change in approach to Elizabeth’s story, suggesting to her father that “‘Elizabeth did get better’” (169). Henry nods and agrees, “‘Not a lot was expected of her when she was little. She did a lot of things. She learned a lot of things’” (169). Despite her untimely death, Elizabeth “got better” in that she learned and grew through relationships with others throughout her life. Although she is not present to tell her own story, through her
parents’ recounting of some of it, Nazeer provides a relational sense of both Elizabeth’s successes and her challenges. Her parents rejoice in her successes of teaching herself to ride a bicycle (160-61) and developing a system for navigating the bus route so that she could travel the city on her own (150), and they recount their efforts to help her when she was overwhelmed by depression. Nazeer notes that “Elizabeth got better because of them, because of their attention” (174). Elizabeth’s story makes clear that life with autism and other disabilities—Elizabeth also had psoriasis, epilepsy, and depression—is not without its difficulties, but that progress, and joy, are still possible. Elizabeth’s complicated trajectory and her suicide pose a challenge to the concept of “getting better,” but the effects of relationality, and progress toward normativity, make themselves known in her life as well. Through her education and through her parents’ attention and care, Elizabeth achieved a great deal that she might otherwise not have been able to accomplish.

Nazeer’s approach to autism and his focus on “getting better” emphasize the role of relationality in helping autistic people make progress from autistic nonnormativity toward increased normativity. While Nazeer acknowledges that autism and its nonnormative characteristics or impairments cannot ever fully be overcome, he makes a case for the ways that relationships with others, whether in educational contexts or personal ones, can help autistic people improve by moving closer to normative experience and achievements. Nazeer obviously does not value the nonnormative aspects of autism in the way that Prince-Hughes does, and he focuses instead on the potential for growth toward normativity for autistic people who learn and develop in relationship with others. However, Nazeer’s account, in its own way, also stresses the importance of
relationality in breaking down binary oppositions between autistic and non-autistic experience, particularly through the relationships that are foregrounded and navigated throughout the text in the effort to respond to existing representations of autism and construct his own. As Ido Kedar’s account will also make clear, autistic autoethnographers may take very different approaches to the role of relationality in the representation of themselves and of autistic nonnormativity, but similarly work toward deconstructing barriers between autistic people and the world around them.

**Ido in Autismland: Challenging Theories and Connecting through Communication**

Ido Kedar’s *Ido in Autismland: Climbing Out of Autism’s Silent Prison* is a series of short, focused essays written when Kedar was between the ages of 12 and 15 and self-published by Kedar and his mother, Tracy, in 2012. Much of this writing was done by Kedar pointing to letters on a communication board, with his mother transcribing letter by letter; more recently he has used a keyboard and now an iPad to write on his own. Kedar’s writing process is in this way physically relational; his mother participates in the writing of the text, and she also contributes a lengthy introduction to the book, offering her own perspective on his story. The chapters are written as individual reflections, almost journal entries, about what Kedar is experiencing at that time in his life. Section

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52 Self-publishing is a rapidly growing phenomenon, as platforms like Amazon’s CreateSpace and Kindle Direct Publishing make the process easier than ever. Self-published memoirs by autistic people or by parents of autistic children have appeared in ever-growing numbers over the past several years; an Amazon search yields about 65 self-published memoirs about autism published since 2011 (as of April 2014). Self-publishing offers a way for writers who might otherwise have difficulties getting their work published—because of the requirements of publishing companies, including perceived marketability and, of course, perceived quality of writing—to make their voices heard and their stories available to others. The advent of online book sales and low-cost, online-only books also makes these texts increasingly available to readers, and the user reviews posted for these books makes evident that people—sometimes in large numbers—are reading and being affected by them. While quality of proofreading and coherence may suffer in the absence of professional editing and publishing services, the accessibility of self-publishing makes it possible for stories and storytellers of all kinds to reach increasingly broad audiences. Online writing such as blogs also make autistic writing more available to a broad reading public (see brief discussion of this genre in Chapter 6); Ido Kedar’s blog is also titled *Ido in Autismland*, and some of the later essays in his book are taken from blog postings.
titles divide the essays by age and characterize the period with a title and brief
description, such as “Age 12, The Year of Anger and Sorrow” (Kedar 41) and “Age 13,
Starting to Let Go of the Past” (92). Kedar is nonverbal, and for much of his childhood
could not communicate, had significant behavioral problems, and was thought to be
intellectually disabled. He began communicating through writing at the age of seven, and
eventually was able to join a mainstream academic program, but he continues to face
more and different kinds of barriers than does someone with fewer communication
impairments, including both Prince-Hughes and Nazeer.

Kedar’s text is autoethnographic in the sense of “ethnic” or “ethnographic
autobiography” (Reed-Danahay 2; Couser, Signifying Bodies 95), very much in line with
Mary Louise Pratt’s definition of an autoethnographic text as one “in which people
undertake to describe themselves in ways that engage with representations others have
made of them” (35). Perhaps more explicitly than either Prince-Hughes or Nazeer, Kedar
seeks to subvert existing expectations, or rather lack of expectations, for people with
severe autism. Kedar is quite aware of what others, particularly “experts,” have to say
about people with autism, and he is especially sensitive to the difficulty for nonverbal
people like himself to respond to others’ misrepresentations. Since he was once unable to
speak for himself and has now gained the ability to communicate through writing, he uses
his autoethnographic text to make his voice heard, to write “in response to or in dialogue
with” (Pratt 35, emphasis original) the theories and representations of people with autism
that have been limiting and harmful to him. Kedar is also interested in advocating for
other nonverbal people with autism who are not yet able to speak for themselves, to
encourage non-autistic others to see the person in addition to the autism, and to promote
better educational methods that foster communication skills for those with limited verbal abilities. The concept of “Autismland” introduced in the title raises the specter of the experience of autism as a sort of separate world, one which is little recognized and largely misunderstood by those outside of it. In Kedar’s view, those in the world of “Autismland” tend to be isolated from others through no fault or desire of their own, and his autoethnographic work seeks both to explain the experience of those in this “world,” and to make better connections between those inside and outside of this group. For Kedar, communication is the key to better connections between autistic and non-autistic people, and the text represents his effort to foster relationships by sharing his own perspective through writing, subverting others’ views of him as uncommunicative and therefore unintelligent. He seeks to break down boundaries between himself and other people as a result of the nonnormative aspects of his experience; in effect, he wants to tear down the walls between those in “Autismland” and everyone else. He acknowledges the qualities that make him different but also emphasizes the potential for relationships between people like himself and those who more clearly meet neurotypical standards to make those differences less isolating.

Because of his nonnormativity, particularly in lack of verbal ability and inexpressive external appearance, Kedar’s text seems to seek to overcome a great deal of skepticism on the part of both “experts” and readers. In the same way that Temple Grandin’s Emergence carries endorsements from Dr. Bernard Rimland, as well as Grandin’s former teacher and mentor, William Carlock, Kedar’s text has two “authorizing” paratexts that offer validation from non-autistic perspectives. The first is a brief foreword by Dr. Yoram Bonneh, an autism researcher who has worked with Kedar
as well as with Tito Mukhopadhyay, another nonverbal autistic writer whose mother, Soma, helped both young men develop their independent writing skills. Despite Kedar’s suspicion of “experts,” who often, in his view, arrive at or resort to the wrong conclusions because they fail to listen to people with autism, Dr. Bonneh appears to be a “trusted” expert, one who listens to what Kedar has to say and who denounces the fact that “therapists and clinicians were typically skeptical about Ido’s communication and largely dismissed it as coming, although unintentionally, from his mother” (10). Bonneh emphasizes that his own research seeks to understand the disabilities that prevent people like Kedar from better learning and communicating, and expresses his hope that Kedar’s book “will contribute to the understanding of the severely autistic by parents and clinicians and lead to better interventions and treatment for those with his condition” (11). Following Bonneh’s foreword is an introduction of nearly 30 pages by Kedar’s mother Tracy. This introduction is a different kind of validation of Kedar’s text, though Tracy also calls attention to her experience as “a mental health therapist by professional background [who] spent years working with the Deaf,” which “ultimately helped [her] to recognize Ido’s ability to understand and communicate” (17). While Tracy’s introduction is insightful and provides a useful overview to Ido’s story and a context in which to read his essays, its length and its placement before Ido’s text might suggest that the reader needs Tracy’s introduction in order to read or accept Ido’s book. Although it is clearly an effort to convince the reader that the words and ideas that follow are in fact Ido’s, Tracy’s introduction could be used to undermine the primacy of Ido’s perspective. Likely the product of the skepticism that Tracy and Ido have long faced from therapists, doctors, and even Ido’s father, the introduction might help to convince suspicious readers of Ido’s
authorship but also has the potential to uphold suspicions by confirming the need for outside validation of the autistic writer’s story.

However, if Kedar’s autoethnographic text is successful in achieving its stated goal, the perceived need for such validation of the writing of nonverbal people with autism may soon disappear, as it largely has for the writings of people with less severe autism, including Prince-Hughes and Nazeer (neither of whose texts contains introductions or prefaces by others). Accounts like Kedar’s, by a person with more severe, nonverbal autism, are rare, though they are becoming more available as he and others gain the ability to communicate through pointing, typing, or the use of new technologies like iPads. The increasing number of autoethnographic texts like Kedar’s may help make improve the visibility and acceptance of such perspectives by a general readership. Rather than being seen as a necessary authentication, Kedar’s mother’s introduction might then be viewed in a relational light, with Tracy’s story being read alongside Ido’s as an illustration of their common yet distinct experiences of life events. Much of their story was experienced together, and having access to their similar, though not identical, accounts reminds the reader that these events did not occur in isolation, but relationally. Tracy’s and Ido’s accounts contain differences in content as well as style, which highlight their separate identities as persons and writers, as well as their different

53 Tito Rajarshi Mukhopadhyay’s The Mind Tree and How Can I Talk If My Lips Don’t Move? and Carly Fleischmann’s portion of the collaborative memoir Carly’s Voice, written with her father, are examples of others writing from this general area of the spectrum. Mukhopadhyay, like Kedar, learned to spell by pointing to letters on a letter board, and later learned to write with pencil and paper. Carly has used a variety of devices, starting with specialized devices for people with disabilities, like the Lightwriter, but gravitating toward laptops and iPads. Kedar, after resisting working with a difficult-to-use keyboard, has transitioned to an iPad. He explains, “My iPad is working out better. No one holds it. It is propped on a table. No one touches my arm, as always, and the voice is more human. I am making another transition as the technology advances” (155). Even this small sampling shows the value of a variety of communication options for autistic people with different needs and preferences, and the greater accessibility of communication as new technologies develop.
positions in relation to autism and normativity. In her narration of the scene in which Tracy realizes that Ido can write on his own, Tracy privileges her own response: “I knew I wasn’t ‘inadvertently’ doing a darn thing. I was supporting his hand, not moving it Ouija-board style. That’s when I knew. I KNEW this time. Ido understood. … He could read and write” (31). She describes the “guilt…regret…[and] joy” she felt when she and her son communicated for the first time (31). In Ido’s account, using shorter sentences and more direct language, he highlights his own response of aggravation once he is able to communicate with his mother: “She cried and apologized for not knowing sooner. I was angry and swore and insulted her. We wrote often then and it was a relief, but…[n]o one believed us as at all. … My mom bore the brunt of my frustration. I was full of anger because I could only communicate with her” (50). Tracy’s introduction, then, offers an additional, relational perspective on Ido Kedar’s account, and rather than a normative endorsement for readers to accept Ido’s text as authentic, might be read as a supplement to Ido’s argument for the importance of relationships among those with and without autism.

Kedar’s desire to challenge the predominance of “expert” views of autism is quite explicit throughout his text. In a glossary entry at the back of the book, he explains, “When I use the term ‘expert,’ I imagine quotation marks. It is not intended to offend. It is based on my own experience. The experts I dealt with when I was young often hindered my progress because they had preconceived biases that interfered with the truth” (164). He suggests that though researchers, doctors, and therapists may be regarded as “experts,” they are far from being the only ones with valuable perspectives about autism. People like Kedar, who have experienced autism on a daily basis throughout their lives,
have important insights to share, but many of them cannot make their expertise known without assistance, and certainly not without education to help them learn to communicate. Kedar’s autoethnographic account is important, not because he is an exception among nonverbal autistic people, but because he challenges others’ preconceptions and speaks as one among many who often cannot speak for themselves. Kedar’s emphasis on communication is an attempt not to overcome or disregard the nonnormative effects of autism, but to facilitate access to autistic reality for non-autistic people. His account demonstrates some of the ways that people with autism deserve consideration, and the ways in which they can be better incorporated into normative society as a whole: by being recognized as fully human persons while also being accepted as individuals with significant differences from the norm.

In an essay titled “Accepting My Illness,” dated May 2010, Kedar writes a sort of mini-manifesto, inspired by his experience of autism:

It gave me a goal in life to help others like me to break free of theories that trap us. … [I]t gave me the courage to write this personal book because it’s a story that hasn’t been told yet in autism books. Out of my autistic mind may come a curiosity to get autism researchers looking at new ideas, parents providing real communication to kids, teachers really teaching stuff—no more flashcards, no more “No, try again”—to kids like me, no more being treated as stupid by lots of kindly but patronizing people. This hope allows me to accept my reluctant membership in Autismland, but it also gives me the strength to live as I am. (113)
Kedar wants not only to break free of the limitations of inaccurate, even if well-meaning, theories, but to use his story to help bring about new, better theories and understandings of autism and the best ways to approach it. He suggests here that though his “membership in Autismland” is not exactly of his, or the other members’, choosing, it provides a sense of cultural identity that must be embraced in order to move forward in a constructive way. Kedar’s most constructive contribution is to use his own autoethnographic account to show the ways that people with autism deserve consideration as a group, and the ways in which they can be better incorporated into society as a whole. Perhaps his most forceful proposal of this comes from his angry, twelve-year-old self: “Do I sound angry? Well, I am. It’s time autistic people told the experts that they have made mistakes. It’s time we told them ‘No’” (61). Since many nonverbal autistic people do not have the ability to verbally say “no” to the experts, Kedar takes on the role of spokesperson, talking back to the “experts,” offering self-representation and interpretation for the good of others who cannot communicate as he can.

Like Nazeer, Kedar takes on some of the most prevalent theories of autism from his own perspective, including the idea that autistic people lack a theory of mind or empathy for others (68, 82), that they are incapable of imagination (96-97), or that, because they cannot speak or their bodies may not respond in normative ways, that they are unintelligent and incapable of learning (48, 55-56). Kedar contends that many of these presumptions on the part of autism researchers are the result of difficulties in communication, or the failure of the “experts” to really listen; for instance, he asks, “How do they know whether non-verbal people have empathy or not? If we lack
communication, we can’t tell people what we think” (68). In Chapter 4, I discuss Krista Ratcliffe’s concept of “rhetorical listening,” applying it to parent memoirs about raising children with severe autism, many of whom have communication difficulties. I argue that those parents who engage in rhetorical listening—sensitive attention to nonverbal forms of communication, including sounds, gestures, body language, and behavior—are more open to accepting their children as persons, even with nonnormative physical or mental experience and expression. Kedar’s protest here is effectively a complaint about a lack of rhetorical listening on the part of “experts” as well as non-autistic family members and friends. In his view, the power of professional theories tends to drown out efforts to listen to or understand the person with autism on a genuine, personal level. He acknowledges that understanding what another person is thinking without spoken or written language can be difficult; in a follow-up to the above questions, he notes, “We can’t write or gesture or show it on our faces or even control our impulses very well, so how do they know what’s in our minds? They guess” (68).

Many of Kedar’s chapters deal with the frustration of being unable to communicate easily with others, and others’ resulting misinterpretations of his behavior. He writes about many behaviors that are responses to sensory overload, including stimming, such as the flapping of his hands, which he describes as helping to relieve his emotions and help him escape reality. But at the same time he is conscious of people’s reactions to his behavior: “It’s painful to see people react like I’m so strange to them. I’d stop if I had another way to release my tension. I hope that writing my feelings to others will let me free myself from flapping’s hold over my response to strong feelings” (43). Here, as in many places in the text, Kedar acknowledges the way his autism inhibits his
control over his body’s responses to stimuli. In this passage he recognizes that many non-autistic people are not accepting of the kind of nonnormative behavior he often engages in; as a result of this lack of acceptance, Kedar hopes to develop in his ability to control his behavior in order to better fit into normative society. This example highlights an ongoing tension for him between accepting the nonnormative aspects of his autistic experience on one hand, and his awareness of and desire to overcome his separation from normative non-autistic people, on the other. His emphasis throughout the text on relationality through communication is an effort at creating a bridge between autistic and non-autistic that will lessen separation between normative and nonnormative experience through better understanding.

The best possible solution, for Kedar, is to make every effort to teach people with autism, particularly those who cannot speak, how to communicate through some means, to enable them to express themselves and to make others aware of their abilities and identities. He is brutally honest in his assessment of the sort of education he received for many years under the auspices of Applied Behavior Analysis (ABA), in which he was treated as unintelligent, given repetitive drills that were difficult for him because of his motor control problems, and seldom taught interesting or challenging material. He makes his own recommendations to specialists: “[T]alk normally to autistic kids…. [T]each autistic kids grade level lessons so that they learn the same stuff as normal kids. You can’t imagine how boring it is to be drilled over and over on baby tasks that you know but can’t get your body to show” (55-56). Similar to Biklen’s premise of the “presumption of competence,” which Biklen describes as the idea “that people classified as autistic, even those who cannot speak, are thinking people with ideas about their lives
and their relationship to the world” (1), Kedar asks experts to start by treating people with autism as intelligent people—thinking, feeling selves—who want to learn and communicate but need help to do so. For him, leaving ABA behind and working with Soma Mukhopadhyay to learn to communicate independently opened the door to doing grade-level schoolwork and eventually attending mainstream high school classes, becoming part of a social and cultural world outside of “Autismland,” an inclusion Kedar’s text seeks to make possible to other nonverbal autistic people.

Perhaps contributing most substantially to a weakening of the constructed binary between autistic and non-autistic experience is Kedar’s observation regarding differences between himself and those with other forms of autism. In particular, he points out how dissimilar his own disability is to that of people with verbal, “high-functioning” autism such as Asperger’s syndrome. Identifying some of the disparities between them, Kedar reflects,

> It’s interesting that people see autism and Asperger’s Syndrome on a continuum. I think they are completely different neurological illnesses. It’s not clear that the symptoms are the same. I don’t think what I have is Asperger’s Syndrome in severe form. It seems like it’s something else. I know kids with Asperger’s Syndrome and we are really different. Their way of seeing life is different from mine. I don’t really understand their highly verbal, obsessive intensity or the challenges some of them have in reading people. I’m not at all like a non-verbal version. It’s not the same in the brain, I think. (63)
Most autistic writers of autobiographical texts, including others I have discussed in this chapter, fall at the less-severe end of the so-called autism spectrum, being highly verbal, often highly educated, and fairly successful in mainstream society. Grandin, Prince-Hughes, and Nazeer, for example, all have Ph.Ds. and high-profile careers. The experiences of those whose autism is more severe, like Kedar, tend to involve more significant behavioral difficulties, problems with motor and impulse control and responses to sensory stimuli, and difficulties with speech and communication. Many parents of children with more severe autism, in a similar way to Nazeer, see the attitude of neurodiversity and acceptance not as liberating but as a form of giving up hope for the improvement for their severely disabled children. Kim Stagliano, for instance, suggests, “Maybe we need an expanded vocabulary. The NDs [neurodiversity advocates] can keep the word ‘autism,’ and my kids get a new label. … Just don’t tell me to give up on my girls and accept their version of autism…as simply a different type of personality” (183). Again posing a challenge to the “experts,” Kedar urges, “We need more research to explore this” (63); since the existing theories and labels do not do enough to recognize the divergences within autism, he calls for more research to be done. The better autism is understood, in his view, the better people with autism will be treated.

Despite his differences from some of the other autistic writers of autoethnographic texts that I have discussed here, Kedar is similarly interested in increasing the connections between autistic people and others, both autistic and non-autistic, particularly for those autistic people who are lacking in communication skills. Again responding to theories by “experts,” many of which frame autistic people as isolated and uninterested in other people, Kedar challenges such views not only by
addressing them explicitly in his text, but also by demonstrating his own interest in connecting and communicating with the people around him. Although dominant theories of autism hold that autistic people lack the ability to perceive or empathize with others’ mental or emotional states, Kedar repeatedly exhibits his ability to do both. In his final chapter of the book, he anticipates its effects on others, explaining, “I hope that our strange ways will start to make sense and that parents, and educators, and others, will re-examine their point-of-view” (156). He also shows his empathy for nonverbal autistic people who are in the same position he once was, unable to communicate and frustrated by others’ failure to recognize their capabilities; he writes, “I see one friend in particular struggle every day to show his intelligence. … He is smart, I’m sure of it” (48). Later, in a direct “Letter to a Friend with Autism,” he empathizes with his friend’s sadness—“When I was twelve I also felt the same way you do” (152)—and urges the friend to continue to try “to communicate, and to join in the world, in the regular ways of school or family,” and not to “give in to sorrow” (152). Kedar clearly appears able to put himself in his friend’s place, giving advice to help his friend better connect with others through communication. For Kedar, communication is the path to a better life for people with autism, as it will help them come out of the loneliness and isolation brought on by the inability to communicate.

While it is a challenge for nonverbal autistic people to learn to communicate and connect with others, Kedar emphasizes the importance of efforts on both sides of the divide, giving advice on “how to be a friend to an autistic person,” including avoiding condescension, making efforts to read their nonverbal communication, and “connect[ing] in the ways you can” (158). He recognizes the necessity for non-autistic people to listen
to people with autism in any way possible in order to dispel inaccurate theories about autism that only reinforce difficulties and isolation. It is Kedar’s project in his autoethnographic text to use his own voice to illustrate the need for new and better theories about autism, ones that lead to greater openness to autistic people’s intelligence and abilities, as well as increased opportunities for people with severe autism to communicate and to create better connections across social and cultural groups.

Conclusion

Autoethnographic writing about autism can provide a way for people labeled autistic to respond to and challenge others’ representations of them while identifying their own connections with the people around them. In such accounts, autistic writers often emphasize their similarities with non-autistic readers, in order to encourage their own recognition as persons, while also seeking to explain and increase acceptance of the nonnormative qualities that set them apart as autistic. The three examples I have discussed here demonstrate some of the diverse ways that autistic autoethnographic writers may draw upon relationality to develop a more nuanced and less dualistic view of normative and nonnormative experience. Dawn Prince-Hughes draws upon her anthropological background to provide an autoethnographic consideration of her journey toward understanding her experience within the context of her autism diagnosis and her relationships with others across species and abilities. Kamran Nazeer uses his own and other autistic people’s experiences to explore the influence of relationships across groups in the progress of people with autism toward normativity and ultimately better integration into society. Finally, Ido Kedar speaks from his position as a nonverbal autistic person capable of written communication to advocate for the rethinking of “expert” theories of
autism and the reconsideration of nonverbal autistic people as individuals worthy of inclusion in larger communities.

Each of these accounts positions itself within social and cultural contexts, consciously interacting with and challenging existing notions of what autism is, particularly the preconception that autistic people are isolated and focused only on the self. Reading texts such as these as autoethnographic enables readers, particularly non-autistic ones, to find new ways not only of understanding autistic individuals, but of recognizing the importance of considering autism in context, not in isolation but as integrated within broader sociocultural settings. At the same time, the tensions between these writers’ attitudes toward autism, toward non-autistic people with whom they are in relationship, and toward their broader communities reinforce the reality that autistic lives and autobiographical accounts are far from uniform and may be inconsistent with one another. Not only does every autistic person have his or her own unique manifestation of autism, life experience, and personality, but the ways in which writers choose to represent themselves to others through literary autoethnography may take a variety of forms. The examples here demonstrate the flexibility and versatility of literary autoethnography as a genre, and show quite clearly that this genre can be used in different ways and to different ends. Though they may approach the topics of autism, nonnormativity, and relationality from different perspectives, and take notably different forms, each of these texts works in its own way to break down the binary opposition between normative and nonnormative, creating space for the recognition and acceptance of each in autistic experience, and the intermingling of the two across relationships.
Chapter 6

Relationality in Autism Life Writing: Looking Forward

“We are like your child. Your child is like us. And we may have difficulties, we are disabled—but there is no denying that we are also awesome.”

- Neurodivergent K, We Are Like Your Child

Throughout the preceding chapters, I have explored various uses of relational writing in the textual representation of life with autism. As I have defined it, relational writing is a set of textual practices that draw upon, and draw attention to, the significance of relationships among people, voices, and discourses, in the narration of lives and the construction of identities. While types of relationships and the forms their representation takes may vary among different auto/biographical texts, relationality clearly plays an important role in constructing narratives and identities for those living with autism and in increasing the number and types of voices that are considered to have authority and ability to speak. Attention to relationships in these accounts works against the stereotypical emphasis on the isolation of, and the denial of personhood and selfhood to, individuals with autism, instead demonstrating the ways that people living with autism are connected, and desire connections, with others, both autistic and non-autistic, and acknowledging both normative and nonnormative ways of being in the world.

Additionally, the sorts of relational textual practices that I have highlighted throughout this dissertation help to expand the possibilities for telling life stories with autism, including by using metaphor to develop better understandings of divergent experiences and relationships between those with and without autism (Chapter 2); challenging norms by narrating stories that destabilize available, conventional narrative models (Chapters 3 and 4); attending to communication beyond the verbal through rhetorical listening and
interpretation (Chapter 4); and making use of autoethnographic techniques to respond to and resist others’ representations and to allow space for both normative and nonnormative aspects of autistic life and identity (Chapter 5). By foregrounding human and discursive relationships and opening up the possibilities for constructing life narratives, these writers also extend ways of thinking about personhood and selfhood for people with disabilities, particularly disabilities like autism that often involve communication impairments, and the ways these aspects of identity can be conveyed and represented in text. Emphasizing relationality in life writing can counteract preconceptions of the autistic individual as lacking the characteristics necessary to be recognized as a person and an autobiographical self, while also demonstrating the ways that people with and without disabilities, and their life experiences, connect and intersect with each other.

In this dissertation, I have examined uses of relationality in published, print texts about life with autism, a genre that has grown significantly over the past several decades. However, relationality, as both a mode of understanding people and experiences and as a textual practice, is certainly not limited to traditional published print writing. Online writing, particularly in the form of blogs, is a burgeoning and continually evolving genre of auto/biography. This is one of the newest forms of auto/biographical writing and one that will likely continue to grow, and so it is worthwhile to consider how relationality is and could be present in this genre of writing as well. As Paul T. Jaeger points, out, the Internet has the potential, only partially realized as yet, to provide substantially increased options for people with disabilities to communicate with others, able and disabled alike:
Online social interactions create opportunities for people with unique disabilities to talk with others who share the same condition, opportunities that may never exist in the physical world. For people with disabilities in general, online social interactions create innumerable new ways to share advice and friendship with others with disabilities and to meet people without disabilities in a manner that does not emphasize the disability.

While Jaeger argues that there is a great need for improved accessibility of websites and digital technologies for people with all sorts of disabilities, the potential for connections to be made via the Internet is clearly very exciting, and many people with autism have made use of a range of websites and blogs to connect with others, both with and without their own disabilities. Harvey Blume writes of the Internet’s effectiveness in allowing autistic people to bypass the difficulties of social interaction in relating to others, particularly others like themselves: he quotes one autistic woman who writes, “[I]t wasn’t until I met other Aspies [people with Asperger’s syndrome] on the internet that I was able to gain a deeper understanding of what being Aspie means. … [O]ne reason it can be so effective as a support system is precisely because it is not ‘in person.’ Ordinarily, the giving of support involves being with someone, and that’s always draining for me.”

Online writing, then, offers opportunities for sharing experience and developing relationships in ways that may be particularly well suited for those living with the effects of autism.

Like print auto/biographical texts, blogs about autism are often written by individuals with autism and those close to them, such as parents, and like such print texts,
these blogs often draw attention to relationships between individuals with autism and others, including non-autistic family members, other people with autism, as well as larger social and cultural contexts. Faye Ginsburg draws attention particularly to this last sort of relationship in her essay “Disability in the Digital Age,” in which she analyzes several examples of ways in which digital media, particularly Internet resources, may make possible new types of self-representation for people with disabilities that have traditionally impaired their communication. In a discussion of autistic activist Amanda Baggs’s YouTube video “In My Language,” in which Baggs explains her own autistic behaviors through video images and text voice-over, Ginsburg reflects on “how, in the twenty-first century, people with disabilities and their supporters—such as Amanda Baggs, those who support her and people who respond to her videos and blogs—are developing emergent forms of digital media practices that enable their self-representation in ways that expand our collective sense of personhood and publics” (102-03).

Significantly, Ginsburg counts as important not only the primary author, in this case Baggs, but also “those who support her and people who respond,” placing emphasis on the connections developed through the production of such digital texts and the effects on others’ recognition of the personhood and place in society of the disabled individual.

Blogs and other digital genres by autistic writers can provide useful insights into autistic experience for non-autistic people, including those whose own autistic loved ones may not be able to clearly or verbally express their own thoughts or experiences. In *Weather Reports from the Autism Front: A Father’s Memoir of His Autistic Son*, James C. Wilson calls attention to many blogs about autism, making a case for their usefulness in helping him better understand his adult son Sam. Listing sites by autistic bloggers
such as Amanda Baggs, Elmindreda, Joel Smith, Autism Diva, and Autistic Bitch from Hell, he assures readers that “[b]logs like these will make you rethink your attitudes and readjust your priorities” (2). Throughout the book, he draws upon the bloggers’ commentaries to aid his attempts to interpret Sam’s behaviors, particularly his head banging and other acts of self-injury. While Wilson does not find definitive answers about specific autistic behaviors or autistic identity, he comments, “Frankly, I’ve learned more about Sam from these blogs than I have from official websites. Not that I agree with all the positions taken by autistic bloggers, some of whom are quite militant. Still, it’s utterly refreshing to find autistic people speaking for themselves” (21). Internet access and the instant publishing power of platforms like blogs make possible the communication of such autistic perspectives to a broad audience, in a potentially more immediate and direct way than traditionally-published or even self-published print texts. Stuart Murray makes some comparisons between published and online autistic writing in Representing Autism, particularly between writers like Temple Grandin and Donna Williams, on one hand, and more radical figures like Amanda Baggs, on the other. He observes that both forms of auto/biographical writing appear “to address a non-autistic audience and to seek to ‘explain’ the condition” (36), but that Grandin’s approach tends to emphasize “the need…to break out of the confines of autistic behavior…, though it is exactly such a view that many of the new generation of online autism advocates seek to overturn” (39). Perhaps in part because of the lack of oversight from publishers or editors, bloggers tend to be less encumbered by convention and ableism than are traditionally-published life writers. Internet availability and technology enables such writers to write whatever they want and to immediately make it available to others online.
I do not have room here to devote to a full comparison between published and online life writing about autism, though further research, particularly into online life writing by autistic writers, is greatly needed. However, I want to emphasize the significance of much online life writing about autism, particularly because of the extension of relationality within these online accounts.\textsuperscript{54}

I see many of the forms and practices of relationality that I have found and discussed in published auto/biographical texts making themselves known as well in autism blogs, in ways both similar to and somewhat different from their print counterparts. Like print texts, there are a great variety of types of blogs available, including those by “radical” autistic self-advocates, such as Amanda Baggs and Kassiane Sibley; those by autistic writers affiliated with or endorsed by large advocacy organizations like Autism Speaks, such as Kerry Magro and Amy Gravino; and those by parents and family members of people with autism, including Kristina Chew and Shannon Des Roches Rosa. These and other forms of online writing about life with autism draw upon relationality in a number of ways, and I will examine just one blog as an example here. \textit{We Are Like Your Child} is a multi-author blog by autistic and other disabled writers, established in June 2013. Of the types identified above, this blog is most closely aligned with that of the self-advocate, and Kassiane Sibley (whose blog pseudonym is Neurodivergent K), is one of the organizers and posters on this blog as well.

\textsuperscript{54}I would like to note here one of the complications of working with online writing, which is the ephemerality of such digital texts. This challenge is acknowledged by Jaeger, who chooses not to include specific websites in his book, “to ensure that the book remains relevant, as the shelf life of most aspects of the Internet tends to be fairly limited, and many websites disappear or devolve due to ‘digital decay’ (Dougherty, 2010, p. 445)” (8). Both Wilson’s and Murray’s books were published in 2008, and many of the references to blogs and websites each author includes were discontinued, changed in name or content, or nonexistent only a few years later. While the transience of online writing can be frustrating and may limit its long-term impact, I would argue that such writing can still have a powerful effect on readers in the short term, and the online space provides unprecedented opportunities for communication by and interaction of new voices telling stories of life with disability.
as her personal blog, *Radical Neurodivergence Speaking*. However, rather than providing a one-sided view of life with autism, *We Are Like Your Child* presents multiple voices and perspectives, offering reflections on life experiences from a variety of writers with autism and other disabilities and offering space as well for readers living with autism to offer their own responses and experiences.

As the title implies, one of the main audiences for this blog is parents of autistic children, and one of its objectives is to provide insight into autistic thinking and experience from the perspective of real autistic people, as a supplement to or substitute for the information that parents and other non-autistic people often receive from medical sources and large autism advocacy organizations. In some ways, these are the same sorts of authoritative discourses that Clara Claiborne Park sought to resist and speak out against in her early parent memoir *The Siege* (see Chapter 2). While Park was reacting to discourse that figured her as a “refrigerator mother” responsible for her daughter’s autism and disregarded her own expertise drawn from living with her autistic daughter, Sibley and the other bloggers of *We Are Like Your Child* seek to respond to discourse circulated by organizations like Autism Speaks, which often describes autism as an “epidemic” and places focus on research to “cure” or eradicate autism, and by popular media, which highlights “Supercrips” and people who “overcome,” rather than live with, disabilities. In an inaugural post titled “So What Is This?”, Sibley explains, “Our messages here are that it is ok to be disabled, it is ok to be disabled and like yourself, and that the stories of ubersuccessful highly privileged autistic folks who had every advantage are not the only stories out there.” Like Park, these writers seek to make their voices and stories heard
over the dominant discourses, which often do not allow for messages such as “it is ok to
be disabled,” especially in regard to autism.

Unlike Park, the writers of this blog have the ability to make their writing
immediately available to readers, and to receive nearly instant feedback on their writing
in an environment in which readers can comment, writers can respond to readers’
comments, and the resulting commentary and conversations can directly affect the shape
of the ongoing blog, making it a sort of living document of relational interaction.
Comments on Sibley’s initial post suggest that the blog has found some of its target
audience of parents of autistic children early on: reader Shannon Summer comments,
“NT [neurotypical] mom of ASD [autism spectrum disorder] kid—this blog is exactly
what I’ve been looking for,” and Momma Dulock writes, “Not only are you ‘like’ my
child, I hope he grows up to be like you: Strong, Empowered, and Engaged.” Adult
readers diagnosed as autistic make their presence known as well, such as Hannah, who
writes, “As an autistic adult (26 years old, still living with my parents, on SSI, and
wishing that I could find employment), I’m eagerly looking forward to seeing future posts
on this blog,” and Alfred G. “Jerry” Laverty, who simply identifies himself as “Age: 62,
Aspergers Syndrome, living quietly in my apartment in Worcester, Mass.” A continuing
challenge for such blogs might be, however, as Jaeger points out, that with “tens of
billions of webpages, hundreds of millions of blogs, and over half a billion users of
Facebook…[i]t seems unlikely that someone who holds negative perceptions about
disability will go searching online for profiles that challenge these assumptions” (157).
While this may be the case to some extent with print texts as well, it is worth noting that
many of the readers of We Are Like Your Child likely came upon it while looking for a
blog of its type, or connected to it via other, related blogs which they were already reading. So while in some ways blogs may make new relational opportunities available, not only within texts and discourses but between writers and readers, there may be challenges in reaching readers beyond those already disposed to hearing the blog’s messages.

Metaphor proves to be as useful a relational strategy for communicating one’s own autistic difference as it is for trying to understand and convey the difference of another, as in Park’s metaphors for her daughter Jessy’s autistic experience. In a post on *We Are Like Your Child* titled “I Am a Pushmi Pullyu,” autistic blogger Sparrow Rose Jones (who also has a personal blog, *Unstrange Mind*) makes use of the image of a two-headed creature from the Dr. Dolittle stories—as Jones describes it, “an animal that gets nowhere because it wants to go in two directions at once.” Jones uses the metaphor of the pushmi pullyu to explain her own inner conflict to readers; on one hand she is an “Autistic extravert, the creature some would assure you doesn’t exist,” who deeply desires involvement and interaction with others, while on the other hand she is “both sensory defensive and has C-PTSD,”\(^{55}\) unable to handle large groups of people or the sensory stimulation of bright lights, high-pitched sounds, or unwanted touch. Identifying herself both as a mythical creature like the fictional pushmi pullyu, and as pulled in opposite directions like that creature by different aspects of her personality and disability, Jones uses this image to seek to explain her experience to those whose own experiences may be very different, both other people diagnosed with autism and non-autistic parents and caregivers. Jones notes that applying this metaphor may allow non-autistic parents to

\(^{55}\) C-PTSD stands for “Complex Post-Traumatic Stress Disorder,” a diagnosis suggested by Dr. Judith Herman for the psychological and emotional effects of chronic or long-term trauma (U. S. Department of Veterans Affairs).
better understand the apparent contradictions in their autistic children’s behavior and to help their children find balance between their two opposing sides: “Help them to learn that they can’t have everything or be everything but that they can learn to stand strong against those who would push with threats or guilt to try to force them to step out of balance with themselves.” Like the pushmi pullyu, whose two sides must cooperate in order to move in the same direction, Jones tells of her own journey to find balance between the two sides of herself, a journey that has taken most of her life so far. She takes an optimistic tone, suggesting that through positive relationships between children and parents, they may be able to accomplish what she has, but more quickly and easily: “Being of two, conflicting natures has been stressful for me, but as I learn to find that place of balance—a place that no one else can prescribe for me; I have to find it on my own and trust my own process—I am coming to love the insights I gain from living with two halves pulling in opposite directions.”

Jones’s metaphor urges not only a sense of balance in relationships between people, but also between different aspects of oneself as one comes to understand and accept one’s own unique identity as autistic or disabled. Responses to Jones’s blog post include comments from both autistic readers and parents, including a parent with the pseudonym Chickenpig, who writes, “I see the same conflict in my son. … I am glad there is another person out there that understands you can want the company of people, and have issues with it at the same time.” The blog offers an opportunity for Jones to explain her experience to others who either share it or seek to better understand it, not claiming that all autistic people have the same exact experiences, but inviting others to read and respond in whatever way they may relate to what she writes. The title of the
blog itself, *We Are Like Your Child*, offers a metaphor in the form of a simile. By comparing themselves with the intended audience’s autistic children, the blog’s contributors suggest a relationship of similarity, though the comparison is softer than a metaphorical statement like “I Am a Pushmi Pullyu,” in which Jones identifies herself directly with this image. The bloggers do not claim “We Are Your Child,” but suggest potential parallels, constructing a flexible relationship between themselves and others with autism diagnoses and providing opportunities for readers to share and interact with these stories by imparting their own.

Like the collaborative auto/biographical texts that I have discussed in Chapter 3, the blog *We Are Like Your Child* is made up of multiple voices, as each post is contributed by a different autistic or otherwise disabled writer, and, as noted above, readers can comment and converse with writers and with one another about the topic of each post. Unlike those published collaborative texts, however, these interacting voices are not necessarily telling stories of shared lives with autism. Instead of two voices diverging as they tell separate versions of a shared life story, as in the collaborative auto/biographies of Judy and Sean Barron or Arthur and Carly Fleischmann, the tendency for the interactions of voices on this blog is to converge, finding points of commonality between separate life stories. These voices are interacting and influencing one another’s writing and understanding of their stories in relation to others, more poignantly because of the ability for writers and readers to communicate nearly instantaneously, but this interaction is perhaps more dialogue than dialogic. In a post titled “Those Pesky ‘Life Skills’ That Everyone Keeps Talking About,” a blogger named Cara Leibowitz (who also has her own blog, *That Crazy Crippled Chick*) identifies herself as having cerebral palsy
and “CP brain damage that mimic[s] effects of autism.” She explains her delayed acquisition of certain basic life skills, such as showering and brushing her teeth, and her frustration at still not being able to do things other twenty-one-year-olds can do, including cooking and driving a car. Leibowitz expresses her frustration with her teachers’ and therapists’ preconceptions that “because I was ‘so smart,’ I would automatically know how to do these things… No one ever took into account that my physical difficulties would mean doing these things differently,” and she argues that “[l]ife skills training should be a part of every school curriculum for students with disabilities—no matter how ‘smart’ they seem.” Conceptions of normative mental and physical ability prescribe normative trajectories for those who in some ways seem capable of fitting expectations. Though blogs seldom follow a long-term trajectory of a life in the way that a published autobiography might, they do offer self-representations of life experiences that resist the patterns of “recovery” or “progress” that traditional narratives dictate.

Readers, particularly those with disabilities, join their voices in the “Comments” section to Leibowitz’s in shared frustration over the lack of support to develop life skills that do not come as easily to them as to their nondisabled peers. “Ohh, this is familiar,” writes apanthropy, and tagAught adds, “Oh, yes, this!” John Mark McDonald, who “grew up before there was an Asperger’s diagnosis,” shares, “I heard variations on ‘you’re too smart to have problems,’ and ‘if you’re not getting it, you must be lazy,’ all my young life. So many people assume a simplified view of either being completely incapable or completely capable. Asking them to treat you as an individual with strengths and weaknesses seems to be too much trouble for most people.” Leibowitz and
McDonald, like the autoethnographers discussed in Chapter 5, identify the frustration of others’ rigid expectations of either normativity or nonnormativity, rather than a recognition of the complex realities of disabled experience. In this way, readers of the blog who have similar experiences in their own lives are able to contribute, simultaneously responding to the original writer, sharing their own experiences, and drawing support from the small but substantial community that grows up around a single blog post. Creating a relational community where multiple voices engage in dialogue about similar experiences can be powerful for many people living with autism who may not have opportunities to connect with others with shared experiences outside of the context of online communication. As Amanda Baggs comments in an NPR interview, “Many of us have a lot of trouble with face to face interaction and are also extremely isolated… A lot of us have trouble with spoken language, and so a lot of us find it easier to write on the Internet than to talk in person. There’s a lot of us where we might not be able to meet anywhere else but online” (Shapiro). Online writing about life with autism opens up space for dialogue and camaraderie among people living with autism, as well as a space to offer narratives which might not be deemed acceptable in other sites.

As noted earlier, there may be some limitations to the range of readers of this, and any, blog, leading to more convergence than divergence of perspectives among writers and readers, as people tend to choose to read blogs that resonate with their own views. However, there is certainly potential for interaction among conflicting views and voices on websites, blogs, and other forms of online presence, and as the genre of online life writing about autism and other disabilities develops further, perhaps such dialogic interaction will continue to grow. As with most topics, there is a wealth of information
about autism available online, much of it from “official” sources and organizations, including the medical and psychiatric, such as the American Psychiatric Association (APA), whose *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is the authoritative source on diagnostic criteria for autism spectrum disorder, and large “science and advocacy” organizations like the Autism Society and Autism Speaks (“About Us”). James Wilson points out that many of these websites “tend to reinforce the worst possible stereotypes about people with autism” (20), such as that included in the “Founder’s Message” by Bob and Suzanne Wright on the Autism Speaks site, which explains, “In 2004, our grandson was diagnosed with autism. Helpless, we watched him slip away into the cruel embrace of this disorder” (qtd. in Wilson 20).

Narratives from the perspective of people living with autism and other disabilities offer alternatives to these sorts of stereotypes, often explicitly, offering a starting point for dialogic interaction among discourses in the online sphere. For instance, in a post on *We Are Like Your Child* called “I Am Autistic,” Heather Johnson outlines her recent autism diagnosis, including extensive quotations from her doctor’s evaluations. Johnson is categorized as “Level 3 – Requiring very substantial support” (Johnson), which is the most severe level in the classification system in the DSM-5. Johnson comments, “So, what does this mean? Well, it means, dear concerned parent of a child with autism, I am not ‘high functioning autistic.’ … It means I am more like your ‘severely autistic’ child than you think.” However, despite her diagnosis of fairly severe autism, Johnson is a mother of two boys (also on the autism spectrum), counteracting expectations of what a severely autistic adult might look like or be capable of. Johnson makes a case for acceptance of people with disabilities like herself, even though they may not neatly match
expectations. In her own case, she writes, “I may have much knowledge gained from memorizing books but it doesn’t mean I can apply it effectively. Just because I can type doesn’t mean I can talk. … Just because I can type, doesn’t mean I don’t have executive function issues.” One ability is not a predictor of other abilities, but at the same time a diagnosis of disability does not preclude other abilities or accomplishments. Similarly, Johnson’s point that being able to communicate through typing does not necessarily mean the ability to communicate through speech reinforces the need for attention to all forms of communication, whether through speech, writing, or body language. Blogs obviously value a particular form of verbal, written communication, and not all people with autism may be able to communicate in this way, but it is, as noted above, a mode that is accessible to far more people than autism than is much face-to-face or oral communication.

Since most blogs, including We Are Like Your Child, are text-based, they do not typically offer opportunities for the sort of rhetorical listening to embodied rhetoric that is often vital to acknowledging the personhood and selfhood of autistic individuals who are nonverbal. However, as Heather Johnson’s account indicates, many autistic bloggers are largely or entirely non-speaking, and the opportunities for expression in writing made available by online platforms enables communication that face-to-face interaction may not offer. While technological developments have made it easier for many nonverbal people to communicate through a variety of text-to-speech devices, there are also often challenges in dealing with social interaction and behaving in normative ways that non-autistic people recognize or accept. As discussed in Chapter 4, there are also many people with severe autism who may never develop conventional speech or writing skills.
Although autistic bloggers possess writing abilities that may not be shared by everyone with autism, the insights they provide into their own experiences can encourage more sensitive attention to all of the ways that people with autism may communicate. In a post titled “Talking Is Hard,” blogger Chavisory (who also has a personal blog, Chavisory’s Notebook) explains that though she is capable of speech, “Talking is almost always an unnatural way to communicate for me. … The strain of doing it too much feels very similar to that of having to multitask too much for too long.” She explains that sometimes she takes “non-speaking days” in order to recharge, and suggests that others might need such down time as well. Her posting calls for greater sensitivity to the difficulties that autistic people may have with spoken communication even when they are capable of it, and encourages parents of autistic children to consider her experience in relation to that of their own children. Reader Nicole comments, “[M]y daughter likes to talk, but she enjoys lots of scripts[,] finds it easier to communicate in one or two words than longer sentences… She also find[s] answering questions so difficult… Its such a fine line between trying to help equip your child so they can communicate their needs to others, and not to push them having to talk more than they want to.” Chavisory’s sharing of her own fraught relationship with speech, but also her self-consciousness and ability to reflect on her experience, promotes recognition of her own selfhood and perhaps that of other autistic people, whether or not they are capable of speech and writing.

Finally, much of the writing that I have discussed so far might fall into the category of autoethnographic writing which responds to and often challenges others’ representations of oneself or others like oneself. Johnson’s description of herself and her diagnosis, above, is a clear example of this, as she cites verbatim her doctor’s evaluation
of her (“Ms. Johnson shows deficits in social-emotional reciprocity. She fails in social approach…and failure of back-and-forth conversation”) and then works to refute the expectations one might have of someone with such a diagnosis. In line with the title of We Are Like Your Child, Johnson and other posters often address parents’ concerns that the autistic adults who write books and blogs such as this one are functioning at a higher level than their own autistic children, and so cannot help them understand their children’s diagnosis or experience. Johnson directly addresses such parents: “I am now 37 years old. How old is your child? Five? Three? And you want to compare his current functioning level to mine?? … I am always improving. Always adapting. So will your child. Please, though, stop comparing your children to the autistic adults you come across.” She offers her own insight as a means to challenge preconceptions about people with autism and to demonstrate her own individuality, including both abilities and disabilities. She also stresses the importance of context in understanding disability and identity; age, history, situation, and relationships all play a role in the experience of autism, and every person’s experience will be somewhat different. The writers on this blog may be “like” your child, but as Johnson suggests, comparisons must be tempered by the knowledge born of relationships with individuals. Importantly, autoethnographic writing in online spaces like blogs creates opportunities not only for autistic people to challenge existing representations of autism and to create their own, but also for people with related experiences and conceptions of autism to find community and work together to establish a presence in the ever-growing and evolving discourse surrounding autism. This does not mean that all people with autism have or claim the same identity; rather, online writing offers a space where these writers can make these autoethnographic moves
and can engage in debate with others, including autistic others, who may have other views and ideas about how autism should be represented.

Online life writing consists of an evolving group of genres and forms, including blogs, websites, online videos, and self-published texts. The Internet has made writing publicly about one’s own life increasingly possible for people with disabilities who may otherwise have no way of representing themselves to others. While, as Jaeger notes, there are still many improvements to be made to achieve universal online accessibility, for many people with autism, the Internet offers unprecedented opportunities to connect and communicate with other people and to share their own stories and experiences. In this way, online writing also makes the development of relationships easier than ever before, particularly for people with disabilities that impede social interaction and communication: as Judy Singer observes, “[The Internet] has begun to do what was thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society” (67). Beyond developing relationships with other people with autism, online writing also encourages the development of relationships between autistic writers and non-autistic readers, and it makes possible the sort of interaction of multiple voices, whether in dialogue or, potentially, dialogic ways, that is unlikely or even impossible in traditional published writing. The immediacy of online writing, though it may lead to a limited “shelf life” for digital texts, also has the benefit of enabling real-time reflections on life experiences and current events, along with immediate responses from readers and potential dialogue between writer and reader. The relationality of such life writing is heightened by the immediacy and the increased
opportunities for interaction among people in relationship with one another and with the

As online life writing makes possible greater access to writing and publishing
venues, expands the potential audience for everyday life writers with disabilities, and
creates new opportunities for relational writing and living, it also encourages greater
diversity of stories about autistic experience, an expanded recognition of the types and
roles of relationships possible for autistic people, and greater acknowledgment of the
importance of context in understanding what it means to live a life with autism. Greater
access to stories of autism in the context of different relationships leads to greater
recognition that disability narrative and identity are contextual, formed by experience,
circumstances, and relationships. These online texts, like the published texts I have
discussed in each of my chapters, make use of strategies of relational writing including
metaphor, interpretation of embodied rhetoric, resistance to common narrative structures,
and autoethnography, in order to demonstrate that people with autism are in fact human
persons and autobiographical selves who have both the ability and the right to tell their
own stories, even if their lives and identities do not follow normative patterns. The
multivocal nature of many blogs, involving multiple authors and sites for instant
commentary, makes possible new and exciting opportunities for relationships between
writers and readers, between disabled and nondisabled individuals, and between
normative and nonnormative stories and experiences. Online life writing may have the
capacity to extend the possibilities for relationality even further than traditional published
texts, providing new and ever-evolving contexts for the development of autistic narrative,
identity, and relationship.
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