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The New Normal: Families, Caretakers, and Adults with Autism

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Abstract

Over the last several decades, the clinical prevalence of autism has increased considerably, as has the amount of popular and scientific attention directed towards the condition. However, discussions of autism tend to focus on children and finding a cause and a cure, while the growing numbers of adults diagnosed with autism have received relatively little attention. This dissertation begins with the argument that popular representations of autism are shaped by the idealism of modern medicine, and its overriding search to discover etiologies and treatments for all forms of biological difference that fall within its purview. And yet, for those responsible for adults with autism, management, care, and support are more relevant concerns to everyday experience than are cause and cure. In order to describe and analyze this everyday experience, this dissertation features a three-year ethnographic study of thirteen families with adult members with severe forms of autism. After reviewing pertinent historical and demographic information, the body of the manuscript explores: 1) the process by which caretakers negotiate between different definitions of problem behavior in the face of persistent situational complexity and ambiguity; 2) the contextual dynamics that make it possible for caretakers to perceive as innocent and/or humorous behaviors that are often viewed as atypical by others; and 3) the ways in which the experience of continued atypicality and dependency comes into conflict with popular representations of autism while at the same time highlighting the reality of the ever-looming future and the care and support required after primary caretakers are gone. At the end of the dissertation, I return to the argument that modern medical idealism discourages popular recognition that, in the case of autism, continued atypicality and dependency constitute the condition's usual prognosis. I conclude with a short consideration of how the themes explored in this thesis resonate with the experiences of those living with or alongside other forms of biological difference (e.g. disability, mental illness, Alzehemier's) that are currently incurable.

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THE NEW NORMAL: FAMILIES, CARETAKERS, AND ADULTS WITH AUTISM

Benjamin DiCicco-Bloom

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THE NEW NORMAL: FAMILIES, CARETAKERS, AND ADULTS WITH AUTISM

This dissertation is dedicated to my parents,

Barbara and Emanuel DiCicco-Bloom

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Ethnography is a very personal research method. It relies on the willingness of individuals who may gain nothing from the research to allow a stranger into their lives. For this alone, I have reason to be grateful to everyone who participated in this study. But the families I spent time with over the course of this project were much more than just research participants. They were friends, teachers, relatives I didn’t know I had, making room for me in their already busy and complex lives so that I could learn a thing or two. As I hope the pages of this dissertation make clear, I learned a lot from their impressive knowledge of and experience with autism. But I also learned a lot from their generosity and perseverance in the context of complexly challenging and rewarding lives. At a time when I was questioning my occupational pursuits, many of them allowed me to move into their homes and collectively reminded me why I wanted to be a sociologist in the first place. For all these reasons, I will always be in their debt. I also want to thank the professionals who participated in this study. Often they were like family to the families I got to know, and so the aforementioned debt extends to them as well.

Among all the faculty at the University of Pennsylvania that played a part in my graduate education, David R. Gibson is the one I can most easily describe as a friend. He always answered e-mails, took calls and meetings, talked me through my work, and kept me laughing. I co-wrote my first publication with him, and in order to explore the relationship between theory and games and, later on, plan my dissertation research, he, his son, and his wife (an accomplished sociologist as well) welcomed me into their home on several occasions. David (now at Notre Dame) remains my friend to this day, and I

look forward to continued laughs and intellectual exchange. I can confidently say that the chair of my dissertation, Charles L. Bosk, is the reason that I got into Sociology. It was while reading Chuck's wonderful book *Forgive and Remember* as a freshman in college that I thought to myself, "I think I could do this for a career." His influence on my intellectual evolution has been as imaginative and colorful as he is, and I count myself as a member of that cohort of University of Pennsylvania graduates who knowingly describe themselves as "Chuck Students." Though he was a latecomer to my dissertation committee, Jason Schnittker was a wise choice indeed. Though his suggestions were always short, sweet, and to the point, they usually led me to completely rework the structure of my arguments. His knowledge of medical sociology also helped me to avoid several weak arguments in my writing (and, of course, any that remain are my own responsibility).

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ABSTRACT

THE NEW NORMAL: FAMILIES, CARETAKERS, AND ADULTS WITH AUTISM

Benjamin DiCicco-Bloom

Dr. Charles L. Bosk

Over the last several decades, the clinical prevalence of autism has increased considerably, as has the amount of popular and scientific attention directed towards the condition. However, discussions of autism tend to focus on children and finding a cause and a cure, while the growing numbers of adults diagnosed with autism have received relatively little attention. This dissertation begins with the argument that popular representations of autism are shaped by the idealism of modern medicine, and its overriding search to discover etiologies and treatments for all forms of biological difference that fall within its purview. And yet, for those responsible for adults with autism, management, care, and support are more relevant concerns to everyday experience than are cause and cure. In order to describe and analyze this everyday experience, this dissertation features a three-year ethnographic study of thirteen families with adult members with severe forms of autism. After reviewing pertinent historical and demographic information, the body of the manuscript explores: 1) the process by which caretakers negotiate between different definitions of problem behavior in the face of persistent situational complexity and ambiguity; 2) the contextual dynamics that make it possible for caretakers to perceive as innocent and/or humorous behaviors that are often viewed as atypical by others; and 3) the ways in which the experience of continued atypicality and dependency comes into conflict with popular representations of autism while at the same time highlighting the reality of the ever-looming future and the care and support required after primary caretakers are gone. At the end of the dissertation, I return to the argument that modern medical idealism discourages popular recognition that, in the case of autism, continued atypicality and dependency constitute the condition's usual prognosis. I conclude with a short consideration of how the themes explored in this thesis resonate with the experiences of those living with or alongside other forms of biological difference (e.g. disability, mental illness, Alzehemier's) that are currently incurable.

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CHAPTER 1

Introduction

Over the last several decades the number of individuals diagnosed with autism, a neurological disorder associated with impaired social ability and restrictive and repetitive patterns of behavior, has increased considerably (Fombonne 2003, 2009; Matson and Kozlowski 2011). Occurring in tandem with the increase in autism prevalence has been a considerable growth in popular and scientific recognition of and interest in the condition (Grinker 2007). However, much of the attention on autism has remained focused on children with the condition while adults with autism have been the focus of relatively little interest (Stevenson, Harp and Gernsbacher 2011; Baily 2012; Greenfeld 2009a, 2009b, 2009c; Wright et al. 2013). The imbalance between children with autism and adults with autism remains an issue even though people who qualify for the diagnosis as children often continue to qualify for the diagnosis throughout adulthood. Drawing on sociological theory concerning the medical model of difference, it can be argued that one of the primary reasons discussions of autism have remained focused on youth is that we continue to speak about autism—both explicitly and implicitly—in ways that suggest that the most important priority is to figure out what causes it and how to cure it.

There are a variety of ways that we might define and represent autism. For example, we might characterize it as a form of diversity, a human difference that is best understood in relation to the environment in which it is situated (Goode 1994; Nadeson 2005; Ortega 2009). Or we might describe those with autism as representing an interest group looking to secure social recognition and services commensurate with their history and location in society. However at present autism is largely characterized as a biomedical entity: a condition that is housed in a person's biology and best measured through clinical-scientific assessment techniques (Rothstein 2012; Gotham et al. 2008; also see Mercer 1973). There is much to recommend the biomedical view of autism: evidence shows that—even if there is no "autism biomarker"[1]—there are considerable genetic, neurological, and cognitive differences associated (to varying degrees) with many individuals with the diagnosis (Frith 2003; Happé 1994; Grandin 2006). Moreover, the perceptual and interactional differences that accompany autism often create considerable barriers to typical social integration and can create a wide variety of negative outcomes for those with the diagnosis (Williams 1992, 1994, 1998; Grandin 1986; Mazurek 2013; Taylor and Seltzer; Shattuck et al. 2012). The medical model is a potentially effective way to signal the social burdens associated with these differences. However, viewing autism in this way can also encourage stakeholders to hope for the kinds of miraculous fixes that often get associated with modern medicine in the popular imagination.

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[1] A biological marker is an indicator of a biological state: "Biomarkers need to be measurable, associated with the particular condition and stable or predictable across and within individuals. Biomarkers can be measured using various biological samples, including blood, urine or saliva. There is increased interest among researchers in so-called neuromarkers, which are biomarkers based on measures of neurochemicals in the cerebrospinal fluid, brain structure measured using MRI, and/or brain function" (Walsh et al. 2011: 605). Biomarkers have several applications including (1) that they can be viewed as risk factors increasing an individual's susceptibility for a condition, (2) they can be used to improve diagnosis and prognostication, and (3) they may be used to develop personalized treatments and measure treatment outcomes over time (Walsh et al. 2011). A variety of autism biomarkers have been proposed, "but as of yet none has been validated for clinical use" (Walsh et al. 2011: 605).

Since the behaviors that are associated with autism show themselves in childhood, the medical model focuses the attention and resources of stakeholders on children with the diagnosis, and encourages the pursuit of treatments with the assumption that "early intervention" can change the course of atypical development and, best case scenario, will discover methods to "defeat" autism (Eyal et al. 2010; Eyal 2013; Fitzpatrick 2009: Silverman 2012; Valentine 2010).[2] A wide variety of stakeholders support the medical model of autism to varying degrees in part because it mobilizes hope. For example, the possibility of finding a cure for autism can be a powerful antidote to parents and other caretakers concerned about the prospect of life-long atypicality (Feinstein 2010; Greenfeld 2009a; Greenfeld 2010; Newschaffer and Curran 2003; Offit 2008). Yet there are some considerable costs that attend the mission of finding a cause and a cure for autism. Among these is the reality that by focusing attention and resources on science into etiology and treatment, we have diminished awareness of and resources for the many who continue to have autism throughout their lives (Eyal et al. 2010; Eyal 2013). A review of some of the social and historical changes that have animated modern medical research and practice will contribute to an understanding of why an increased focus on etiology and treatment is often associated with a decreased focus on long-term outcomes.

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[2] In the words of Silverman: "Medical and popular understandings of development both reflect and promote invisibilities in care and lapses in services. The definition of autism as a disorder of childhood has had tragic consequences for families of adults with disabilities who have fallen outside the purview of state-sponsored educational or therapeutic programs" (2012: 17).

Autism joins a list of popular social problems that have been the target of medicalization, a process by which phenomena (which could be defined as moral, social, or legal) come to be defined and treated as medical conditions. As one of the most powerful arenas through which the "social problems"[3] of the 20th century have been addressed, the language of medicine has been applied to an increasing variety of troubling phenomena (Conrad and Schnieder 1992; Zola 1972). This stems directly from the notable successes of clinical intervention in the first half of the 20th century, and the attendant increase in public and institutional praise, support, and lobbying for medical science energized by this success (Starr 1982). One of the effects of medicalization has been a mania for "specificity," the idea of a perfect "correspondence between pathological mechanisms, diagnostic categories, and disease specific-treatments" (Silverman 2012: 13). However, in a recent article questioning the utopian goals of biomedical science, Neuman and Bosk (2013) argue that "all scientific research necessitates some degree of abstraction," and too often health policy fails to acknowledge, "that the very acts of categorization and measurement required for research to proceed also create important rifts between clinical research and clinical reality" (1177). Thus, it is not surprising, for example, that an increasing number of writers and public commentators have produced critical analyses of the medicalization of social problems that consider both the benefits *and* the costs of applying medical concepts and language to solving issues like hyperactivity, mental illness, and aging (Mishler 1983;

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[3] The social problems tradition analyzes processes of collective definition that shape problems as worthy of public attention (Blumer 1971; Gusfield 1981; Hilgartner and Bosk 1988; Eyal 2013).

Conrad 2007).[4] Specific to autism, recent advocates and writers have wondered, "to what extent the focus on prevention and treatment means valuing or devaluing lives of affected individuals" (Rothstein 2012:114-115). However, the potential dark sides of speaking about autism as a medical entity go beyond undermining "neurodiversity," an appreciation of the strengths and talents of those with the condition (Happé and Frith 2010; Kapp et al. 2012; Robertson 2010). Indeed, possibly the most damaging result of the search for treatment is an attendant lack of recognition and exploration of "prognosis," or the long-term trajectory of the behaviors, challenges, and individuals associated with the diagnosis.

Offsetting modern medicine's increased focus on etiology, pathology, and treatment, has been a decreased interest in conceptualizing and exploring prognosis. Medicine has not always viewed prognosis as unimportant. Indeed, when medicine had few effective interventions, the focus of most clinicians was precisely on describing the "natural history" and "long term" outcomes of the disease entities they handled. However, once effective therapies began to be discovered—for a comparatively impressive, if not unlimited, array of conditions (e.g. smallpox, tuberculosis, whopping cough, measles)—the focus of medical knowledge shifted to finding a cause and a cure for any and all conditions of interest. In an article exploring this evolution, Nicholas Christakis (1997) uses changes in the conceptualization of lobar pneumonia to document

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[4] Of course, both the Internet and the consumerization of medicine have challenged the authority of clinicians even as it has spread the application of medical language beyond the bounds of medical institutions (Conrad 2007).

how this shift in priorities brought about an “ellipsis” or increasing disinterest in exploring or even talking about prognosis:

> Before the emergence of effective therapy, physicians viewed symptoms against the ground of “natural history,” which is how they understood what was happening to the patient. After the emergence of effective therapy, disease was no longer expected to pursue a “natural” course (indeed, pursuit of a natural course was viewed unfavorably). The new ground is that of effective therapy, and symptoms, which indicate that therapy is not effective, are singled out as particularly problematic [. . .] Technical advances and discoveries since the turn of the century have held such promise that society has endowed physicians with the duty and the privilege to eradicate disease. From the triumphalist perspective, death connotes failure—not just of the therapeutic armamentarium to achieve its objective, but also of the physician to fulfill his or her social role (305-306, 314).

With his analysis of a popular medical textbook over the course of decades, Christakis demonstrates how the introduction of antibiotics as a relatively effective treatment for pneumonia meant that the typical course of the condition was transformed into one where diagnosis was followed by treatment and cure. Thus, what was once “natural” or “typical”—that a person with pneumonia would go through a bumpy course of symptoms before getting better (or perishing)—had now been transformed into what clinicians described as an “atypical” course (Christakis 1997). Though demonstrated in the case of lobar pneumonia, the increased focus on etiology and treatment and decreased focus on natural (i.e. untreatable) course and prognosis describe the changing conceptualization of many conditions to which the medical model is applied. While Christakis’s (1997) article considers how the focus of doctor’s has been transformed, research has explored how others, including patients and caretakers, are also complicit in encouraging research into cause and cure (Christakis 1999; Conrad 2007; Fitzpatrick 2009; Silverman 2012). This includes stakeholders associated with conditions that, like pneumonia, are contagious and threaten life, as well as stakeholders that are associated with conditions, like autism, that are neither contagious, nor deadly, nor generally treatable.

The lack of attention that has been paid to adults with autism is one of the primary costs of viewing the condition through the concepts and world-view of the modern medical model. There are several ways in which autism is not like lobar pneumonia. For one, it is not infectious. Secondly, we do not yet have a clear understanding of its etiology. Thirdly, autism is not life threatening. And finally, there are no generally accepted therapeutic options that actually cure autism. Christakis (1997) hypothesizes in his article that "we would expect that when therapeutic options are substantial, prognosis would be relatively neglected—in large part because the prognosis would be assumed" (301). However, it seems that in the case of autism, the lack of therapeutic options that actually cure autism has not accrued in an increased focus on prognosis. Rather, despite the reality that most children with autism grow up into adults with autism, a majority of the discussions around the diagnosis are still focused on the etiology, pathology, and treatment of children with the condition. While the value that modern medicine places on etiology and treatment makes more sense when applied to those conditions that are life threatening and for which effective treatment is available, an overwhelming focus on cause and cure has some particularly troubling consequences when applied to conditions like autism that are generally neither treatable nor deadly. Reframing Christakis' summation that "death connotes failure," it would appear in the case of autism that failure (to cure) has been translated into a form of (social) death. In other words, it is not that adults with autism do not exist; indeed, they exist in sizeable numbers. Rather, it is a property of the knowledge that we have created about autism, the goals and assumptions that undergird our understanding of autism, that drives the sense that adults with autism do not exist or are not important. It is for this reason that this dissertation uses ethnography, a form of data collection well suited to exploring phenomena and experiences that are invisible because of the way in which those phenomena are popularly conceptualized in the public sphere.

In order to understand autism in a way that begins to describe the social reality of adults with the diagnosis, this dissertation will employ ethnographic methods to explore the continued atypicality and dependency that are associated with many individuals with the condition as they age. Using the medical model to talk about autism has meant that we have understood autism as a biological condition that children have. At the same time, it has meant downplaying the social elements of the condition and the reality that most people with autism are adults (Bishop-Fitzpatrick, Minshew and Eack 2013). Ethnography is a method that relies on interviews, participant observation, and forms of social emersion over an extended period of time in order to record and analyze the meanings that people assign to their experience. It is suited to gaining purchase on a variety of phenomena that may, for various reasons, elude other forms of data collection and analysis. One of the primary characteristics shared by questions that are best addressed through ethnographic investigation are those related to topics that are, for various reasons, “hidden in the foundations of the social world” (Katz 2012: 272; Katz 1997). Because autism has been described as a condition of childhood—a biological entity that should be understood through etiology, pathology, and treatment—we have collected relatively little data about those with the condition that live into adulthood, and particularly little about their social (as opposed to biological) reality.

Another group of phenomena that are well suited to ethnography are those that—because of their particular characteristics—represent with "special clarity phenomena that exist widely but in diluted form elsewhere" (Katz 2012: 259; Durkheim 1982). Since popular discussions around autism tend to explicitly and implicitly direct focus towards the potential for treatment and cure, recognition and discussion of the reality of continued atypicality and dependency for many adults with the condition, particularly those with severe autism, are implicitly discouraged. While the specific characteristics that qualify an individual for a diagnosis of autism have considerable differences from other developmental disabilities, physical disabilities, and chronic illnesses, the reality that many such conditions are difficult to cure means that atypicality and dependency represent important components of the lived reality of those conditions as well. An ethnographic investigation of autism in adulthood presents the possibility of understanding the disservice rendered by the assumptions of the medical model when applied to conditions that elude treatment. Put differently, "ethnography can help to map out the differences between what health policy asks of clinical research and what such research is actually equipped to provide" (Neuman and Bosk 2013: 1177). Though Neuman and Bosk (2013) addressed this comment to the expectations placed on clinical trials and effectiveness studies, it is possible to extend their insights to the many conditions whose nature and reality have the potential to be misrepresented by the utopianism of modern medicine. While the ethnographic data analyzed in this dissertation is specific to a variety of individuals caring for adults with severe autism, the themes explored have relevance to other medicalized conditions for which magic bullets have remained elusive and the social mechanisms of care, management, and support are paramount.

In order to explore the symbolic and social reality of severe autism and the prognosis of atypicality and dependency with which it is often associated, this dissertation focuses on those responsible and caring for adults whom are diagnosed with significant forms of the condition. At its core, this dissertation follows thirteen families caring for individuals with severe autism. As defined in this study and more generally, “significant” and “severe” translates into having or qualifying for a diagnosis of intellectual disability (a comorbidity, in the language of medicine) alongside autism. This population often requires more substantial support than individuals with higher functioning forms of autism (e.g. Asperger’s Syndrome) whose atypicality has been increasingly associated with the successes of silicon valley or the erratic behavior of famous artists, writers, and thinkers (Silberman 2001; Fitzgerald 2006). Unless otherwise stated, when I use the term autism in this dissertation I am referring to those with more severe forms of autism. Recent critiques of the study of autism have described the way in which those texts that do focus on the social reality of the condition tend to derive their perspective from the voices and concerns of those connected to but who do not have the diagnosis (Murray 2008). While this might be partially ameliorated by speaking to individuals with higher functioning forms of autism, the issue faced when trying to measure the social reality of those with more severe autism is that the impairments and behaviors associated with their condition *undermine their ability to produce the interpretive descriptions of experience that are an important component of ethnographic findings*. Though one might gain information about the social reality of those with significant autism by interacting with them in others ways—which I do—the value placed on meaning in ethnographic methods, and qualitative sociology more broadly, is often intimately linked to individuals speaking about their experience. The goal of this study is to understand the social reality of autism in adulthood, and what continuing atypicality and dependency mean to those responsible and caring for adults with autism. In order to achieve this, this dissertation analyzes the experienced of families and other caretakers as they live with, manage the behavior of, and care and support adults with severe autism. The main questions that this study seeks to address include: what does the behavior of adults with autism look like in the social settings in which they are located? What does the everyday life of families and other caretakers of adults with autism look like? How do caretakers interpret and respond to the atypicality of adults with autism? How do they interpret and respond to the dependency of adults with autism? The rest of the dissertation is organized into five chapters as follows.

In Chapter 2, I describe the early history and formalization of autism, the social processes that have contributed to the increasing number of children diagnosed with the condition, and a review of the small but growing literature on adults with autism. Though this is a dissertation in sociology, much of the study of autism has been in disciplines like psychiatry, epidemiology, and neurology, and in the literature review I draw on work from these and other fields. This chapter is not meant to provide an exhaustive review of the massive literature on autism, but rather to provide targeted information in which to place recent descriptions of the “crisis of autism in adulthood” into a historical (and less hysterical) context. The literature review suggests that the challenges faced by families with adults with autism have a long history. It also suggests that the limitations of contemporary discourse around autism make it important to explore the atypicality and dependency associated with the condition in the context of the social milieu in which it is embedded. In so doing, I hope to uncover and rediscover those parts of the experience that do not accord with the concepts and language that often attach themselves to modern medicine and the conditions that fall into its purview. I then go on to describe the study participants, the methods I used to collect and analyze my data, and some other notes about the logic and structure of the dissertation.

In Chapter 3, I describe and analyze how caretakers interpret and respond to problem or “maladaptive” behaviors in adults with autism. As an individual with autism ages into adolescence and early adulthood, maladaptive behavior—including aggression, self-injury, and other forms of socially inappropriate actions—can become an increasingly difficult problem. Though such behaviors are not unknown in childhood, the physical maturing of an individual with autism only makes these behaviors more dangerous and challenging to manage by those caring for them. Drawing on the sociological literature of deviance, medicalization, social problems, framing, and symbolic interactionism, this chapter seeks to understand the process by which caretakers frame (define), interpret (explain), and socially control (respond to) the maladaptive behaviors of adults with autism. The chapter finds that though caretakers draw on frames of deviance (sickness, badness, handicap) evidenced in both popular and historical cases of deviance, application of these different frames in everyday life must contend with the complexity and opposing definitions that are available in naturalistic situations. In order to theoretically account for the tensions and negotiations that characterize this process, I employ concepts from both Goffmanian structuralism (with its focus on frames, or popular definitions of deviance) with those of symbolic interactionism (with its focus on situations, and the context of meaning). In so doing, I contribute to sociological theory by exploring how the seemingly oppositional conceptions of social interaction put forth by Goffman and Symbolic Interactionists can and do coexist in everyday life. The chapter concludes with a discussion of how the causal narratives and metaphors applied by both professionals and laypeople to various forms of atypicality are always open to challenge by the often-unremitting complexity and ambiguity that lurk under the surface of all social interaction.

In Chapter 4, I explore one of the more positive findings in this study of individuals caring for adults with autism. Many have complained about popular descriptions that suggest that autism, and those who have the diagnosis, constitute a tragedy. While it is true that some elements of the experience of caretakers of adults with autism are best characterized as a form of chronic sorrow (grief linked to a “living loss”), these elements often exist side by side with elements of the experience of caretaking that were defined as very positive. Two such elements that found expression in many of the relationships I observed were the experience of innocence and humor that characterized caretaker's interactions with adults with autism. Drawing on sociological theory from the study of humor, adolescent development, childhood, and social interaction, I explore the social dynamics that allowed for the atypicality and dependency of adults with autism to be experienced as innocent and humorous. The chapter concludes with a discussion of the reality that, despite critiques of those who have romanticized autism, caretakers who experience the brunt of the challenges associated with the condition often themselves describe positive experiences that derive from what some might view as a "tragedy" or a "living loss."

In chapter 5 I explore in more depth the ways in which the empirical reality of caring for adults with autism stands in opposition with the fundamental assumptions that undergird the medical language and images associated with popular representations of the condition. As explored in this introduction, the language of the medical model pervades the way that we talk about autism. However, the "clinical view," as some theorists describe the lens through which atypicality is understand and addressed medically, tends to get applied to two very different kinds of abnormality. The first, pathological abnormality, describes conditions that actually threaten the fundamental operation of an organism. The second, statistical abnormality, describe conditions which, though they are sometimes linked to varying degrees of dependency and atypicality, are not life threatening. The issue with describing both of these with the clinical view or the language of medicine (e.g. symptoms, etiology, pathology, treatment) is that we can begin to think about conditions best described as statistical as if they were actually pathological. This chapter explores how the experience of caretakers of adults with autism challenges the language of pathology that sometimes permeates the way that autism is discussed in the public sphere. This includes suggestions (literal and metaphorical) that individuals with autism do not continue to exist and grow. It also includes suggestions that when an individual with autism does show improvement, it is akin to a cure for autism as opposed to something less miraculous, more gradual, and considerably uneven.

In the second half of Chapter 5 I draw on sociological theory concerning the process by which people anticipate the future in order to explore the ways in which responses to continue atypicality and dependency shape the experience of caretakers of adults with autism. The first half of Chapter 5 demonstrates that in contrast to popular representations of autism, individuals with the diagnosis continue to survive and develop (albeit in the context of atypicality and dependency). This reality means that while growth and development are an important part of the experience of those with autism and their caretakers, planning for future support needs is an ever present challenge hanging over those associated with the individual with the condition. In order to explore the ways in which caretakers conceptualize and respond to this challenge, I look to see how their actions vis-à-vis the future unfold on multiple levels or modes of future coordination. I find that the ambivalence and complexity that surround a problem that many argue lacks an entirely satisfying solution can be viewed in the ways in which actions coordinated to different modes of the future seem to come into subtle or explicit conflict with one another. I conclude the chapter with a discussion of how the use of pathological language in the case of other forms of non-lethal (or non-acute) abnormality (e.g. mental illness) continues to discourage recognition of important realities. Though the focus on cause and cure makes more sense when dealing with pathological abnormality, when dealing with non-curable statistical abnormality the language of pathology discourages recognition and discussion of the importance and challenges of securing management, support, and care in the future.

In Chapter 6, I conclude the dissertation by returning to a discussion of the ways in which the orientation of modern medicine does a disservice to the lived experience of caretakers of adults with autism and individuals with other forms of significant atypicality and dependency. The triumphs of modern medicine have encouraged viewing clinical conditions as ontological entities in which etiological and pathological mechanisms, diagnostic categories, and disease specific-treatments clearly correspond. This evolution is in keeping with the successes and optimism of 20th century healthcare, and the continued suppression or "ellipsis" of outcomes that do not conform to preferred ends. However, given important demographic (aging population) and epidemiological (the "transition" to chronic illness) changes, the focus on etiology, pathology, and treatment threatens to push the rhetoric surrounding medicalized abnormalities increasingly out-of-sync with the experiences and needs of those dealing with these conditions in everyday life. We are unable to cure a variety of entities—everything from developmental disabilities to "transmuted" diseases—and yet these conditions place great demands on lay and professional caretakers as those with the diagnoses continue to live albeit atypical and dependent.

I suggest that the other conception of medical entities—the physiological view, which focuses on individual level variation and social context—pushes us to look at the lived experience of such conditions in order to discover understandings and goals that are more in line with the management, car, and support that benefit individuals with these conditions. Since ethnography is highly suited to exploring individual complexity and social contexts, the chapters of this dissertation suggest new concepts and language that potentially provide access to the lived reality of an increasing number of chronic conditions. Genuine representations of the lived reality of these conditions are continually threatened by the progressivism of modern medicine and American culture. I end with a review of each chapter along with extended quotes from a variety of texts that resonate with my findings. This allows for an understanding of how the contours of the lived reality of autism in adulthood might provide important insights into other, increasingly common, ways of being in the world.

CHAPTER 2

LITERATURE REVIEW & METHODS

AUTISM: ITS BIRTH AND EVOLUTION

Like so many other pivotal moments in the history of autism, the story of the diagnosis begins with an interaction between a child, his family, and a professional. Donald had been difficult as a young boy: physically awkward, often withdrawn and unresponsive, and apparently uninterested in human beings. One set of behaviors that stood out were his obsessions, including a "mania for spinning blocks and pans and other round objects" (Donvan and Zucker 2010). From the age of three, his refusal to feed himself, along with other behavioral issues, prompted his doctor to recommend that he be placed in an institutional setting. In accordance with this suggestion, Donald's parents—Mary and Oliver Triplett—placed their son into a state run sanatorium located about 50 miles from their home. Since the sanatorium's primary purpose was to isolate youth thought to be at risk for catching tuberculosis, the staff had little idea how to deal with a child like Donald who was thought to be—even by his own mother—severely mentally ill. For a while he did poorly at the sanatorium, withdrawing further into himself, sitting "motionless, paying no attention to anything" (Donvan and Zucker 2010). However, after some time, he did improve, and began playing alongside, though not with, other children, eating more regularly, and regaining his physical health.

Despite evidence that he was getting used to life at the institution, Donald's parents decided in August 1938 to get him out and take him back home (Donvan and

Zucker 2010). While institutionalization was the default option for all kinds of atypical children at the time, the Triplett's were determined to get a more targeted form of assistance for their son. Though he had become acclimatized to life in his new home, Donald's diagnosis had remained unclear. The director, who tried to convince the Triplett's to leave their son in the institution, could come up with nothing better than "some glandular problem" to account for his atypical behavior (Donvan and Zucker 2010). However, someone specializing in psychiatry at the time would most likely have diagnosed Donald with schizophrenia or feeblemindedness (Trent 1994; Grob 1994; Shorter 1997; Eyal et al. 2010).

'Feeblemindedness,' now a woefully outdated term, was primarily a label for individuals who would today be described as intellectually disabled (Trent 1994). However, a diagnosis of feeblemindedness was also sometimes given to individuals who had IQs greater than seventy, but were for other reasons deemed unfit to live in the community (Trent 1994). Then again, it is likely that some specialists at the time would argue that though Donald was "oddly distant, uninterested in conversation, and awkward in his movements," he had enough striking skills—"flawless ability to name musical notes as they were played on a piano" and "a genius for multiplying numbers in his head,"—that the diagnostic criteria for childhood schizophrenia were a better fit to his condition (Donvan and Zucker 2010; Eyal et al. 2010). Though psychiatrists rarely diagnose schizophrenia in childhood today, back then childhood schizophrenia was a broad and widely used label applied to a variety of youth (Eyal et al. 2010). However, getting a relatively sophisticated diagnosis for Donald relied on attaining access to an individual who had some degree of specialized psychiatric knowledge, and for this the Tripletts would need to travel. Given their resources—Mary came from a wealthy family of financiers, and Oliver was a successful lawyer—they decided to get the best professional help available, and scheduled Donald to see a famous specialist working on the east coast.

In October 1938, Mary, Oliver, and Donald boarded a train for Baltimore in order to go see Leo Kanner[5], an Austrian doctor working at the Johns Hopkins University Hospital, author of the first English-language textbook on child psychiatry, and widely regarded as "the world's foremost expert on childhood emotional development" (Mnookin 2011: 76). Before their trip to Baltimore, Oliver—a high-strung individual, known by those close to him for his moods, intensity, and several nervous breakdowns—spent a period of time writing a detailed letter describing his son's medical and psychological history (Donvan and Zucker 2010). When he had finished the letter, Oliver sent it to Kanner in preparation for their visit (Donvan and Zucker 2010). Though Kanner remarked several times on the "obsessive detail of the letter," its contents offered "the

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[5] Kanner first became known for his research on the mentally retarded. Despite the focus on etiology and treatment that has come to shape our understanding of autism, Kanner's early engagement with developmental disabilities was very much focused on long term outcomes: "Long before his work in autism, he demonstrated profound concern for mentally retarded children at a time when most psychiatrists excluded them from clinics. Significantly, in the 1930s, he undertook a follow-up study of 166 patients who had been released from Maryland state training schools for the retarded via habeas corpus writs secured by lawyers over the previous two decades [. . .] The vast majority, he discovered, had worked as domestic servants before being dismissed as inadequate to the task and ending up in city slums. When Kanner revealed the truth of what was happening in 1938, his paper received massive media coverage leading to action to end the practice of lawyers being able to obtain the release of the mentally retarded into the community" (Feinstein 2010: 23).

first detailed listing of symptoms that are now almost instantly recognizable to anyone who knows autism" (Donvan and Zucker 2010).[6] Soon after the Tripletts visited him, Kanner became conscious of several other children whose unique constellation of behaviors had notable enough similarities to Donald's that he came to believe they constituted a concrete (i.e. categorical) diagnostic entity (Silverman 2012).[7] In 1943, Kanner wrote about eleven such cases that he argued represented an up until then unidentified condition in his now classic paper entitled "Autistic Disturbances of Affective Contact" (Kanner 1943).

Autism[8] was first scientifically described as a standalone diagnosis in 1943, with the main features of the condition including an "extreme aloneness from the very beginning of life" and an intense desire for the "preservation" of "sameness" (Kanner

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[6] Indeed letters and descriptions created by parents like Oliver constituted data and insights that were fundamental to professional understanding about autism. Without the dedication and work of parents—and not just basic information, but complex intellectual analysis—autism would not have been identified and described as it is today. One activist spoke of Kanner's observations about autism parent's and their obsessiveness as follows: "when *he* is struck by the same phenomenon and writes thirty-three pages of detailed description of these children's unusual behavior *based on those mothers' notes and good recall*, he is called 'the father of autism' and hailed as a gifted observer, which, of course, he was" (Sullivan 1984: 239). It is also important to note that, though he later apologized for it, Kanner did express the belief early on (in the Freudian fashion of the day) that parent behavior (e.g. aloofness) might be responsible for a child's autism (Silverman 2012; Dolnick 1998).

[7] However, at first Kanner wondered whether it was childhood schizophrenia, as a journal entry after his first meeting with Donald posed the question: "schizophrenia?" (Donvan and Zucker 2010).

[8] The term autism—derived from the Greek word *autos*, which translates as "self"—can be traced back to the Swiss Psychiatrist Eugene Bleuler. In 1911, Bleuler changed the definition of the popular diagnosis dementia praecox (first described by Emil Kraepelin) and renamed it Schizophrenia (Noll 2011). Listed among the compound symptoms that Bleuler described as definitive of Schizophrenia was "autism": the "detaching" of "oneself from outer reality along with a relative or absolute predominance of inner life" (Bleuler 1911: 304).

1943: 248, 249). Kanner believed that there were five primary features (i.e. diagnostic criteria) that linked Donald (to whose story I will return to later) with the other ten children he wrote about in his paper: 1) "a profound lack of affective contact with other people"; 2) an "obsessive desire for the preservation of sameness in the child's routines and environment"; 3) "a fascination with objects, which are handled with skill in fine motor movements"[9]; 4) "mutism or a kind of language that does not seem intended for interpersonal communication"; and 5) "good cognitive potential shown in feats of memory or skills on performance tests"[10] (Feinstein 2010: 24; Kanner 1943). He ruled out feeblemindedness because of what he argued were significant signs of intelligence, and he ruled out schizophrenia because the condition was apparent from the earliest of days (Kanner 1943). Kanner believed that these five features could be used to differentiate autism from other childhood disorders.

Despite these commonalities, there was an impressive array of diversity in the children that Kanner wrote about. Indeed, one colleague argued that it was a credit to Kanner's prodigious memory that he was able to "sort out the commonalities" of children that he had seen over the course of years "given the disparities in these kids" (Feinstein

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[9] This is just one of the criteria that has been broadened, as many individuals who are diagnosed with autism today struggle with fine motor movements (Volkmar and Wiesner 2009).

[10] This is another of the criteria that has been broadened, since many individuals with more profound, measured intellectual disability have been diagnosed with autism. Of course, there are complications that many have argued call into question Kanner's original assumptions about how intelligence manifests. For example, "sometimes a child with autism may have average or above-average abilities when it comes to tasks that are nonverbal, whereas the same child's ability with verbal tasks can be very significantly delayed" (Volkmar and Wiesner 2009: 5). Suffice it to say that the pattern of cognitive performance in autism tends to be unusual and complicated.

2010: 19). Despite their diversity, Kanner strongly believed and actively pushed for autism's specificity and application to only those cases that clearly fit his definition (Eyal et al. 2010). He argued that autism was a rare condition, and was so upset when the diagnosis began to catch on with psychiatrists (during what one group of authors described as "the first autism epidemic" of "1951-1959") that he wrote: "almost overnight [. . .] the country seems to be populated by a multitude of autistic children, and somehow this trend became noticeable overseas as well" (Kanner 1965: 414; c.f. Eyal et al. 2010: 129).[11] Though this trend passed by 1965 (as the "fashion" moved on to the "brain-injured" child [Eyal et al. 2010: 129]), changes made to the definition and conceptualization of autism in the 1970s allowed for it to be applied to a much more heterogeneous group of individuals than those first described by Kanner's "classic autism."

Since Leo Kanner first introduced the idea of autism to English speakers, the condition's formal and applied definition has changed from one used to describe those with a relatively specific behavioral profile to a label applied to a wide variety of individuals with behaviors that fall within three broad domains. [12] Kanner's

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[11] Kanner goes on to say, "It became habit to dilute the original concept of infantile autism by diagnosing it in many disparate conditions which show one or another isolated symptoms found as a part feature of the overall syndrome" (Kanner 1965L 414; c.f. Eyal et al. 2010: 129). It is likely that Kanner was worried that autism might go the way of Childhood Schizophrenia, which he described at the time as a "pseudo-diagnostic waste basket into which an assortment of heterogeneous conditions were thrown indiscriminately," including "infantile autism" along with "everything else" (Kanner 1965: 417; c.f. Eyal et al. 2010: 128).

[12] Not everything has changed. Even from the earliest of days, finding a cause and a cure was central to autism's conceptualization: "Kanner's ultimate goal was to use his

conceptualization of autism was challenged in the 1970s by research performed by Lorna Wing and Judith Gould (1979) who argued that autism was not a specific and rare disorder, but rather a "spectrum" of impairments that fall within three broad categories: 1) issues with social interaction and 2) social communication, and 3) repetitive and stereotyped behaviors. Wing and Gould started out wanting to show support for Kanner's restrictive criteria, but they found that the idea of a neat barrier between Kanner's autism and other forms was "rubbish" (Feinstein 2010: 151). Though the term autism was present in the official diagnostic document of the American Psychiatric Association from the time it was first published in 1952, the changing definition of the term in successive versions of the *Diagnostic and Statistical Manual of Mental Disorders* (the DSM, often described as the "Bible" of Psychiatry [Shorter 1997]) is a good reflection of the complex evolution of the diagnosis in the professional and public conscience.

When DSM-I was published in 1952, the concept of autism was still formally defined and viewed by many in the world of psychiatry (despite the protestations of Kanner and others) as a behavioral feature (dream-like thinking, withdrawal into oneself) of schizophrenia as opposed to a unique categorical diagnosis (APA 1952: 28; Rimland 1964). Changes over the course of successive versions were considerable. For example, in 1980 the DSM-III assigned autism its own diagnostic category, and by 1987 the "triad of impairments"—based on Wing and Gould's work—was incorporated into the manual (APA 1980; APA 1987). DSM-III also placed autism (along with several other related sub-conditions) under the mantel of Pervasive Developmental Disorders (APA 1980).

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classification as a tool to develop more effective treatments—but before he could do that, he had to determine the disorder's root causes" (Mnookin 2011: 76).

Another change included requiring four out of four criteria symptoms listed in the 1980s to requiring only six out of twelve criteria symptoms in more recent editions (APA 2000). One startling fact (cited as a "remarkable example of the arbitrary nature of diagnostic requirements") is that a typo in the DSM-IV published in 1994 created much less restrictive criteria when an "or" was typed instead of an "and"; one study found that under the mistaken guidelines, four times the number of children could have qualified for a PDD than was originally intended (Mnookin 2011: 83; Kirk and Kutchins 1992). The DSM-IV-TR, the edition that was in use when I began this study, defined autism as qualitative impairments in social interaction and communication, and restrictive, repetitive, and stereotyped patterns of behavior, interests, and activities (APA 2000). It featured multiple sub-types of autism (all placed under the larger heading of pervasive developmental disorders), including Autistic Disorder, Pervasive Developmental Disorder Not Otherwise Specified, and Asperger Syndrome (generally Autistic Disorder is applied to the most impaired, and Asperger Syndrome to the least; in the DSM definition, Asperger Syndrome does not include the impairment in communication).[13]

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[13] With the release of the DSM-5 in 2013, big changes have come again to the formal definition of autism: changes from the DSM-IV diagnosis include "shifting from a multicategorical model to a single diagnostic category of autism spectrum disorder (ASD), replacing the three-domain model with a two-domain model, relaxing the criteria for age at onset, and adding symptoms not previously included in DSM-IV, such as sensory interests and aversions" (Huerta et al. 2012: 1056). In other words, gone are the autism subtypes (e.g. Autistic Disorder), replaced with a severity scale ("requiring very substantial support," "requiring substantial support," "requiring support"), and social interaction and communication have been collapsed into one domain ("persistent deficits in social communication and social interaction") (APA 2013). According to David S. Mandell (in-person conversation), scraping the autism subtypes (which were invalid, as too many people switched between them over the course of development [or between one doctor visit and another]) is a sign that the science of autism diagnosis has failed.

Despite what can easily be viewed as a dry and technical history of psychiatric nosology, the changes to autism in the DSM clearly demonstrate just how much the formal conceptualization of the condition has changed over time. From DSM-I to DSM-5, autism has gone from being described as a manifestation of schizophrenia to a category by which to label a wide variety of individuals sharing a broad spectrum of loosely related impairments. This evolution convincingly suggests that one of the main factors behind the increasing diagnosis of autism is its changing definition. And the broadening of diagnostic criteria and other changes to the formal definition of autism are indeed some of the main factors cited by epidemiologists as responsible for the increase in prevalence (Croen et al. 2002). However despite these arguments, a good deal of the focus on autism over the course of the last decade, and continuing today, remains on why there has been such a sudden increase (Grinker 2007). Some of this focus is driven by the reality that changes to dry technical minutia are a poor match for what appears as, feels like, and is often described as a transformation of epidemic proportions.

And in indeed, changes in definition are not the only thing that explains the increase. One study argues that important preconditions include the deinstitutionalization of children, the return of a population of atypical youth to their homes and school districts, the sudden search on the part of parents for education and other services in the community (as opposed to the old answer of institutionalization, or children hidden from public view), and networks of collaboration, communication, and expertise between caretakers and other, often marginal, professionals (Eyal et al. 2010; Eyal 2013). These details are beyond the scope of this literature review. However, given that autism has come to shape the way we define the needs of a large and heterogeneous group of atypical youth, it is useful to delve deeper into the other main drivers of diagnostic change cited by epidemiologists: “diagnostic switching from other” disorders to autism, “service availability,” and “awareness of autism spectrum disorders” in both the “lay and professional public” (Elsabbagh et al. 2012: 160).

HOW DIAGNOSTIC CHANGE HAPPENS

Autism is a diagnosis that is increasingly applied to individuals who exhibit behaviors that can be characterized as impairments in social interaction and social communication along with repetitive and stereotyped actions and routines. Research shows that though these behaviors tend to co-occur in the population, there is no biomarker for autism—no independent quantitative test against which we can determine whether or not the behaviors being observed belong to an easily identifiable, autonomous biological phenomenon (Happé 1994). Moreover, evidence suggests that these behaviors are linked to a variety of underlying biological processes, a finding that has led many researchers to claim that there are many “autisms” (Coleman and Gillberg 2012; Bentancur 2011). Thus, while the behaviors the diagnosis describes are real, the determination to label such behaviors as representative of autism is a decision made by a clinician using diagnostic instruments[14] which report on observed actions and questions about patient and family history (Johnson and Myers 2007; Rossi 2012; Pinto-Martin et al. 2008; Lord et al. 2011). To understand how the changing official definition of autism, along with more

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[14] Usually using the DSM, but sometimes with more sensitive tools like the Autism Diagnostic Observation Schedule (ADOS) or the Autism Diagnostic Interview (ADI).

awareness and services, has driven an increase in diagnosing individuals exhibiting atypical behavior as autistic, a specific case (maybe best described as a thought experiment) will prove informative.

In the mid-1970s, David Goode (1994) spent time with several children with congenital rubella, a condition that had rendered them deaf, blind, “profoundly mentally retarded” and without any formal language (7). Goode got to know one of these girls, Bianca, over the course of 200 hours of observation and interaction with her and her family in their home (Goode 1994). One of Goode’s interests was to document how the physical and social environment of the family home created opportunities for Bianca’s caretakers to communicate with her in ways that could only be perceived and documented by those embedded in the situation (Goode 1994; Bogdan and Taylor 1989; Gubrium 1986; Pollner and Goode 1990; Pollner and McDonald-Wikler 1985). For example, while an apparently random lift of the hand might seem like just another “symptom” to an outsider, when performed at 10am in the morning at the breakfast table Bianca’s mother knew that her daughter was asking for the milk that she always received at that time (Goode 1994). Goode concluded that “routine constituted so great a communicational resource for the family that in order to understand many of Bianca’s gestures and actions, one already had to be familiar with the routine” (Goode 1994: 68). Goode’s study provided me with thoughtful material and a clear endorsement of the importance of spending extended time with families in their homes. However, his study also serves, though possibly unbeknownst to the author, as a potential case study of an individual who might today be diagnosed with autism.

Though Bianca was diagnosed with congenital rubella back in the 1970s, it is quite possible that today she would be diagnosed with autism. In some cases, congenital rubella gives rise to issues with social interaction, communication, and can lead to repetitive and stereotyped behaviors. Though scientists know that a fetus contracts congenital rubella when the mother gets the rubella virus in the third trimester, the reality that some cases qualify for the criteria of autism allows for the possibility of diagnosis (though, technically, a doctor should rule out autism since the behavior is attributable to another neurological condition). If a doctor saw Bianca today and were to think 'this looks like autism,' even if he knew that it had been caused by rubella, he might still decide to give her a diagnosis of autism. Why? Well for one thing, he has heard of autism (awareness). Also, "part of the reason [children are classified as autistic] is that clinicians are more likely to give a child a diagnosis that he or she thinks will help the child receive the best services or school placement than a diagnosis that conforms to the DSM but will not facilitate the best form of intervention" (Grinker 2007: 141; Shattuck and Grosse 2007; Mandell and Palmer 2005; Palmer et al. 2005). Moreover, even if a clinician was hesitant, parents might push for a diagnosis of autism because it is more common, less stigmatized, and might suggest a better outcome (Grinker 2007; Eyal et al. 2010; Johnson and Myers 2007). Or, and this is another important distinction, an educational institution (as administrative records are one of the sources for data for epidemiological studies) might place a child in the autism category for the sake of services even though a clinician might prefer another diagnosis (though recent surveillance research suggests that the majority of children placed in the special education autism category do meet case criteria for Autism Spectrum Disorder) (Shattuck 2006).

Given these changes, Bianca, from Goode's study, might today have been diagnosed as having autism, and she would have been counted as one among the many children whose diagnoses aggregated together have led to the increasing prevalence and awareness around the disorder. That congenital rubella is a potential cause of the behaviors associated with autism is not a new revelation. Indeed, in (1971) Stella Chess published a paper showing that some children from the U.S. Rubella epidemic of 1964 did qualify for a diagnosis of autism (and this was based on the much more specific diagnostic criteria of the 70s). The process of giving one diagnosis over another is called diagnostic substitution, and its effects on the number of people who are now diagnosed with autism are profound.

Congenital Rubella is a small part of the increases in autism linked to diagnostic substitution (Wing and Potter 2002). Cases making up the largest part of the increase are, on the more impaired end of the spectrum, individuals who would once have been diagnosed as intellectually disabled/mentally retarded[15] (King and Bearman 2009; Shattuck 2006). It is important to note that almost all of the individuals in my study were also diagnosed with or qualified for a diagnosis of ID. Other substitutions include

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[15] Mental Retardation is a now an outdated term, having been replaced by intellectual disability. That being said, some institutions and organizations still refer to intellectual disability (ID) as Mental Retardation (MR). This includes one of the major organizations providing services to individuals with ID, the Association for Retarded Citizens (ARC) (which also provides services to many adults with autism, including some in my study). Throughout this dissertation I will use the term Intellectual Disability unless it conflicts with the use of the term Mental Retardation by the researchers, individuals, or organizations being cited or discussed.

individuals previously diagnosed with schizophrenia, psychosis, emotional disturbance, traumatic brain injury, and other forms of mental illness, disability and developmental delay (Shattuck 2006; Mandell et al. 2012). On the higher end of the spectrum, individuals with language disorders (Bishop et al. 2008), ADHD, and OCD would be included (Gillberg and Billstedt 2000; Liu, King and Bearman 2010). Cases of autism can also be linked to or are associated with tuberous sclerosis complex[16], epilepsy, and Fragile X Syndrome, among other conditions (Newschaffer et al. 2007).

As mentioned earlier, the changing definition of autism in the DSM is one large factor that has made this possible (Kielinen, Linna and Moilanen 2000). Others are increased awareness of autism among parents, teachers, and professionals, and greater availability of services once autism was added to the Individuals with Disabilities in Education Act (IDEA) in 1991 (Eyal et al. 2013). Indeed, sociological and epidemiological research has suggested that increases in the resources directed towards autism services, diagnosis, and research is an important factor driving up rates of diagnosis, including screening resources, service availability, educational spending levels, number of school based health centers, and number of pediatricians in a community (Barbaresi et al. 2005; Mandell and Palmer 2005; Palmer et al. 2005). Thus, the professionals and institutions that keep track of diagnostic labels—clinicians and hospitals, teachers and schools, bureaucrats and administrative records, insurance companies and case files—are more likely to describe an individual as having autism

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[16] The difference between having tuberous sclerosis or congenital rubella and autism, and intellectual disability or ADHD and autism is that the former are conceptualized as the underlying cause of the autism in those cases.

then many of the other conditions for which they qualify or might have been labeled with in the past. Though this evolution provides a relatively good explanation for the increase in autism prevalence, it still leaves people somewhat ambivalent and unsatisfied as to the two big questions that continue to get asked. Is any of the so-called autism epidemic due to an increase in true prevalence (as opposed to being entirely composed of an increase in clinical prevalence)? And is there a cure for autism?

Is there a true (i.e. secular) increase in the prevalence of autism? Let's put that question another way. Is there a true increase of people behaving in ways that would allow them to qualify for a diagnosis of autism *if the definition of the condition had remained constant and diagnosticians and epidemiologists actually diagnosed and counted the condition in the same way over time*? Possibly. However, given the complexity and social changes explored above, we do not have a clear answer to this question. In the words of Michael Rutter, "we simply do not know" (Rutter 2009; Fombonne 2001). Of course, much attention has been placed on whether vaccines, or toxins, or mercury, or other environmental factors and pollutants could be linked to an increase (Lawler et al. 2004). And it is possible that at least some of the cases of autism, even if only the minority, might be linked to these mechanisms (Newschaffer et al. 2007). However, other, less sensational factors could also be responsible for a secular increase in autism.

For example, changes in the average maternal and paternal age at conception have been linked to increased risk of a variety of developmental disabilities, including autism (Kong et al. 2012; King et al. 2009). Another possibility is that changes in medical technology have kept alive low-birth-weight babies and other more susceptible populations, thus inflating the number of individuals who qualify for a diagnosis of autism (Pinto-Martin et al. 2011). A third possibility is that injury during pregnancy could have some responsibility, or even in vitro fertilization (Newschaffer et al. 2007). But in the end, we just don't know ("largely because it is very difficult to develop quantifiable estimates of diagnostic effects and virtually impossible to prove or disprove temporal changes in autism population risk profiles given the condition's unknown etiology" [Newschaffer et al. 2007: 239]). Of course, there have been other conditions the prevalence of which has greatly fluctuated due to diagnostic practice: "dementia praecox" and "childhood schizophrenia" being too interesting examples (Noll 2011; Eyal et al. 2010). And, as was the case for many of these other conditions, the question of whether there was or could be a cure was a significant aspect of the attention they received.

Is there a cure for autism? The short answer is no. Most individuals diagnosed with autism as children, will continue to qualify for a diagnosis of autism as adults (Seltzer et al. 2003). Moreover, the single best predictor of outcome is IQ at the time of diagnosis; other important indicators are presence or absence of communicative speech at age five or six, and educational functioning in childhood (Billstedt 2007; DeMeyer et al. 1973; c.f. Coleman and Gillberg 2012: 31). However, could there be an intervention that works for some children who are diagnosed with autism? Let's put that question another way. Is it possible that their are children whose behaviors qualify them for a diagnosis of autism, but are then given some treatment that makes those behaviors go away enough that they no longer qualify for the diagnosis? Yes, it is possible. We know, for example, that some kids have vitamin deficiencies that lead them to express particular forms of autism that are potentially treatable (Novarino et al. 2012).[17] Of course, that only applies to those with that particular deficiency, or, put another way, with that particular form of autism. It is also possible for an individual's behaviors and impairments to change enough over time that they stop qualifying for a diagnosis of autism (Fein et al. 2013; Fountain, Winter and Bearman 2012; Helt et al. 2008;).[18] However, once again, the "optimal outcome" trajectory represents only a minority of those diagnosed on the autism spectrum, and thus does not describe autism in general. Just as with other developmental disabilities (e.g. intellectual disability) there is no general cure for autism.

Given that there is no general cure and most people do not age out of autism, the ire targeted at sensational claims of cure are at the very least understandable. In his coverage of Jenny McCarthy, who became popular for claiming that autism could be cured, Karl T. Greenfeld (2010) provides an interesting perspective on why talk of cure can be destructive:

> McCarthy began to try almost every treatment that turned up on Google. Evan went through conventional, intensive Applied Behavioral Analysis (ABA) therapy as well as a host of alternative approaches, including a gluten-free and casein-free (GFCF) diet, hyperbaric oxygen chambers, chelation, aromatherapies, electromagnetics, spoons rubbed on his body,

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[17] We also have preventative measures for some forms of intellectual disability. For example, iodine deficiency is known to cause "abnormal neuronal development, mental retardation, congenital abnormalities, spontaneous abortion and miscarriage, congenital hypothyroidism, and infertility" (Lancet 2008: 88; Shorter 1997). Thus, public health efforts to have iodine supplements provided to all humans (e.g. through iodized salt) represent an effective preventative measure against the prevalence of intellectual disability.

[18] Don't have enough data to determine if it is intervention or natural development. Some cases seem more likely to be natural development because no formal intervention was provided.

> multivitamin therapy, B-12 shots and a range of prescription drugs. McCarthy says she made a deal with God. “Help me fix my boy,” she prayed, “and I’ll teach the world how I did it.” She believes that she did fix her boy. A psychological evaluation from UCLA’s neuropsychiatric hospital, dated May 10, 2005, was “conclusive for a diagnosis of Autistic Disorder” [. . .] [now] McCarthy’s boy is a vivacious, articulate and communicative child who seems to have beaten the condition [. . .] Or is this the truth? There are dark murmurings from scientists and doctors asking, Was her son ever really autistic? Evan’s symptoms—heavy seizures, followed by marked improvement once the seizures were brought under control—are similar to those of Landau-Kleffner syndrome, a rare childhood neurological disorder that can result in speech impairment and possible long-term neurological damage.

Maybe Evan, though qualifying for a diagnosis of autism, did have Landua –Kleffner syndrome (just as someone who qualifies for autism can also have congenital rubella). Or maybe he was among that group who outgrow their symptoms. The stakes surrounding cure have made cases like Evan’s closely followed and hotly debated. The important point for this study is that most children with autism will grow into adults with autism. And no matter the degree to which they improve, many of them will continue to remain atypical and require significant supports as they age (Coplan 2000; Newschaffer and Curran 2003; Ganz 2007). Thus, though research on adults with ASDs is scant relative to the burgeoning literature on children with the diagnosis, the lived reality of this population and its caretakers is an important issue if we are to have a complete and accurate understanding of those with autism and those who care for them.

ADULTS WITH AUTISM

One of the most popular questions associated with the increase in autism is, “if people with autism have always been around then why did we not hear about them before?” As the above literature review suggests, the reason is that they were just called by a lot of other names (or given no name at all). A convincing answer to the more recently asked question, “how is the increase not secular if there are so many children with autism, but apparently no adults with autism,” is provided by Grinker and Chew (2007):

> When scientists respond that there has been no true rise in autism, that we are diagnosing autism more, and counting it better, believers in an autism epidemic— mostly parent advocates, philanthropists, and politicians— argue triumphantly that if there is no epidemic, then 1 of every 150 adults in the United States must, in fact, have autism. Along with journalists, they repeatedly ask, "Show me where the one in 150 autistic adults are. We can't find them." Just where might those 1 in 150 adults with autism be? As surprising as it may seem, they are living and working among us. Some live at home with their aging parents or siblings. Some live in group homes, or in institutions. Some have jobs and live independently. Many have other diagnoses given to them when they were children, such as mental retardation, seizure disorder, or schizophrenia. Recently, one of us met a severely autistic 60-year-old woman in eastern Tennessee, who we'll call Donna. Donna's internist diagnosed her with autism ten years ago, when she was 50. Her mother said that Donna's first label, in 1950, was "mentally retarded with emotional block and obsessive compulsive traits." Today, for the purposes of public assistance, she is classified as mentally retarded. There is no record anywhere to suggest that Donna is "autistic." Now, imagine another, more mildly autistic adult, who has a job with minimal social demands (filing medical records, perhaps), has poor eye contact, and some anxiety. Perhaps he is even married. After all, as they get older, many people with autism, like the well-known writer, Temple Grandin, make significant advances. First, he may not seek treatment or even think he has problems. Second, even if he did, he may not go to a psychiatrist, but rather to an internist who could treat his anxiety. Third, even if he did go to a psychiatrist, it is not likely the psychiatrist would diagnose an adult with autism, especially if the psychiatrist had no clinical data on his early childhood (autism is still a developmental disorder diagnosed in childhood, and the tools for diagnosing autism in adults are not nearly as valid or reliable as those for children).

Grinker and Chew provide one real and one hypothetical case of autism in order to show how there can be so many adults who would have qualified for the diagnosis as children yet who remain seemingly invisible. [19] The case of Donald T. is another great example of how an individual with autism can disappear in adulthood. Now in his 70s, Donald still lives in his hometown of Forest Mississippi (Donvan and Zucker 2010). He continues to have odd behaviors: difficulties with the "art" of conversation; assigning numbers to all of his acquaintances; difficulty with abstractions like "implication," "mood," and "emotion" (Donvan and Zucker 2010). Yet, he is able to live independently, has traveled all over the world (alone), drives a car, and plays golf every week. Most people in his neighborhood don't realize that "DT," as he is locally referred, has autism, but many "shrug off his oddities" and even "openly admire his strengths" (Donvan and Zucker 2010). While this would seem to support the argument made by Donvan and Zucker

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[19] This essay continues: "We will likely continue to hear some journalists and some autism advocates say 'We can't find autistic adults.' But the reality is that they are not looking. And for good reason. Children with autism are, of course, much easier to count than adults, because they are in schools, but they were once as invisible as many autistic adults are today. Indeed, Thomas Insel, the Director of the National Institutes of Mental Health, told Newsweek in November 2006 that during his psychiatric training in the 1970s he saw 'not one child with autism." It's not because he wasn't looking, or because Insel was not trained in child psychiatry. It's because they were misdiagnosed, institutionalized, and treated by neurologists (if at all). In the 1970s, psychiatrists seldom saw children and there were only a few hundred child psychiatrists in the entire country. One of our spouses, who did her residency at Massachusetts General Hospital in the 1980s, never saw a case of autism because the hospital had no developmental program at the time [. . .] But just because we cannot count adults with autism does not mean that they do not exist; nor does it mean that the prevalence rate for autism in adults must be lower than it is in children. Adults with autism are, in fact, becoming increasingly visible as autism awareness continues to rise and as more and more adults begin to identify themselves as autistic, and speak and write about their experiences growing up and living with autism. Their invisibility is not a sign that autism is a childhood epidemic, but rather of how different out knowledge of autism is today. So it isn't surprising when Donna's mother, now eighty-two, looks at parents like us with envy. 'I wish my child had been born today,' she said. 'She would get a proper diagnosis, have different therapies we could try, and we wouldn't be so isolated as a family.' We hope Donna's mother is right, that we really are in a better place today, and that when our children become adults they will not be invisible" (Grinker and Chew 2007).

(2010) that acceptance is key to overcoming the challenges created by autism, Donald's impairments are not as severe as many others on the spectrum. Appreciating the heterogeneity that characterizes the population of individuals that presently carry a diagnosis of autism is an important step to recognizing the diversity of challenges that face adults on the spectrum and their caretakers.

The reality that diverse individuals now qualify for an autism spectrum disorder means that heterogeneity and varied outcomes are a fundamental part of understanding the condition in adulthood. One of the first and few articles to focus on adults with autism was published by non-other than Leo Kanner (1971) when he released a paper entitled "Follow-Up Study of Eleven Autistic Children Originally Reported in 1943." Kanner found that the outcomes of the eleven individuals he first reported on in 1943 were in keeping with the diversity that characterized the sample then, though all retained many signs of their original diagnosis. While Donald and Frederick were relatively independent, for example, six of the original eleven were living in institutional settings (1971). One, Elaine, was living in a State Hospital at the age of 39, and was described in an administrative report thusly:

> She is up and about daily, eats and sleeps well and is acting quite independent. She is able to take care of her personal needs and is fairly neat and clean. Her speech is slow and occasionally unintelligible and she is manneristic. She is in only fair contact and fairly well oriented. She cannot participate in a conversation, however, except for the immediate needs. If things do not go her way, she becomes acutely disturbed, yelling, hitting her chest with her fist, and her head against the wall. In her lucid periods, however, she is cooperative, pleasant, childish, and affectionate. She has epileptic seizures occasionally of grand mal type and is receiving antiepileptics and tranquilizers. Her general physical condition is satisfactory (Kanner 1971: 140).

So with some in institutions and some living independently in the community, the atypical characteristics of Kanner's eleven were associated with a diverse range of social situations and support needs. The considerable broadening of the spectrum since autism's early days has meant that an even wider range of behavioral profiles and outcomes are associated with the diagnosis (particularly with the introduction of Asperger's Syndrome in 1994).

However, on the whole, the average outcome for autism, if compared to the ideal or "optimal outcome" (i.e. living independently, working full time, being married, and having friends) is relatively poor (Helt et al. 2008). Though the focus of research is on treatment and the potential for a typical adulthood, many caretakers responsible for individuals aging with the condition—who often remain significantly atypical and dependent—increasingly turn towards questions concerning care, management, and support (Gray 2002). Though it is true that happiness is different for everybody, and we shouldn't assume that normative outcomes are something that should always be pushed for, more basic needs (e.g. housing, medical care, physical safety) are concerns that most would agree are compelling.[20] And yet, the description of the "coming crisis of adulthood" in a variety of newspapers is a bit misleading, as adults with autism have always been around and stakeholders have been trying to figure out what the best course of action for their integration and care is for centuries (Houston and Frith 2000; Wing 1989). Though we are still struggling to come up with the best answer for them, it is the new reality—the new normal, if you will—that many characterized as socially atypical

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[20] See Maslow's (1970) hierarchy of needs.

and dependent are increasingly being diagnosed with autism. For those who have more severe forms of the disorder, the requirement of life-long care and support are a relative certainty.

Though individuals with autism represent a heterogeneous group, those with more significant forms of the condition generally remain significantly atypical and dependent throughout their lives. In a recent paper Eyal (2013) draws on Wing and Gould's work to construct summaries of the four behavioral profiles that characterize individuals on the spectrum. The two most severe groups are described thusly: 1) along with the three impairments of autism, the most severe cases "are associated with profound aloofness and indifference in most situations, accompanied by repetitive self-stimulatory behaviors such as hand flapping and head banging. There is almost certainly comorbidity with MR [. . .] and potentially also epilepsy"; 2) at a lower level of severity, children may speak, but in "stereotyped and idiosyncratic phrases, often repeating how they were addressed without reversing pronouns [. . .] they are typically indifferent toward other children but not toward adults, whose company they eagerly seek, though failing to use nonverbal communicative behaviors such as eye-to-eye gaze to regulate the interaction and insisting inflexibly on the repetition of certain routines" (2013: 866). These two groups roughly represent the individuals who make up my sample, modified for the developmental changes that are associated with adulthood (though, after time spent in the field, the maxim "once you have met one individual with autism you have met one individual with autism" resonates with me more clearly than ever). The needs of those who fall within these two groups are considerable.

Though few studies of adult outcomes focus only on those with more significant forms of the condition, the numbers of more inclusive samples speak plainly enough. According to one study of a sample of young adults with all forms of autism, since graduating from high school 87.1% had ever lived with parents or another guardian, 16.6% had ever lived independently, and 11.8% had ever lived in a supervised living situation (Anderson et al. 2014). A low estimate of unemployment among adults with all types of autism is 66% but others say between 80 and 85% (Walton 2011). Very little literature on adults is focused solely on those with more severe forms of the condition (Coleman and Goldberg 2012). Almost no literature exists on individuals with more significant forms of autism that are older than 45, though some recent research looks at populations in psychiatric hospitals that qualify for a diagnosis of autism (most of whom are currently diagnosed with something else, e.g. schizophrenia) (Mandell et al. 2012). Howlin and Moss (2012) argue that individuals with ASDs are significantly disadvantaged in issues of employment, social relationships, physical and mental health, and quality of life. Though another study found that a majority of young adults with autism have a better than expected “quality of life,” it concludes that they usually remain dependent on caregivers for support in educational, accommodation and occupational situations (Billstedt, Gillberg and Gillberg 2005). Outcomes in adolescence and adulthood are dependent on many factors including autism severity, cognitive functioning, language development, additional psychopathology, and access to intervention programs and services (Levy and Perry 2011). Between 38% and 62% of individuals with autism also qualify for a diagnosis of intellectual disability (have an IQ less than 70) (Amiet et al. 2008). Being responsible and caring for these individuals requires managing and planning for present and continuing atypicality and dependency.

The individuals in my study are among that group that is unlikely to live independently at anytime during their life, are diagnosed with or qualify for a diagnosis of intellectual disability along with their autism, and for whom management, care, and support often require considerable resources and present a difficult challenge for families and other caretakers. Many individuals with ASD also have intellectual disabilities (ID) and approximately 70% have a lifelong disability requiring substantial social support (Wright et al. 2013). Families tend to be the first line of support, and are instrumental in shaping the outcomes of those with the condition (Power 2008). Marsha Mailick Seltzer and colleagues (Barker et al. 2011; Smith, Greenberg and Seltzer 2012; Seltzer et al. 2011; Taylor and Seltzer 2011) have chronicled some of the challenges and stressors facing families of adolescents and adults with autism, with a particular focus on the stress and burdens associated with caretaking duties.[21] Particularly challenging to manage and care for are those individuals whose autism is associated with aggressive, violent, or other forms of maladaptive behavior (Gray 2002). However, it is not necessary for maladaptive behaviors to be present in order for caregivers to become convinced that they have no good options. One chilling story explores the worst along with more promising situations:

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[21] One important finding is that, since states have had systems of care set up for those with intellectual disability for some time, there may actually be less services for those with autism who do not have ID (Taylor and Seltzer 2011). This, however, does not diminish the challenges that surround providing care for individuals like the adults with autism in this study.

> We will never know the complete story of what happened on Nectarine Avenue in San Jose this past Tuesday evening, but sadly, we can guess. According to news reports, Elizabeth Hodgins, 53, shot her 22-year-old son George, who was severely autistic. People who knew the family said Ms. Hodgins was overwhelmed with the demands of caring for her son, who had recently aged out of his educational program. This heartbreaking story hits home to any parent of a child with autism, because our worst fear is: what comes next? Will my child be able to live a productive and happy life as an adult? [. . .] The stories aren't always as sad as this one from Sunnyvale. Last week, I spent several hours visiting The ARC[22] of San Francisco, a wonderful option for families of adult children with developmental disabilities. I met one young man with autism who runs a "micro-enterprise," a coffee stand in the building that has become a great training ground for eventual jobs in customer or food service. Other clients stopped in to meet up with counselors or friends before heading out for a day of community-based learning or internships. In the evenings, there are support groups for parents, and activities (including a nightclub complete with disco balls) for clients. The staff at the ARC is warm, welcoming and committed to adults with disabilities leading fulfilling and productive lives as fully-integrated members of our community (Norton 2012).

This article shows how caretakers can feel that there are no options, and that they will never escape the needs of a loved one. It also demonstrates that loved ones sometimes find themselves in circumstances that are very much ruled by the availability of services in an area (Gray 2002). Service availability and professional support has the potential to make a big difference to both caregivers and adults with autism. That being said, the emotional challenges associated with autism are shaped not only by service availability but also the financial reality of life-long dependency. A recent study found that the cost

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[22] ARC stands for Association for Retarded Citizens. Several individuals in my study received services from this organization (e.g. sheltered work-programs, evening social programs). Much of the services for families located in one of the states in my study were covered by MR (Mental Retardation) waivers. To have this waiver, a diagnosis of intellectual disability was required. It is possible to view individuals with autism acquiring an MR diagnosis as their primary diagnosis so that they can get access to a waiver as a form of reverse diagnostic substitution. It once again shows how services and funding play an important role in determining what diagnosis an individual is given.

of supporting an individual with autism and intellectual disability in the U.S. during his or her lifespan was $2.4 million (Buescher et al. 2014). The largest cost components in childhood were "special education services" and "parental productivity loss," and in an individual's adulthood "residential care or supportive living accommodation" and "individual productivity cost" (Buescher et al. 2014: E1). While the rhetoric of "epidemic" and "crisis" might appear as one way to raise the alarm about the needs of adults with autism and their caretakers, pitching these needs in medicalized and hysterical terms can distort the nature of the real and complex challenges that families and other caregivers face.

To understand the contours of the challenge that face caretakers of adults with autism while avoiding the rhetoric of epidemic, crisis, and other hysterical descriptions, the lived experience of those facing the challenge presents an important and nuanced resource to learn from those on the front lines. Families come to realize that when their child ages out of school mandated services, they are faced with understanding and relying on a service system with an entirely different logic. Funding can come from a variety of sources: Medicaid, Medicare, SSI, SSDI, Office of Vocational Rehabilitation, and other public and private organizations. However, resources for adults are organized around eligibility and availability as opposed to the legal "entitlements" that describe special education funding. The goal for many is to find a supportive and meaningful social situation that provides individuals who remain atypical and dependent with dignity, productivity, and purpose. While large state institutions used to house and care for many individuals with developmental disabilities, the landscape for housing since deinstitutionalization is more complex. Group homes, adult foster care, supervised living, supported living, and transitional living are all options, but given the new complexity and decentralization families most do a lot of the leg work.[23] Of course, even during the age of the major institutions, families and community care were still an important part of the picture (Power 2008). Understanding how families and other caretakers interpret and respond to the care, management, and support that adults with autism require is crucial for starting to understand the social dynamics that are the context in which those who remain atypical and dependent exist.

FIELDWORK

In the summer of 2010 I embarked on a study that was originally intended to be an ethnographic exploration of the domestic lives of families with young children with autism. The study was pitched as a "dinner study," in which I would join families for a typical evening meal and conduct interviews with parents. With the support of the Center for Autism Research (CAR)—a cooperative venture between the University of Pennsylvania and the Children's Hospital of Philadelphia (CHOP)—I began recruiting families from the *Autism Match* list: a recruitment initiative to connect researchers with families interested in participating in a wide variety of autism studies (https://autismmatch.org/). A research assistant assigned to my project made first contact, and I would follow-up with those families that showed interest. If, after talking on the

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[23] Some individuals with autism are also among the ranks of the homeless, inmates of the criminal justice system, or residents in the growing number of nursing homes (Grob 1994).

phone, families agreed to participate, I would drive to their home—usually arriving in the early to mid-afternoon—and get acquainted, share dinner, and conduct semi-structured interviews.

For those families who were open to further participation, I conducted follow up visits and interviews both in the home and the community. At first, I restricted recruitment to families with one child on the spectrum and those who had a diagnosis of autistic disorder. However, I soon lifted both these restrictions. I lifted the first restriction because my sample was too small to get seriously concerned about "controlling variables" (though most families in the study did end up having only one member with autism). I stopped limiting myself to families that had individuals with a diagnosis of Autistic Disorder because of the fuzzy lines between Autistic Disorder and PDD-NOS (illustrated by the reality that several of the individuals in my study were given both of these diagnoses at different times). Indeed, issues with diagnostic validity and reliability represent one of the main reasons the DSM-5 definition of autism replaced the sub-categories of Autistic Disorder, PDD-NOS, and Asperger's with a single diagnosis of Autism Spectrum Disorder along with a three level severity scale (APA 2013). That being said, my focus and the individuals in my sample remain limited to those with more severe forms of autism: individuals who have or are likely to qualify for a diagnosis of intellectual disability alongside their diagnosis of autism, and those who, in the words of the two highest levels of the DSM-5 severity scale, require "very substantial support" or "substantial support" throughout their lives (APA 2013).

Three of the first four families in my study (when I was still focusing on young children with autism) came from the *autism match* list (the Murphy, Lewis, and Boyles family) and one I met while attending a parent-panel session at a workshop for families with newly diagnosed children (the King Family) (See Table 1). Between June and December 2010 I joined all four of these families for dinner and interviews in their home, and then a varying number of follow-up visits in the home and/or the community. Besides hanging out and watching TV, drinking wine in the kitchen while dinner was made, or playing video-games in the basement, I participated in school observations, baseball games, soccer practices, and birthday parties. The interviews I conducted were organized around several general questions (e.g. tell me what meals are like with your family, how did autism come to your child, with whom do you talk with about autism), but I allowed the interview to progress organically and probed on those terms and topics that interviewees themselves highlighted as relevant (DiCicco-Bloom and Crabtree 2006). I also participated in several support group meetings in order to better understand the issues facing families caring for and professionals working with young children and adolescents with autism.

Though my time with families with young children with autism confirmed my belief about the importance of understanding the condition through the perspective of caretakers, soon after entering the field I began to consider switching the focus of my project to families and professionals associated with adults with autism. Besides arguments in the autism literature and from faculty mentors[24] as to the importance of collecting more data on adults with the condition, the caretakers already in my sample and those I met through them were constantly telling me how important a project on adults would be. I quickly realized that the topic was ideally suited for ethnography, since one of the methods "warrants" is to understand populations about which little is known (Katz, 1997, 2012).

Fieldwork with adults with autism and their families occurred in two phases. The first phase was conducted between January and August 2011. During this period I continued using the approach I had used to recruit and collect data from families with children with autism. Over the first half of 2011 I built a sample of thirteen families with adult members with autism between the ages of 17 and 43 (See Table 1). As I came to see how important professionals were to the experience of adults with autism and their families, I also started to interview them as well (e.g. job coaches, transition counselors, non-profit executives) (See Table 2). Some of the individuals in the professional sample were also members of the families in my family sample, and were included in both samples and taken through at least two separate interviews to understand their multiple relationships to autism.

Almost all of the professionals I interviewed for the study I met through the families. Five of the families with adults with autism I met through *Autism Match*: Clarke

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[24] Professor David S. Mandell of the Center for Autism Research and Professor Peter S. Bearman of the Columbia Sociology Department were particularly clear on this point.

Yates (66) and his son Allen* (29)[25]; Marge (50) and Anderson (50) Vogler, and their three sons Tom (18), Brian* (17), and Jack (14); Eva (57) and Ross (58) Downing, and their son James* (21); Yveline (50) Bryan and her son Roger* (19); and Ross (64) and Molly (63) Zago, and their son Martin* (31). The other eight families I met through word of mouth or other informal means. Sally (59) Emerson, and her daughter Shirley* (20); Davis Barba (67), and his son Lewis* (31); Kate (56) and Evan (59) Lane, and their son Ziggy* (23); Ken (51) and Kelly (51) Fischer, and their daughter Jessica (22) and son Jeff* (20); Winnie (49) and Warren (52) Barclay, and their son's Tyson* (17) and Taylor (19); Chrissie Hamilton (62), her ex-partner Heather (53), and their children Meg (23) Drew (21), and Byron* (20); Jack (70) and Vale (70) Lee, and their two children Miller* (43) and Bianca* (40); and Caroline (48) and Fischer (50) Fini, and their sons Tim (20) and Bill* (18). I met the Barclays through Alison King. I met the Finis through the Barclays. I met the Lanes years before graduate school, when I worked as a teacher in an autism school. I met the Hamiltons through Kate Lane. The Downings introduced me to Jack and Vale Lee.

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[25] * =Diagnosed with autism. Also, as per IRB #812120 of the University of Pennsylvania, all names are pseudonyms.

TABLE 1: Sample of Families

Family	Members (Age)[26]	Connection	Geography/Race -State: One of Three (A, B, C) -Urban/Suburb/ Rural -Race	Fieldwork -2011: # visits -2013: # days lived with -Interviews: # with family members	Notes
Fischer	Kelly (51) Ken (51) Jessica (22) **Jeff** (20)	Met Jessica through Faculty	State A Suburb Caucasian	2011: 3 2013: 5 Interviews: 5	Global Developmental Delay with features of PDD-NOS.
Lane	Kate (56) Evan (59) **Ziggy** (23) Rebecca (21) Arietta (84)	Met through a personal connection	State B Rural Caucasian	2011: 3 (lived with them) 2013: 4 Interviews: 4	Originally PDD-NOS, DSM-III. Later, Autistic Disorder.
Vogler	Marge (50) Anderson (50) Tom (18) **Brian** (17) Jack (14)	*Autism Match*	State A Suburb Caucasian	2011: 3 2013: 7 Interviews: 8	Initially PDD-NOS. Later, ASD.
Barclay	Winnie (49) Warren (52) **Taylor** (19) **Tyson** (17)	Met through Alison King [See bottom of this chart]	State A Rural/Suburb Caucasian	2011: 3 2013: 8 Interviews: 4	Tyson: Originally PDD-NOS, Later Autistic Disorder. Taylor: Asperger's Syndrome

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[26] Ages reflect those given when I first made contact with the families in 2010 – 2011. Logically, everyone was a couple years older when I lived with families in 2013.

Yates	Clarke (66) Sophie$^{\wedge*!}$ **Allen** (29) Kay (26)$^{\wedge}$	*Autism Match*	State A Suburb Caucasian	2011: 2 2013: 7 Interviews: 2	
Zago	Ross (64) Molly (63) **Martin** (31) Alexander (29)$^{\wedge}$	*Autism Match*	State A Rural Caucasian	2011: 2 2013: 7 Interviews: 4	Classic Autism
Emerson	Sally (59) Moore (58)$^{\wedge*}$ Murphy (25)$^{\wedge}$ Ester (21)$^{\wedge}$ **Shirley** (20)	Met Sally through a Professor	State A & B Urban Caucasian	2011: 2 2013: 1 (did not sleep over) Interviews: 2	In 2013 I accompanied Sally (from State A) for one day to visit Shirley in her Group Home (in State B).
Downing	Ross (58) Eva (57) **James** (21)	*Autism Match*	State A Urban/Suburban Caucasian	2011: 2 Interviews: 2	Son had severe epilepsy. Was unsuccessful reconnecting in 2013.
Fini	Caroline (48) Fischer (50) Tim (20) **Bill** (18)	Met Caroline through Winnie Barclay	State A Suburban Caucasian	2011: 3 2013: 1 (did not sleep over) Interviews: 2	In 2013 I accompanied the Finis and several other families to a play organized especially for families with individuals with autism.
Barba	Davis (67) Laura$^{!}$ James (37)$^{\wedge}$ Nelson (33)$^{\wedge}$	Met Davis through Kate Lane	State C Suburban Caucasian	2011: 1 Interviews: 1	Never got to meet Lewis because of his sensitivity to strangers since his

	Lewis (31)^				mom's death. Was unsuccessful reconnecting in 2013.
Lee	Jack (70) Vale (70) **Miller** (43) **Bianca** (40)	Ross Downing introduced me to Jack and Vale	State A Suburban Caucasian	2011: 1 2013: 5 Interviews: 6 2014: 2	Miller is non-verbal. Bianca is verbal. In 2014 I lived with the Lees again for two days.
Hamilton	Chrissie (62) Heather (53)% Meg (23) Drew (21) **Byron** (20)	Kate Lane introduced me to Chrissie	State C Suburban Caucasian	2011: 1 2013: 2 (did not sleep over) Interviews: 5	In 2013 I spent a day with Chrissie visiting Byron at his Group Home. I also spent some time, separately, with Drew and his girlfriend, Heather, and Meg.
Bryan	Yveline (50) Robert (49)* **Roger** (19)	*Autism Match*	State A Urban African-American	2011: 1 2013: 3 (did not sleep over) Interviews: 2	In 2013 I hung out with the Bryans from morning until night, but, at the request of Yveline (space issues) did not sleep over.
FAMILIES FROM ORIGINAL SAMPLE WITH YOUNG CHILDREN WITH AUTISM					
Murphy	Idalyz	*Autism*	State C	2010[27]: 6	

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[27] Numerals after "2010" are the number of times I visited with a given family with a child with autism.

	(39) Michael (36) Anthony (6) **James** (4) Nick (2)	*Match*	Suburban ½ Caucasian ½ Latino	Interviews: 3	
King	Alison (37) Morgan (43)^* David (10) **Ashley** (8) Robert (6)	Met Alison at an Autism Event	State A Suburban Caucasian	2010: 7 Interviews: 4	
Lewis	Joyce (35) Lewis (37) Jim (7) **Wilson** (4)	*Autism Match*	State C Suburban Caucasian	2010: 2 Interviews: 2	
Boyles	Tina (43) Colvin (51)^ Time (16) **Perry** (10) **Cameron** (10)	*Autism Match*	State C Urban African-American	2010: 2 Interviews: 1	Perry and Cameron are Identical Twins.

Key: **Bold** = Diagnosed with Autism; ^ = Never Met; * = Separated/Divorced; ! = Deceased

TABLE 2: Sample of Interviews with Autism Professionals

Professional	Age	Connection	Institution	Position	Interviews[28]
Alison King	37		Non-Profit (Services)	Project Director	1
Jean Gilbert	59	Met through the Fischer Family	School	Transition Coordinator	3
Sally Emerson	59		Research Organization	Clinician/Researcher	2
Ross Downing	58		Non-Profit (Services)	Executive	1
Douglas Schultz	48	Met through Alison King	Non-Profit (Services)	Executive	1
Rose Richard	24	Met through Alison King	Non-Profit (Services)	Program Manager	1
May Harker	30	Met through Alison King	Non-Profit (Services)	Program Director	1
Grace Sharon	NA	Met through Faculty	Research Organization	Social Worker	1
Miller Mulroney	NA	Met through Clarke Yates	Sheltered Workshop	Manager	1
Lisa Tapley	49	Met through Barclay Family	School	Vocational Coordinator	1
Rachel Davis	55	Met through Vogler Family	School	Special Education Supervisor	1
Mary Wagner	62	Met through Vogler Family	School	Teacher	1
Ran Grobler	23	Met through Vogler Family	School	Paraprofessional	1
Michelle Jager	28	Met through Vogler Family	School	Transition Coordinator	1
Jackie	52	Met through	Day	Director	1

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[28] Interviews with professionals who also happen to be members of the families in my sample are separate from family interviews. They occurred in an occupational setting, and featured the same kinds of questions I asked other professionals.

Jackson		Zago Family	Program/Sheltered Workshop		
Sandy Beadnall	34	Met through Lane Family	Residential/Farm Campus	Residential Director	1
Betty Keane	35	Met through Lane Family	Residential/Farm Campus	Day Program Coordinator	1
Ann-Marie Sabell	49	Met through Lane Family	Residential/Farm Campus	Chief of Residential Services	1
Chrissie Hamilton	62		Non-Profit Organizations (Services & Advocacy)	Founder & Executive	1
Kevin Fester	24	Met through Hamilton Family	Non-Profit (Services)	Group Home/Day Program Staff	1
Hannah Haden	35	Met through Fischer Family	Non-Profit (Services)	Residential Director	1
Jack Lambert	65	Met through Fischer Family	Non-Profit (Services)	Executive	1
Ellen Hacker	NA	Met through Fischer Family	Non-Profit (Services)	Director Community Integration Services	1
Jane Mahler-Bace	39	Met through Fischer Family	Non-Profit (Services)	Habilitation Director	1
Sarah Loewe	56	Met through Fischer Family	Non-Profit (Services)	Autism Specialist	1

By the end of summer 2011 I had shared dinner with members of all but one of the thirteen families with adults with autism in my sample. The questions I asked during interviews included: tell me about how your adult child [sibling, etc.] with autism is at home; tell me about the outside activities you engage in with them; tell me about how you understand your loved one with autism; tell me about the services they receive; tell me about how you think about the future. I also had follow-up visits with most of the families with adults with autism. Besides the probing method used before, I also asked specific or follow-up questions from subjects of interest that had arisen during past informal conversations or participant observation. For professionals, interviews were also general but were based around a different set of broad questions: tell me about your job; tell me how you got into this line of work; tell me how your work relates to families with adults with autism; can you tell me about work you did with a particular family that went well?; can you tell me about work you did with a particular family that was more challenging?; can you tell me about aspects of the system in which you work that facilitate your work?; can you tell me about aspects of the system in which you work that have made your work more challenging?

Between September 2011 and December 2012 I exited the field in order to transcribe interviews, analyze my data, start drafting my dissertation, and finish up some other projects. During this period I became increasingly convinced that I should conduct another phase of research. The strength of ethnography is that you immerse yourself among people, and really learn about their everyday lives. Longitudinal observation matched with interviews, documental analysis, and reading also allows one to "triangulate": compare findings from one time or form of data with those from another (Denzin 2009). By recruiting over time, I was able to select diverse families that challenged my findings (because of family income, race, or geographic location) (Small 2009). By collecting data over time, I was able to seek out aspects of the situations under study that had been excluded from previous fieldwork (Duneier 2011). Revisiting families would allow me to achieve something that much sociology lacks, a consideration of how the characteristics of my sample changed over a longer period of time (Collins 1999). Living with families would provide me with a feel for the issues in which I was interested that can only be gotten from what one ethnographer described as a deep immersion among one's population of interest (Avery 2010). In the fall of 2012 I started reconnecting with the thirteen families in order to determine if each of them would be open to my living with them for a short period.

Between January 2013 and June 2013 I lived with eight of the thirteen families with adult members with autism, and spent time with all but two of them (see Table 1). I moved into basements, guest rooms, and bedrooms. I ate breakfasts, lunches, and dinners. I joined family members when they went grocery shopping, to parties and cookouts, to charity events and restaurant outings, to farmer's markets and carnivals. In short, I sought to be a member of the family. I also wanted to get a better understanding of the social context in which the adults with autism in my study lived their lives. These adults resided in a variety of different settings: four lived in family-owned, non-profit run group homes, one on a residential campus, and six still lived with their parents. In order to get a clearer picture of their lives, I gained entrance to and spent time with them at their day programs, group homes, residential settings, schools, and work sites, and met, talked, and, in some cases, formally interviewed staff and administrators at them all.

By the end of the research I had conducted 1000+ hours of participant observation, conducted 80+ semi-structured interviews, and collected 1000+ pages of documental information about the individuals and families in my study. I also met and informally talked with a significant number of other families and professionals over the course of the study. Many times while in the field I had a digital audio recorder running. I used the recorder in order to help me capture the details and nuances of the interactions I observed (Duneier 1991; Desmond 2012). Before using the recorder I would let family members know that I wanted to audio record our interactions in order to capture the dialogue and verbalizations of adults with autism and those caring for them. I asked whether this would be ok. I only used the recorder when participants agreed to its use. Sometimes I brought a computer during visits to group homes, work sites, or residential campuses so that I could type during breaks. Other times I wrote notes to myself through texts, e-mails, and an electronic notepad on my phone (Goffman 2009). At night and with the support of the day's jottings, recordings, and recollections, I would write detailed field notes about that day's events.

Though I entered the field with broad interests in the experience of caretakers planning and providing care for individuals with autism, the questions and topics recorded and explored in interviews and field notes evolved during my time in the field. Data analysis also reflected an evolving process. I worked inductively with my data, generating topics of interest and follow-up questions from initial analyses; these directed further forays into the field. Over time, I honed themes through the manual comparing and contrasting of data, and created inductive propositions that I would confirm, disconfirm, or modify with additional information (Lee 2013). When I encountered new or disconfirming data, I would revisit and change my analysis so that it would correspond with the findings of my fieldwork (Katz 2001). Though I had some control over the shape of my sample, I was restricted by the *autism match* list and the networks of previous participants who introduced me to other potentially interested families. One such limitation is that most of the families in my study are linked with young adults with autism (concentrating on the transition period out of high school, and almost all younger than 45). Though this matched my interests in how families and caretakers plan and experience the transition to adulthood, the issues faced by caretakers of individuals 45+ with autism are less represented.

Of course, I met many caretakers and adults with autism that were connected to those already in my sample. This allowed me to collect data, though more limited, on individuals representing a variety of ages and situations. Throughout the dissertation I draw on field notes, informal conversations, interviews, and published material to represent the lived experience of those caring for adults with autism. Extended quotes and passages from my data are presented in this dissertation in two formats: *italics* represent material from written field notes; normal text represents material from transcribed interviews. In Chapter 5, some of the material presented in normal text derives from typed, facilitated conversations with an adult male with autism. As per the stipulations of the University of Pennsylvania IRB, proposal #812120, names and locations are changed or omitted in order to protect the anonymity of those in my study.

CHAPTER 3

The Ambiguity of Deviance: Framing and Social Control Among Caretakers of Adults with Autism

INTRODUCTION

Microsociology—a body of techniques and concepts used to systematically explore the dynamics of everyday interaction—was created and rose to prominence in 20th century America (Garfinkel 1967; Collins 1981). Erving Goffman, possibly the most renowned practitioner of microsociology, created a language to describe and explain the interaction rituals that constitute our face-to-face encounters (Goffman 1959; Collins 2004). Given his interest in how interpretation and meaning organize interactional dynamics, Goffman tends to be categorized as a member of the symbolic interactionist tradition (Dreitzel 1970; Gonos 1977). Symbolic interactionists adhere to the assumption that the "situational context of meaning" is central: that "meaning as an interpretive process" is "located in interpretive acts," and that the study of meaning requires "close attention to the uniqueness and variability of situations" (Rochberg-Halton 1982:456; Blumer 1969).

Though Goffman's interest in the encounters through which people make meaning seems to fit him in nicely with the symbolic interactionistist tradition, a closer look at his work shows the affiliation to be more apparent than real (Gonos 1977). For example, in *Frame Analysis* (1974), his most ambitious attempt to craft a theoretical statement about his approach to social life, Goffman sought to describe the extra-situational structures that shape social interaction regardless of the contours of any specific encounter. In so doing, Goffman's goal was to "see behind" the constant activity of everyday interaction to the "structures," "frames," or "worlds" in which a particular language of reality is binding (Gonos 1977:857). For example, forms of everyday activity—the classroom, the dinner table—have a symbolic structure in which people are assigned roles—student, teacher—that shape their behavior and interpretations, to varying degrees, regardless of the vagaries of the situation. This would place Goffman more cleanly in the camp of "structuralism," in which frames serve as a lens through which a focused activity is influenced by the meanings of wider society—a screen which "not only selects but also transforms and modifies what is passed through it" (Goffman 1961a:33; c.f. Gonos 1977:861; Lévi-Strauss 1967). Though theoretical discussions about how best to bring understanding abut structures and frames together with the complexity of situations and interactions have appeared at times, there have been relatively few explorations of how qualitative data can be used to explore the nature of their empirical relationship (Snow 2001; Diehl and McFarland 2010; Moore, Jasper and Gillespie 2011). This chapter will draw on concepts that grow out of the sociology of deviance—a subject area of interest to both symbolic interactionists and Goffman—in order to explore how caretakers of adults with autism dealing with problem or maladaptive behavior negotiate between different frames or definitions of rule-breaking in the face of the ambiguity and complexity of lived experience and its situations.

Given the degree to which they increase the burdens of caretaking and disrupt daily life, maladaptive or problem behaviors have long been highlighted by the literature on autism as a major challenge for those caring for individuals—particularly adults—

with the condition. The developmental disabilities literature describes maladaptive behavior as actions that jeopardize the physical safety of the individual engaging in them or others, significantly limit or delay access to or use of ordinary community facilities, and/or cause difficulties in "developmental progress, socialization, and or success in a specific environment" (Neisworth and Wolfe 2005:129; Clarke 1996). Some maladaptive behaviors associated with autism include self-injury, physical aggression, screaming or other disruptive noises, inappropriate sexual behavior, and, the target of increasing awareness given recent media attention, elopement (also known as wandering or darting) (Gray 2002a; Solomon and Lawlor 2013; McIlwain 2013; Hart 1989; Greenfeld 2009a). Though maladaptive behaviors are present in a considerable number of children with autism, their expression in adulthood is of greater concern because of the "increasing size" of the maturing individual, the "vulnerability of parents and siblings" and other caretakers, and the harsher penalties—enacted by various stakeholders (e.g. law enforcement, the general public)—for these forms of behavior when engaged in by an adult (Gray 2002b:220; Debbaudt 2002). It is also important to note that individuals with autism who also have a diagnosis of intellectual disability (i.e. all in my study) are more likely to engage in maladaptive behaviors during the course of their development (Shattuck et al. 2007). While maladaptive behaviors are mentioned in the formal definition of autism, there remains little exploration of how caretakers understand and manage them (APA 1994; Shattuck et al. 2007).

Though individuals with autism engage in a wide variety of atypical behavior, maladaptive behaviors—particularly the most extreme forms (e.g. self-injury, aggression, inappropriate sexual behavior)—are those that most easily qualify, in the terms of sociology, as deviant or rule-breaking behavior. There is a long tradition in sociology of describing unwanted/rule-breaking behavior that constitutes a threat to role performance and the stability of social systems as deviance (Durkheim 1982). Much of the focus in the microsociological literature on deviance has been on the social processes by which certain behaviors are labeled deviant and then made the target of social control (Becker 1963; Bosk 1979; Duneier 1999; Meier 1982; Scheff 1966; Goffman 2009). Of much less focus has been the process by which those behaviors that are already labeled as deviant get further defined as a certain kind of deviance in naturalistic encounters. Explorations of how deviance is defined or framed does occur, but the data used tends to be historical or quantitative; more recently the deviance in question tends to be described as "social problems" given the analytical level of the data and increasing disappearance of the explicit use of the term deviance in sociology (Barry et al. 2009; Conrad and Schneider 1992; Conrad 2007; Gratett 2011; Saguy, Gruys, and Gong 2010). In the exceedingly rare cases when definitions of deviance are explored through qualitative data, analysis shows that applications are very messy as, for example, different individuals apply different definitions of deviance to the same behavior or phenomena (Bosk 2013; Hoppe 2013, 2014). An examination of how caretakers of adults with autism frame, interpret, and respond to maladaptive behavior represents an opportunity to explore how the "binding reality" of popular frames holds up against the vagaries and ambiguity of deviant behavior in naturalistic situations. Such an examination will also uncover how caretakers of adults with autism negotiate over how best to interpret and socially control deviant actions, potentially providing insight into the process by which people pick and choose among several options for defining deviance in relation to a wide variety of behaviors and situations.

This chapter will look at how caretakers use frames to shape interpretations and social control strategies for maladaptive behavior in adults with autism, and how the application of these frames is challenged by the framings of other stakeholders and the ambiguity inherent to many social situations. In their classic study of historical change in the definition of deviance, Conrad and Schneider (1992) explore how a variety of rule breaking behaviors have increasingly been defined as a sickness as opposed to a crime or a sin (badness). While Conrad and Schneider (1992) perceive themselves as descendants of the symbolic interactionist perspective, it can be argued that popular definitions of deviance constitute structures that select and translate reality in ways similar to how Goffman imagined his frames doing. More explicitly drawing the link between the medicalization of deviance and Goffman's frame analysis, more recent studies of "social problems" (e.g. obesity) have described popular definitions as "frames" or "metaphors" (Saguy, Gruys and Gong 2010; Barry et al. 2009). Of course, as opposed to Goffman's frames, which are based on the definition of a situation (e.g. classroom), these studies are more interested in the definitions that respondents ascribe to phenomena (e.g. "the obesity epidemic") that are an aggregate of individual behaviors and characteristics (Saguy 2013). Though it would seem plausible that the methods of microsociology could be used to explore the application of such frames in the naturalistic situations studied by symbolic interactionists, most individuals studying the definition of deviance continue to use historical or survey data (see studies cited in Conrad 2007).

Below I review some of the literature that describes definitions of social problems (i.e. publically targeted deviance) as frames, and then identify the three frames (misbehavior, sickness, and handicap) that were induced from ethnographic data with caretakers of adults with autism. I then move on to introduce the three cases of maladaptive behavior (two among families, one in a school setting) that are the focus of this paper. In the results I review evidence of the frames preferred by different caretakers in the three cases, and then explore how the ambiguity of reality and interpretations and control strategies of other stakeholders led to conflict and negotiation. In the conclusion I consider how, as structures that are available to individuals in their personal and professional life, frames of deviance should be viewed as options that stakeholders test against the ambiguity of reality as they try to come to terms with troubling behavior that compels interpretation and response.

FRAMING & DEVIANCE

The concept of framing was first introduced into sociology through one of the later works of Erving Goffman (1974). Goffman defined a frame as a "schemata of interpretation" that renders events and occurrences as meaningful, and in so doing functions to organize experience and guide action (1974:21; Snow et al. 1986). Studies that analyze framing are usually concerned with how the media, organizations, and opinion leaders shape general views of social phenomenon, particularly phenomena deemed to be social problems (Armstrong 2003; Benson and Saguy 2005; Conrad 2007; Entman 1993; Gamson and Modigliani 1989; Hilgartner and Bosk 1988). Though many of these studies do not explicitly link themselves to the sociology of deviance, in their theoretical and substantive analyses they rely on themes that were thoroughly explored in that subfield (Gratett 2011). These studies conceptualize frames as definitions the basic assumptions of which shape the interpretations of and responses to social problems. An example of three broad frames often applied to deviant human behavior—in this case the rising rates of obesity—are delineated in an article by Saguy, Gruys, and Gong (2010): 1) "those on the political right frame higher body mass as the product of unhealthy choices, casting fat people [. . .] as morally deviant or even 'villain'"; 2) "those on the political left blame social-structural factors including the food industry, car culture, urban planning, or the prohibitive cost of fresh fruits and vegetables for contributing to an 'obesigenic' environment"; and 3) "others attribute body size to biological (including genetic) factors" (591). The article goes on to explore how these three frames of obesity—individual choice, socio-structural casualty, and biological symptom—operate in news coverage of obesity in the French vs. the American media. Despite the similarity between these three frames and those which will be explored in this paper, my analysis is not interested in dissecting some of the issues (e.g. the association between political position and preferred deviance definitions) that studies of framing in the media often are. Moreover, while the older labeling studies of deviance often focus on "formal agents of social control" in "institutional settings"—guards in prisons, workers in mental institutions—a considerable portion of this paper occurs in the privacy of people's homes (Meier 1982:47). I decided to draw on data from private and public settings in part because during my analysis I noticed some striking similarities in the way conflict and negotiation over frames occurred in both. I felt this provided an opportunity to talk about framing in both public and private settings, and to reconsider the distinction that exists between theoretical characterizations of the nature of problem solving in these two realms (Abbott 1988; Nussbaum 2006).

MISBEHAVIOR, SICKNESS, HANDICAP

Though outlined here with the naturalistic settings that are the focus of this paper in mind, the three frames that characterize stakeholder negotiations over the care of individuals with autism—misbehavior, sickness, and handicap— roughly correspond with the individual choice, biological symptom, and socio-structural casualty frames featured in the paper by Saguy, Gruys and Gong (2010) mentioned above.

Misbehavior refers to deviance that is engaged in willfully, and has as its source manipulative or malicious intent. In past research this frame has been called "badness," and, given the literature's focus on formal cases, is usually applied to actions defined as either "sins" or "crimes" (Conrad and Schneider 1992). However, I change the name of this frame from badness to misbehavior because the stakeholders that are the focus of this paper don't typically use words like "sin" and "crime" to describe the actions of those with autism that are in their care. Caretakers who draw on the misbehavior frame define the rule-breaker as a rational actor who behaves as they do in order to fulfill "basic human desires" that they are unable to satisfy through "socially sanctioned" means

(Tucker 1999:222). Given the self-directed nature of misbehavior, the logic of this frame suggests that punishment—a response in which punitive measures attempt to make the fulfillment of basic desires through unsanctioned means a less attractive endeavor—is the most appropriate social control strategy.

Sickness refers to deviance stemming from disease, a pathological state that warrants therapeutic intervention. Framing deviance as sickness leads to interpretations of behavior in which motivation is removed from the person's will and relocated to their body or mind (Conrad 2007). The ontological view of sickness—associated with modern conceptions of pathology—views disease as caused by an alien biological agent that somehow enters the body, causes structural damage (e.g. a lesion), and results in a person having "symptoms" or physical/psychic expressions that deviate from the norm (Aronowitz 1998). Though the ideal case is disease linked to an infectious agent (e.g. a virus), damage associated with genetics, toxins, bacteria, or other factors are also relevant. More importantly, the concept of "compulsion"—actions shaped by forces beyond a person's control—has long allowed for medical explanations of behavior "without requiring conclusive evidence of organic cause" (Conrad and Schneider 1992:273). Based on the logic of the sickness frame, attempts at social control must focus not on punishing deviance but on treating the underlying pathology and restoring the individual to their original self. Though the generic response of public health is prevention as opposed to treatment, interpretations and social control strategies that borrow from public health concepts—such as "contagion" and "quarantine"—also get subsumed under the umbrella of the sickness frame in popular usage (Hoppe 2013; Tucker 1999).

Handicap refers to deviance stemming from a disability, a permanent structural atypicality best controlled through changes to the physical and social environment. The handicap[29] frame defines deviance as behavior that stems from normative motivations, and is only made deviant by the inability of the disabled person, because of their handicap, to gratify these needs in a socially acceptable fashion. The ideal case is a physical handicap, such as an amputated leg or a paralyzed arm. The most basic response to a handicap is to change the physical environment by way of a "prosthesis," a replacement for the compromised structure (e.g. a prosthetic limb, a wheelchair) that facilitates normative function. The disability rights and anti-psychiatry movements expanded the handicap frame from physical to neurocognitive disabilities and extended the technique of environmental change from the concrete to the social world. Specifically, it was proposed that the marginalization of the disabled was due largely to discrimination and stigma (social barriers) and not the organic processes responsible for their disability (Eyal et al. 2010; Goffman 1961b; Shapiro 1993; Scotch and Schriner 1997). In one of the major syntheses of this extension Wolf Wolfensberger (1972) argued that the mentally retarded (today, the intellectually disabled) could be deinstitutionalized if people in the community acted like social prostheses. In other words, just as a

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[29] "A note on terminology: in the disability literature, 'impairment' is a loss of normal bodily function; a 'disability' is something you can't do in your environment as a result; a 'handicap' is the resultant competitive advantage" (Nussbaum 2006:423). Though I am not concerned with how an impairment influences competitive advantage, I use the word handicap instead of disability in order to retain the focus on the disabled person's relationship with others.

prosthetic limb allows a physically disabled person to function more normatively, a social prosthesis—an aid, a friend, a family member—can act as translator between the cognitively disabled individual and the human community around them (Eyal et al. 2010; see also Goode 1994). In so proposing, Wolfensberger (1972) made communication a crutch by which the seemingly deviant behavior of the cognitively disabled was overcome, allowing them to be "normalized" so that they could navigate and participate in everyday social life. His is among the most influential of the "social-contextual" approaches to disability that formed the backbone of the disability rights movement (Shakespeare 2006:9).

THE VOGLERS, THE HAMILTONS & MARIA WAGNER'S CLASS

The Vogler family consists of Anderson (52), Marge (52), Tom (20), Brian (19), and Jack (16). I lived with the Voglers for eight days in the spring of 2013. Brian, diagnosed with autism at the age of four, supplies a frenetic and quirky element to his family's domestic life. His interactions with family members, and theirs with him, are often affectionate, empathic, and humorous. I first got to know the Voglers over the course of three separate days in the summer of 2011. Despite leaving me, the first time I visited, with the overall impression of a happy family, signs of a more ambivalent relationship between Brian and his loved ones quickly surfaced. Jack's hesitance around his brother, Marge's mention of a "tough period," and Anderson's reference to weekly aggressive tantrums served as preamble to a more complex reality.

Brian’s tough period was characterized by unpredictable and dogged physical violence. For roughly two years, Brian Vogler (age 14-16) engaged in routine aggression towards his family and home. In attacks usually targeting his parents, Brian persistently tried to bite shoulders, scratch faces, pinch arms, and kick legs. Sometimes the proximate cause of his agitation was clear: orders given (“Brian close the refrigerator!”) or desires blocked (a tape jammed in the VCR). Other times the proximate trigger was a mystery. However, everyone recognized the primary antecedent: a “dead look” composed of clenched teeth, slack mouth, and blazing eyes. Three times out of four Brian would go for his father. Weekly attacks—lasting fifteen minutes to an hour—were punctuated by epic meltdowns—like the time Brian attacked his dad on a plane, forcing the pilot to execute an emergency landing. The damage and injuries caused by Brian’s tantrums, and the anxiety and logistics of preparing for their occurrence pushed all members of the Vogler family to analyze the source of the violence. Brian’s aggression quickly dissipated a month before I visited the family in 2011, around the same time that the doses of two medications he was taking—Zoloft and Risperdal—were decreased.

The Hamilton family consists of Chrissie (64), Heather (55), Meg (25), Drew (23), and Ross (22). Though Heather and Chrissie are now separated, they were in a relationship for almost 30 years. Ross, who is diagnosed with autism, is Chrissie’s biological child, and Drew and Meg are Heather’s. Since Chrissie and Heather used the same sperm donor to conceive their children, Ross, Drew, and Meg share the same father. I first met Chrissie and Drew—along with Chrissie’s girlfriend, Sally—when I joined them for dinner in 2011. I reconnected with them and spent time with all the other members of the family—including Heather—intermittently over the span of a couple weeks in the summer of 2013. When I first met Ross, I immediately noticed his striking features: close-cut auburn hair, trim beard, blue eyes, and a charming, devious smile. I also noticed his perseverative behavior—defined as the repetition of a particular response, such as a word, phrase, or gesture, despite the absence or cessation of a stimulus—that is commonly associated with a diagnosis of autism, and is believed to stem from efforts to deal with anxiety (Volkmar and Wiesner 2009). During a lunch I shared with Ross and Chrissie, Ross asked for soda dozens of times—"sodabilet" he would say (his phrase for "soda please"). Throughout the meal, Chrissie tried hard not to grant Ross's request (he had already had a soda earlier in the day). Though Chrissie obviously loves spending time with her son—she often says things like "isn't he just the cutest" and "he's such a great kid"—it was clear how time-consuming Ross could be (eventually Chrissie gave in and got Ross a soda, and then another one on the way back to his group home). However, the energy associated with managing Ross's perseverative behaviors seems mundane when compared to all that went into dealing with the self-injury that characterized his two-year long behavioral crisis.

Soon after Chrissie and Heather separated and right before his 18th birthday, Ross began to engage in increasingly severe self-injurious behavior. Ross's behavioral crisis started innocently enough when he began picking a spot on the back of his neck after a routine haircut. Besides Chrissie's break-up with Heather, other changes in Ross's life included his brother leaving home for college and two in-home aids—both of whom had been working with Ross for six years—leaving to pursue other opportunities. Within weeks the spot on the back of Ross's neck had grown into a garish wound, and he began picking at other parts of his body as well. Ross's new staff did not have the experience to respond to his self-injurious behavior. Moreover, things got so bad that the school Ross attended—one of the best autism specific schools in the country—decided that they were not equipped to manage his behavior anymore. Over the course of six months, Ross was shuttled between local hospitals and a major psychiatric crisis center. He dropped down to 102 lbs. Since he was six feet tall, this weight loss left Ross emaciated. At the nadir of his suffering, he contracted a dangerous infection and almost died. Ross turned a corner in the months after Chrissie moved her son to a developmental center at the urging of a friend who worked there. Chrissie believes that the center took "pressure" off of her son, but it still took about a year before Ross was moved back into the community.

Maria Wagner (62) is a special education teacher at North Point (NPHS), a public high school in a suburban school district; she teaches a group of six students who are all diagnosed with autism. I personally got to know Maria in the winter of 2013 when I followed one of her students—a seventeen-year-old male with autism from one of the families in my study—to school. During the course of that week I spent time with Maria, her students, her staff, and other individuals working in the special education department. Through interviews, conversations, and observations, I learned about the level of coordination often required in order to serve developmentally disabled youth in the context of a mainstream high school. Given the reality that she is there teacher, my analysis of Mrs. Wagner's class will revolve largely around her experience working with her students while at the same time being responsible for controlling their actions (a responsibility enforced by Maria's superordinate's). Maria is exceptionally warm to those around her, particularly her students. Despite the seeming softness that her affection lends to her manner, Maria takes her responsibilities very seriously and speaks fluently about the strenuous and demanding nature of her job. She is constantly observing and analyzing her student's behavior. For example, she spends first period every day "getting a read" on her students' moods because it helps Maria to determine what type of behavior to expect from each of them that day. Maria also told me about—and I was able to observe—the physically challenging aspects of her job. Trained in physical education and a girl's soccer and field hockey coach on the side, Maria claims that her athleticism is important because, "you have to be healthy when you work with these kids." Indeed, despite her belief—professed to me several times—that her student's participate as equally as possible in the social life of the school, Maria has faced a variety of situations in which behavior on the part of her kids has challenged the ideal of inclusion that she values so highly.

Maria described several incidents to me in which she had to deal with behavior from one of her students that was so disruptive that it threatened the smooth operation of the school and their membership in the community it represents. A few years before we talked, one of Maria's students, Zach, pulled a fire alarm in the hallway of the school. Zach was hauled down to a conference room in the main office where fire police, in the presence of school administrators, "yelled" at him, and tried to determine "why he did that." Two days later, another one of Maria's male students, Preston, also pulled a fire alarm in one of the school's hallways. In this case the alarm was initiated only moments before the end of the school day, and the consequent delay in buses (the high school, middle school, and elementary school share the same batch of vehicles) pushed back pick-up times for the entire district. Given the degree to which Preston's behavior, even more so than Zach's, disrupted the smooth flow of the school day, the fire police and school administrators were even more upset and Maria and her students became the targets of even more negative attention.

Another challenging experience that Maria shared with me featured a student in her class, named Darrin, who became the focus of the principal's concern after he learned that Darrin was liable to undress and masturbate in public. In response to his increasing predilection to strip down naked and stimulate himself, Darrin's parents, in consultation with a behavioral therapist, created a program in which he was taught to go to his room and close the door when he wanted to masturbate. For sanitary purposes they also taught Darrin to use a diaper for clean up. Unfortunately, this led Darrin to associate diapers—indeed, a variety of padded objects—with masturbation. During a couple unfortunate episodes in middle school, Darrin saw an object that resembled a diaper and consequently initiated the behavior in public. On one occasion Darrin's middle school teacher tried to intervene, and in response Darrin gave his teacher a punch that landed her in the hospital. When Darrin started high school he was placed in Maria's class. Maria was well informed about the behavioral issues that had been such a challenge to Darrin's previous instructor. Maria devised a variety of methods (e.g. not allowing Darrin to visit a local market with the rest of the class for fear he would undress in the aisle that sold diapers) in order to avoid scenes. Maria also decided to inform key school personnel who she believed would support her efforts to accommodate Darrin's challenging behavior. It was because of this second decision that Maria had a challenging run-in with the school principal. Below I explore the Voglers' framing of Brian's aggression, Chrissie and Heather's framing of Ross's behavior in the decades before and then during his crisis, and the framing of various difficult behaviors exhibited by Mrs. Wagner's students by North Point school administrators, community authority figures, and Maria herself.

MISBEHAVIOR: ANDERSON, HEATHER, AND THE NORTH POINT FIRE POLICE

The intensity and regularity of his son's aggression, his role as primary target during the attacks, and his sense of responsibility for protecting his family all contributed to Anderson Vogler's view of Brian's tantrums as misbehavior. During Brian's 14th year, the increasing frequency and severity of his rages convinced Anderson that in order to effectively respond to his son's behavior he needed to change his own daily routine. As a husband and father, Anderson felt it was his duty to protect his wife and two other sons. To this end, Anderson started coming home everyday before Brian got off the bus. After Brian got home, Anderson would keep a vigilant eye on him, hoping to catch any signs of trouble. If a few days went by and no tantrum occurred, Anderson and his family knew that one was likely imminent. When an episode did invariably occur, Anderson would do his best to take the brunt of the abuse: "biting was the worst, I still have scars to this day." Sometimes Anderson was able to re-direct Brian by saying things like "you're hurting me!" In response, Brian might, for example, go to his bedroom and spend his aggression on the walls. Other times, verbal complaints were not as successful in deterring Brian, and he would continue to scratch, hit, and/or bite his father. Sometimes, when his son continued to aggress against him, Anderson's own response would become aggressive in character. For example, he might restrain Brian or push him away from other family members. In the periods between Brian's tantrums, Anderson would often ruminate over possible explanations for his son's violent actions. These explanations typically characterized Brian's behavior as willful and predatory:

> I'll kick it around in my head all the time, just trying to figure out why he'd get aggressive and why only at us. Is it just like he's holding it in and like I'm just going to take it out on you? Are we doing something to highly piss him off or it's that old you only hurt the ones you love kind of thing?

The specificity of Brian's targeting shaped Anderson's sense that the attacks were intentional and malicious—"I'm just going to take it out on you." Even if it was possible that he and his family might be triggering Brian's behavior—"are we doing something to highly piss him off?"—Anderson still found it very troubling that Brian limited his attacks to loved ones. Given his framing of his son's aggressive behavior, Anderson's offensive tactics were meant to control the tantrums and make it clear to Brian that his actions were unacceptable. In other words, Anderson employed his physicality as a punitive measure meant to deter actions that he defined as misbehavior.

The unpleasant and persistent nature of Ross Hamilton's most challenging childhood and adolescent behaviors increasingly shaped Heather's belief that they were most accurately framed as misbehavior. In addition to perseverating on his favorite snacks (e.g. soda), Heather Hamilton listed public nudity, masturbation, feces smearing, and “elopement” (wandering away, see Anderson et al., 2012) as some of her son’s toughest behaviors:

> He went through years of smearing feces. That was a lot of fun to clean up [. . .] Then he got into this masturbating phase, that was just about as much fun [. . .] When he masturbated, not only did he masturbate, but anything that was pourable he would pour on his penis, and masturbate with that. It could be shampoo, so the entire bottle he would pour on himself [. . .] or, you know, lotions, anything, again, that was pourable, he would just pour all over his body, all over his bedroom, and then go to town. You never knew what you were cleaning up.

Though these experiences were challenging to everyone in the family, Heather increasingly became the one most likely to frame Ross’ actions as misbehavior. She believes that despite Ross’s impairments, he often knew when he was doing something naughty. Heather also believes that the most effective response to Ross’s problem behaviors would have been stricter discipline. To illustrate how she tried to act on this belief, Heather told me that she would often tell Ross to “get back to your room” when he engaged in the habit of, for example, walking around the house naked:

> Fifty percent of the time he would listen, and run upstairs, and maybe put a pair of underpants on, or maybe go to his room [. . .] he was being defiant, he knew what that meant to go to his room and get clothes on, he knew exactly what that meant, but he wasn’t getting attention.

Though Heather recognized that sometimes Ross did listen, she viewed his actions and half-hearted compliance as examples of him manipulating those around him. As Ross aged, Heather became increasingly distressed by the burdens of managing his behavior. She spoke about him running around the house naked and making noises while friends of her other children were over; though some friends got used to it, Heather was bothered by not having any control over the environment of the house. The situation became ever more volatile as Ross’s increasing size made it difficult for Heather to have recourse to more physical means of control (e.g. picking him up, and putting him in his room). Indeed, it was his physical maturation that fully convinced Heather that Ross needed a disciplinary structure that she and her family were not equipped to provide.

When two of Maria Wagner's students initiated false fire alarms only a couple days apart, the misbehavior frame of deviance shaped the response of community authorities. Before lunchtime on a regular school day Zach, one of Maria's six students, yanked the lever of one of the red fire alarm pull stations in the school's hallway and set off a school wide fire drill. When the fire police who responded to the call learned that there wasn't actually a fire, Zach was taken to a conference room in the main office for questioning. Maria explains what happened next:

> The boy was nonverbal, and they had him in the conference room, yelling at him, saying 'why did you do it?' And this boy just smiles. That's all he did. Because he didn't talk.

The fire police who responded to the drill interrogated Maria's non-verbal student hoping to determine why he pulled the alarm. Their reaction to the boy's behavior was anchored in the misbehavior frame of deviance because: (1) they asked the boy to account for the reason he pulled the drill—a question that frames his behavior as self directed, and (2) they posed their questions in an angry tone, an emotional valiance that often carries punitive overtones. In response to the "yelling," the boy—unable to speak—sat in a chair smiling. The fire police interpreted this as a sign of obstinacy. They also interpreted it as further evidence that the boy did indeed pull the alarm out of his own volition, and thus felt more secure in their presumed definition of the situation. Despite this conviction, once Maria arrived she convinced the police to let the boy off the hook: "I said, 'No, no, no, you don't get it. Let's just take care of him, and then I will talk to any questions you have." Two days after Zach pulled the fire alarm, another student in Maria's class—a boy named Preston—did the same thing. This time around the fire drill set back the entire district's bus-pick-up schedule, and the fire police extended their framing of the situation to include Maria: "'We cannot have this happening. You're endangering lives,' and it was all directed at me [. . .] because I don't have control of the two students that did it." Though Maria wasn't the one who pulled the alarm, she was defined as misbehaving because she was unable to stop her students from undermining the normal operation of the school. Though the fire police were the ones asking the questions, Maria explained that school administrators who were present did not try and defend her or her students: "They were firing at me. My department head was standing there not saying anything." Besides disagreeing with the way that the police were framing the situation, Maria also had major critiques of the social control strategy they advocated based on their definition of the situation: "I just sat there saying in my head, 'You guys have no idea what you're talking about.' They said, 'We need to come talk to your kids.' I said, 'That would be great. You come talk to my kids.'" (If it is not obvious from this comment, Maria's tone, when she told me about this particular response, carried clear overtones of sarcasm).

HANDICAP: TOM, CHRISSIE, AND MARIA WAGNER

Tom Vogler's belief that his younger brother's aggression stemmed from a struggle to communicate with the family shaped his interpretation of and response to Brian's tantrums. Around the time his tantrums began, Brian's weight ballooned to 230 lbs. In the first year of the tough period, Tom, a freshman standing 5’ 2’’, could do little more than get out of the way during Brian’s attacks. However, by his junior year Tom had experienced a growth spurt, and his maturation gave him the courage to start assisting his father during violent episodes. Yet, despite his willingness to help his father, Tom had a different interpretation of Brian’s aggression:

> A lot of the time it was provoked by pushing him too far [. . .] Me and Jack used to play basketball in the hallway and we would ask Brian to play, and a lot of the time he just did not want to play. We kind of encouraged him, ‘oh Brian take another shot dude, pass the ball,’ and he would all of a sudden get frustrated [. . .] he would usually give you a look or he’d repeat something back angrily like ‘shoot the ball.’ He’d say it like he really was pissed off. There were a lot of times where he would give you a quick reaction, like he’d give you a pinch, or he’d give you a push. Then it would be done. ‘I’m done, leave me alone.’ He probably learned that from me and Jack. ‘These guys express themselves to each other by hitting each other and wrestling’ so maybe he was just trying to emulate that.

Tom framed Brian’s aggression as a reasonable response to the challenges associated with his functional deficits. While Anderson viewed Brian’s attacks as mystifying (“why would he attack his family?”), Tom believed that pinches and pushes were often associated with clear situational stressors like being “pushed too far.” Moreover, while Anderson viewed Brian’s attacks as unacceptable (“you can’t do this”), Tom viewed them as stemming from Brian’s need to share reasonable desires that his disability made it difficult for him to communicate in a non-deviant fashion. Tom expressed the possibility that Brian might have started to use aggression to communicate because he observed his brothers doing the same (for a discussion of sibling roughhousing as the most prevalent form of violence, see Collins, 2008). Whether or not this was the case, the handicap frame shaped Tom’s interpretation of his brother’s aggression.

The handicap frame also shaped the tactics Tom used to respond to Brian's attacks. When Tom helped to control his brother's tantrums, he would often start by getting Brian away from Anderson:

> I would never like try to hurt Brian or anything, it was just get him away from my dad because, you know, sometimes those two would like go at each other and it was not helping for my dad to like return fire because it's not going to do anything. And I know he was just trying to separate, like just trying to get him away and tell him like you can't do this, but a lot of times it was just like you'd need to separate the two rather than like keep them going at each other and like wear him out or something.

While Tom was not opposed to using his body to move Brian away from his dad, once he transitioned Brian to another location he worked to keep himself out of his brother's reach. He would then use words to try and determine what was making Brian so frustrated. "Brian, what's wrong" he would ask. Sometimes Brian would answer, saying things like "head hurts" or "don't do that." In pressing his brother to use words, Tom worked off the assumption that Brian's aggression stemmed from a struggle to communicate. Physically isolating his brother and questioning him were changes that Tom made to Brian's social environment, and he hoped that these changes would allow his brother to satisfy his needs using a less deviant mode of communication.

Chrissie Hamilton believes that a majority of her son Ross's most challenging behaviors represent determined attempts to communicate his social desires to those around him. During the lunch I shared with Chrissie and Ross, I had an opportunity to observe how persistent Ross's perseverations—like requests for soda—can be. Chrissie explained to me that she believes her son's perseverations manifest themselves when Ross feels excluded from social interaction:

> If I am with him, and I'm just talking to him the whole time, he can have a glass of soda there and he won't sip it at all [but] you're there, and I'm talking to you, and I'm trying to include him, but ah, and that happens a lot, I think, you know, not so much at this [group home] because I think they do engage, but in the other [group home] they would be in the room, nobody would ever talk, and he is going to do something to get your attention.

Chrissie interprets her son's atypical behaviors as the only way—given his impairments—for him to communicate a typical human desire. Chrissie points to the reality that when she is alone with her son, he will not obsess over his favorite treats, like soda, even if they are sitting right in front of him. She also states that Ross's behavior has improved since moving from his old group home, where a neglectful staff caused his attention-seeking behaviors to increase. Given that most people desire social inclusion, Chrissie sees her son's problem behaviors as a reasonable response to the functional deficits that characterize autism.

Maria's preference for the handicap frame of deviance is driven by her desire to integrate her students into the social life of North Point High School as much as possible. When she talked to me about the homeroom period that North Point struck from the schedule some years back, Maria implicitly illustrated the import she places in having her kids interact as much as possible with other students in the high school: "It was homeroom here until a couple years ago [. . .] that was one time they were out in the mainstream [. . .] there were good role models around them." Maria views interaction with North Point's "mainstream" students as important, both in its modeling of social behavior for her students and—as she explained during another conversation—by exposing typically developing students to individuals representing another form of human diversity. Her desire for inclusion is one of the forces driving Maria's distaste for ideas that might cause her students to be segregated. Included in this are applications of the sickness and badness frame of deviance, definitions that tend to stigmatize individuals labeled as rule-breakers (Conrad & Schneider 1992).

In cases where Maria is able to predict that one of her student's—because of some habitual behavior—is likely to invite negative attention, she looks to shape the school's social environment so that the social control strategy used is in accordance with the handicap frame of deviance. For example, when Maria learned that a student assigned to her class (Darrin) had, on several occasions, undressed and masturbated while in middle school, she decided to notify school administrators and security guards:

> Well first of all [. . .] I made everyone aware of it in the school that needed to, like I needed to tell security and the head of security and then the guards look at, found his picture to make sure that if I make a call to them they knew who I was [. . .] [I] talked to the principal and I met with him for a long time. Well, my supervisor and everybody, I mean, everybody needed to know.

Maria let the security guards know who Darrin was so that if he was found doing something inappropriate and someone called them about it they would understand that his behavior was a result of his disability. She also explained to them that if they tried to intervene in his public nudity or masturbation, it was possible that Darrin would strike out at them. Once again, Maria explained to the guards that this behavior was to be framed as a misunderstanding, and not further evidence of any malicious undercurrents driving Darrin's actions. Finally, Maria asked all of the security guards, in the event that Darrin was caught masturbating, to contact her immediately so that she could respond to the behavior according to the handicap frame of deviance. For Maria this means working with the school's behavioral specialist to figure out a way to communicate with Darrin when it is and is not appropriate to masturbate. What it does not mean—and what she explained to the security guards—is trying to physically restrain Darrin once he has already initiated the behavior: " [. . .] according to the behavior specialist if you try to stop it, it's just not a good thing [. . .] [Ben: he'll flip out?] [. . .] So she suggested [a woman who Maria used to work with who still gives her counsel], you know, she told me to tell the security guard and work with the behavioral specialist." This is why Maria told the security guards that if they intercepted Darrin acting deviantly, they should just call her and she would handle it.

SICKNESS: MARGE, CHRISSIE, HEATHER, AND NORTH POINTS'S PRINCIPAL

The language that Marge Vogler uses to describe Brian's tantrums is clearly a product of the sickness frame. Marge links a majority of her son's aggressive episodes to somatic processes over which he had no control:

> It is as if someone else comes into him, and he is not himself [. . .] To me there was always something underlying, it wasn't his personality, and being medical [Marge is a Nurse], he always had these ear infections [. . .] I think part of it was the way his head felt when he was on all of these drugs.

Marge does not believe that Brian ever intentionally attacked his family. Rather, she characterized the difference between his usual behavior and behavior during tantrums as "a split personality type of thing that he isn't there" but could see what he was doing. One of the most compelling pieces of evidence supporting this interpretation was that in the aftermath of his tantrums, Brian would sometimes go up to a person he had hurt and say

“’I so sorry,’ literally crying and making all of us cry.” Marge posits a reaction to prescription drugs as one of the primary culprits. These include Zoloft, first given to treat Brian’s obsessive behaviors (e.g. vigorous hand washing), and Risperdal, given in tandem with Zoloft when a psychiatrist suggested that the Zoloft might be responsible for Brian’s aggression and weight gain. To support her view of Brian’s aggression as likely caused by drug reactions, Marge points to the association between tapering his doses and the virtual disappearance of tantrums. However, Marge also blames dietary allergies for her son’s behavior. She told me that her son was diagnosed with Celiac’s disease and a milk allergy, and that she noticed improvements in his behavior as she took wheat and dairy out of his diet. Marge employed the sickness frame to interpret her son’s aggression as the result of various biological processes. Drawing on the logic of this frame, Marge “weeded” out the etiological factors that she believed were the source of the underlying pathology.

Marge’s preferred social control strategy for dealing with Brian’s tantrums was also shaped by the sickness frame. Marge learned how to handle patients with psychiatric issues when she worked as an ER nurse: “the most important thing to do is de-escalate the situation [. . .] put something in between you and the person, and talk them down as opposed to getting physical.” Marge applied this tactic to her son, arguing that the best way to handle his tantrums was to separate him from the rest of the family. As with mentally unstable patients in the ER, Marge felt that using physical tactics with Brian would only make things worse. While the use of words might seem contraindicated if Brian was not himself, it is possible to make sense of “talking someone down” if we interpret it as appealing to their true, though at the moment compromised, self. Essentially, Marge advocated a form of quarantine so that the processes controlling Brian's behavior might run their course while at the same time minimizing the damage they did to others.

Though Chrissie and Heather Hamilton disagreed about how best to interpret and respond to Ross's behavior when he was younger, both women switched to a medical frame of deviance to make sense of their son's actions during his behavioral crisis. Heather saw sickness as the only logical explanation for the profoundly self-destructive behavior her son exhibited during his crisis:

> It was just very self destructive [. . .] I think hormonally he was in a rage [. . .] I don't know if Chrissie showed you the pictures [. . .] you know he gauged his skin down to the muscle. Uhm, by the time we got him to the ER, he looked beyond what a battered child would look like if you took a baseball bat to them. He had black and blues up and down his body from pinching. He would just sit there, I don't know how anybody could do this. And would pinch his skin until it turned black [. . .] And then he would start gauging, gauging until he was drawing blood, and then going into his muscle. How do you not feel that? [. . .] No this was almost a psychotic break of sorts [. . .] At one point we had him wearing a football uniform [. . .] The paddings, the helmet, the shirt. He even had to wear it to bed.

Heather compares Ross's deviance during the crisis to a psychotic break. Following through on the logic of the sickness frame, she grasps for some biological process—a "hormonal rage" in this case—to explain Ross's behavior. Placing him in a football uniform demonstrates one strategy the family used to protect Ross from the processes that had hijacked his body. Of course, it might seem contradictory that the Hamiltons used a football uniform—essentially, an outfit meant to physically restrain Ross—when Marge Vogler used the same definition of Brian's behavior to justify avoiding physical restraint. Yet, Chrissie points to Ross's *own* growing preference for physical restraint during his crisis as evidence for starting to define him as sick:

> [At first] there was an attention-seeking piece, but once it became kind of imbedded as one of his routines, it became kind of a compulsion. So he didn't seem to be able to stop himself. That's when we began to first see the self-restraining behavior [. . .] where he would wrap his hands up in a towel or anything to keep himself from hurting himself.

Chrissie believed that though at first Ross's picking was similar to earlier attention-seeking behavior, soon his self-injury took on a life of its own. Ross's attempts to restrain himself or have others restrain him seemed to indicate that he required outside mediation to stop his body from doing things that his true self did not want it to do. A particularly stark example of this was when Ross, while in a psychiatric ward, came to prefer being in a straight jacket. For Marge, her sense that Brian was not in control of his tantrums, that his violence towards others were symptoms of an underlying pathology, made physical restraint too punitive a response. Given Chrissie's belief that forces beyond his control drove Ross's violence towards his own body, she determined that the best way to protect her son was to interfere with his attempts to injure himself.

When Maria Wagner explained to the principal of the school that one of her students (Darrin) was liable to strip naked and masturbate at the site of diapers and objects that resembled them, the principal responded in a fashion that opposed the handicap frame of deviance. On the advice of an ex-supervisor that she continues to consult to this day, Maria decided to tell key school administrators about the potentially problematic consequences of Darrin's home program for his behavior in school:

> I met with [the principal] for a long time [. . .] he reacted like ‘what is he doing here, why, he should not be in this school’ [. . .] ‘From what I understand he was in middle school?’ ‘Did he do it in middle school?’

Despite Maria’s belief that Darrin’s behavior must be dealt with through effective staff communication, the principal’s question as to why a boy who masturbates in public is allowed in the school at all suggests a social control strategy shaped by a definition other than the handicap frame. However, the certainty ends there as to the principals’ preferred frame of deviance, as I did not schedule an interview with him and thus had to rely on Maria’s sparse comments to chronicle his response. Removing Darrin from the school is a social control strategy that, in this particular case, could be based on the logic of either the sickness or the misbehavior frame. Specifically, principal might have viewed Darrin’s behavior as pathological, and thus his response—“he should not be in this school”—would constitute a social control strategy akin to a quarantine. Having Darrin quarantined for sexually inappropriate behavior is analogous to the response of some court precedents that frame those with certain forms of sexually deviant behavior as having a “highly contagious disease” that society is justified in “quarantining, if they [threaten] to contaminate the public at large” (Tucker, 1999: 226).

Despite evidence that the principal’s interpretation and preferred social control strategy were shaped by the sickness frame, his question as to how long the behavior had been going on—“did he do it in middle school?”—suggests the possibility that he defined Darrin’s actions using the misbehavior frame of deviance. Emily Bosk (2013) has demonstrated that youth with behavioral issues who are framed as sick and then fail to ‘get better,’ are at risk for having new episodes of the same deviant behavior reframed as instances of badness. The principal's question as to whether Darrin had engaged in public masturbation in middle school suggests that he was weighing the possibility that his continued deviance was actually a sign of misbehavior. If the principal's preferred frame of deviance for Darrin's public masturbation was misbehavior, then having Darrin removed from the school—though apparently the same as a "quarantine"—would actually constitute a punitive measure as opposed to a therapeutic or preventative measure. If the principal had suggested what type of institution should replace the school in coordinating Darrin's daily care—a behavioral health unit, or a disciplinary school—it might have provided more clues as to which frame of deviance he preferred for Darrin's case. Of course, the ambiguity of the principal's preferred frame rests in this case on the small amount of information we have about his views of Darrin. However, even if I had been able to talk to the principal, it is possible that his comments would not have lain to rest all ambiguity concerning his position. Indeed, in most of the cases that I explore in this paper, stakeholders—despite various comments that suggested a preference for one frame over others—provided evidence of considering interpretations and/or social control strategies that were in accordance with opposing frames of deviance.

AMBIGUITY

Despite having compelling arguments for the frame that they chose, Anderson, Tom, and Marge Vogler all mentioned interpretations and/or acted on strategies of social control that contradicted the assumptions underlying their chosen frame. While Anderson's frame interpreted Brian's aggression as self-directed, he also mentioned his belief that drugs probably did play some role in his son's behavior. In so doing he acknowledged that Brian's behavior was at least partly due to biological processes that were outside of his control. Moreover, looking back at Anderson's comments about his son earlier in the paper—specifically, his suggestion that the family might be doing something to "highly piss him off"—suggests that his behavior might be a form of communication, an interpretation inline with the handicap frame of deviance**.** Tom viewed Brian's aggression, and the way that he targeted his family, as the result of frustrations associated with difficulty communicating. However, he also admitted that the few times he experienced an injury during Brian's tantrums led him to sympathize with his dad: "[then] I kind of understood why my dad might get really frustrated." Tom's comment highlights that if he was in his dad's role he might be more inclined to see Brian's behavior as self directed and predatory. Moreover, though Tom didn't mention this explicitly, the reality that he primarily targeted his father complicates the interpretation that his behavior was entirely a form of communication. Though Marge preferred to frame Brian's aggression as a symptom of an underlying pathology, she also told me that it is possible that her son learned some of his aggressive behavior from students in his autism class who got violent. I just so happened that around the time Brian began getting violent he became the target of some aggressive behavior from another individual with autism. Now, according to Tom—who suggested that Brian's aggression might have been a form of communication he learned from his brothers—imitation is a behavior best interpreted by the handicap frame of deviance. Thus, Marge's suggestion that Brian imitated violence from his classmates is an interpretation that is based on the assumptions of a frame different from the one she prefers. Besides providing interpretations that were at least partly in contradiction to their preferred frame of deviance, I encountered instances in which ambiguity was based in the reality that the same piece of evidence was used to support a different definition of Brian's aggression.

The ambiguity the Voglers faced in trying to understand Brian's behavior is also nicely demonstrated by those instances when Anderson, Marge, and Tom all used the same piece of evidence to support their chosen frame. One characteristic of Brian's tantrums that Anderson, Tom, and Marge interpreted differently was the persistence with which Brian tried to make physical contact with someone during his tantrums. Anderson viewed Brian's determination as a sign that it was his son's intention to hurt his loved ones. Tom applied the handicap frame, arguing that Brian's persistence showed how strong was his desire to communicate with his family. Marge spoke of her son's need to make contact as a form of "physical feedback," the result of the compulsions that shaped his behavior. These different interpretations highlight the reality that the ambiguity of deviance rests not only in the diversity of evidence, but also on the multivocality often inherent in the same piece of evidence.[30]

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[30] In an example of a caretaker struggling between the sickness and misbehavior frame of deviance, I overheard one father state in a conversation with friends about his adult son with autism: "You know we had the knobs of every freakin door in the house changed [. . .] we had combo locks, so what's the big deal, but this is our son, if it was a stranger, he'd be out of there [. . .] believe me, I've had times, and I am not proud of this, but I have had times where I have gotten in his face, and screamed, because quite frankly, like any other kid, he knows what he's doing is wrong. Now some things are, some things he is driven to do, but some things he just willfully does [. . .] You know he is bad too sometimes, he is not good all of the time, and you know, you think you say, yeah, he knows, and to sit there and say that he doesn't, he doesn't do bad things, is incorrect."

Though the rift between Chrissie's framing and Heather's framing of their son Ross's behavior continued to widen through his adolescence, both women did and said things that acknowledged the logic of the other's point of view. Chrissie's view was that Ross's difficult behavior when he was young constituted his way of communicating a reasonable desire for social inclusion. However, she admitted that sometimes his attention seeking became manipulative or compulsive in nature. For example, she pointed to instances when Ross, in the midst of a perseveration, would act in a way that suggested a level reflexivity and devious intent: "when he's doing things, like he's doing it and he's looking at you, and then he's doing it, and that's probably manipulation." Though Heather had her commitments to the misbehavior frame, an interview with her daughter, Meg, suggested that she was open to other definitions. Meg told me that when she was young there were many times that Ross would go into her bedroom and destroy her belongings. When she got angry with him, believing that he acted intentionally and "knew what he was doing," Heather would scold her and say, "you shouldn't get angry at him, he doesn't understand." This comment demonstrates Heather's view that Ross did not always know what he was doing, or act with the intention of doing damage. As Ross got older and more difficult to manage, Heather had a harder time viewing his behavior as free of intention. Chrissie's interpretation of Ross's attention-seeking behavior as he grew differed in that she saw it as a further expression of his need for inclusion.

Despite agreeing that Ross's self-injurious behavior during the crisis is best understood through the sickness frame, both Chrissie and Heather behaved in ways and said things that undermined this shared definition. When Ross entered his behavioral crisis Chrissie and Heather switched from applying their earlier preferred frames (Handicap and Misbehavior) and both started to define their son's new deviance as evidence of sickness. Despite showing increasing loyalty to this new definition, they both said things which seemed to contradict the assumptions of the sickness frame of deviance. For example, though Chrissie felt that her son was not in control of his behavior during the crisis, she struggled, at times, with the implications of his behavior if analyzed using her old preferred frame, the handicap frame. Meg attested to this conflict when she told me about conversations she had with her mom while Ross was in the hospital: "That's what she said, that he was upset, you know. Whenever Ross is upset, Chrissie gets very upset, just like, 'he can't communicate why he's upset, so he's doing this, and I don't know what he wants,' and that like really like gets her." Though at times Chrissie interpreted Ross's self-injury as out of his control, at other times she interpreted it as a desperate attempt to communicate something—a message she was unable to decipher. In these instances Meg would try to shift Chrissie back to the medical frame of deviance by saying that "it is not because of you" and "we've got to trust the doctors." Though Heather framed Ross's self-injury as a sickness, on more than one occasion she described his behavior as beyond explanation. While this section has explored the ambiguity that undermines definitions of deviance, Heather's statement suggest that the inability to even apply a frame might be the ultimate form of ambiguity (Frank 1995).

Despite her steady resistance to the frames of deviance preferred by some school and community authorities, Maria Wagner's interpretations of student behavior did not always fall in line with the assumptions of the handicap frame. Maria's approach to her student's deviant behavior stresses communication with them, and modifications to the social environment around them. However, some of the comments she made concerning actions that got her student's in trouble demonstrate that she is ambivalent about whether the frame she prefers is always a valid definition of a student's deviant behavior. For example, while talking to me about Preston—the student that initiated a fire drill two days after Zach, and set back the entire school district—Maria described her response to the angry questions of school and community authorities thusly:

> I didn't respond. They were firing at me. My department head was standing there not saying anything. And then my supervisor wasn't there. I just – because I knew, Ben, I knew what I was doing was okay. I was confident in myself that I would be able to handle whatever this is and not the way that they would handle it [. . .] I'm not going to let them upset me, because I know the boy. The boy might have done it on purpose, but not really, I don't know.

Though Maria's comments suggest that she is confident in the assumptions that guide her social control strategies, her reflection on the motivations shaping her student's deviant behavior introduce a line of doubt concerning her analysis of the situation. Specifically, Maria claims that she "knows the boy," that her view of his behavior in this particular instance is backed up by a substantial catch of evidence collected over the course of a long student-teacher relationship. However, the comment "he might have done it on purpose" contradicts the assumptions of the handicap frame while at the same time supporting the misbehavior frame preferred by the police. The follow up comment "but not really" moves her interpretation back into the realm of handicap—despite elements of self-determination, the behavior occurred in the context of larger structural forces that the student, because of his handicap, didn't understand and couldn't accommodate. However, Maria’s final comment—“I don’t know”—leaves her feelings about the correct definition for her student’s behavior squarely in the unknown. It is an admission that her preferred interpretation and control strategy are shaped by a frame whose fundamental assumptions, at least in this instance, she questions.

Though, during our interview, she didn’t address the specific incidents that have been the focus of our discussion of Maria Wagner’s students (e.g. the fire drill fiasco), Rachel Davis (Maria Wagner’s Supervisor) provided me with a compelling example of the ambiguity school administrators face when trying to frame and respond to the deviant behavior of student’s with autism. Rachel Davis is a special education supervisor at NPHS. In her professional role she is responsible, along with a co-supervisor, for overseeing all of the teachers and programs serving the 580 students at the high school who have an Individual Education Plan (IEP). Though they have a good working relationship, Rachel and Maria have not always seen eye-to-eye on how best to control the deviant behavior of students with autism. Indeed, Maria mentioned a couple cases in which she had pushback from Rachel concerning particular precautions she wanted to take in order to minimize the likelihood of behavioral issues. For example, Maria wanted to have an extra aid—an individual who knew her students well—accompany her on a lengthy class trip, but despite the logic of having someone who knew the students (more able, because of their knowledge, to act as a “social prostheses,”) Rachel objected because of budgetary constraints. Though Rachel didn’t comment on this episode, some stories she shared with me demonstrated her struggle to employ the right frame when faced with deviant behavior. One example stems from her discussion of helping to organize the people required to support a girl with autism in a community vocational program:

> That was a huge experience for me. I was so amazed at how hard it was to do. How labor intensive it was. How many people it involved getting from place to place and getting people where they needed to be [. . .] I think she [the student] made the transition and it was a combination, with her, in particular, she was having—she didn't have a job coach with her, she was using the supervisor there, and she was doing pretty well, and then I think they brought in the chocolate [candies] and she couldn't resist [. . .] I don't know how much she did it, but then I started thinking, and again, this was after she left us, so I don't have any witnessing, so how many are you allowed to eat when you're on this spectrum and how many are you allowed to eat when you're not? I don't know. But that was not acceptable. I understand that. They're in business. So that was kind of her chance for meaningful work.

Rachel recounts the effort and logistics that went into placing a female student with autism at a job in a factory that makes candy. While some special education students have the funding for a one-on-one job couch when attending a vocational position during the school day, this individual did not and was overseen by the onsite supervisor. Rachel notes that while the girl started out doing well, once she started to eat the candies (she couldn't resist the chocolate flavor) the job site explained that they were not going to tolerate her rule-breaking. Though the employer framed the student's deviance as misbehavior, Rachel's view was more ambivalent. On the one hand, Rachel states that she "doesn't know how much she did," thus implying that maybe it was not correct to frame her behavior as self-directed and justifying punishment. On the other hand, her question "how many are you allowed to eat when you're on the spectrum?" presents the possibility that at some point handicap (or sickness) is no longer an acceptable definition for deviance. Rachel also notes that the girl's employer has the right to protect their interests, and as supervisor she is not only responsible to individual student's but also to the school's reputation in the community (since the school relies on community business to provide employment opportunities for developmentally disabled youth). Though she laments the harsh reality that this opportunity might have been the girl's only one for what she labels "meaningful work," Rachel exposes questions of validity that often lurk in the assumptions upon which interpretations and social control are based. Through her story, Rachel also demonstrates how conflict and negotiation over frames becomes only more complicated when people liable to behave deviantly operate in social systems with distinct goals that are still trying to coordinate their activities with one another (in this case, a school and community businesses).

CONFLICT & NEGOTIATION

Despite the reality that Tom, Marge, and Anderson Vogler all applied a different frame of deviance to Brian's aggression, only Marge and Anderson struggled over conflicting social control strategies; Tom's decision to start assisting during tantrums took pressure off his dad while conforming with his mom's preference for de-escalation. While Anderson felt that his psychical approach to Brian's tantrums was justified by his frame, Marge's belief that her son was not in control of his behavior brought her into conflict with her husband: "Anderson and I have big disagreements sometimes about how to handle him and how to—because he was a lot more physical [. . .] that's not the way to do it when they're in that state."[31] The difference in their approaches continued to be a matter of dispute until Tom started assisting his father in controlling Brian during tantrums. Though Tom believed that his brother's aggression constituted an attempt to communicate, his social control tactic was similar enough to his mom's that she was satisfied. For his part, Anderson was grateful that he no longer had to shoulder the burden of Brian's abuse on his own. This example demonstrates the reality that though different frames are associated with divergent interpretations of deviant behavior, distinct definitions do not necessarily lead to mutually exclusive strategies for social control.

Heather and Chrissie Hamilton used distinct frames to understand Ross's problem behaviors when he was young, and this led to conflict between the two women.

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[31] In another example of a caretaker negotiating with other caretakers about the best social control strategy, the director of a day program for adults with autism told me about her attempts to convince her staff to use the handicap frame of deviance over the misbehavior frame (my attribution): "I explain to them that we are all communicating non-verbally all the time. Where we look, how we say it, the rate of our speech, everything from the tip of our head to the tips of our toes, we're communicating, and so are the people we are working with [for useful elaboration, see Birdwhistell 1970]. Most of the people that we support downstairs have some sort of impaired verbal ability. So, those non-verbal communication skills are often times more advanced in them then they are in us. So, a lot of it I would say to be involved is really just studying people. [. . .] I think when somebody is acting aggressively towards you, or is acting in a way behaviorally that makes you very uncomfortable, you feel threatened, you feel scared, it's inconvenient. And those are all things that we can bring with us into a situation. But I think the thing that we have to understand with that, is when somebody is driven to that point, it is much more frustrating for them then it is for us. I might be at a five out of ten, but if you are driven to the point where you have to yell at me, or rush at me, or shake me, or grab me to communicate your point, you are at a ten out of ten. And I guess one of the things is that we all get there, you know, one of my favorite things is cell phone customer service. You know how many times have I screamed at somebody. After the fact, you know, you feel horrible, you feel about this big, you've probably just ruined someone's day over something you had a million other choices of ways to deal with. And I think that, uhm, that they do get very frustrated. They're just trying to communicate with us and we are not getting it."

Meg told me that there have always been differences in the ways that her moms' approached parenting: "Heather wanted [there to be consequences] when [Ross] did do something bad [. . .] Chrissie was, well, she was a more positive reinforcer." Ross's problem behaviors were a common source of consternation in Chrissie and Heather's relationship. In one story that Heather shared, the family was at a restaurant and Ross was acting out. Heather wanted to leave, but Chrissie wanted them to stay. Heather agreed to watch Ross while Chrissie and the two other kids got food; just as Chrissie got back to the table Ross urinated while sitting in his chair. Heather told me that she felt they should have left the restaurant the moment that Ross started acting out: "I fully, fully believe that other people in restaurant had the right, because they were paying for their quiet meal, to not have to experience Ross." In other words, if Ross's behavior broke the implicit social rules of that situation, he should be removed. Though Chrissie did not comment on this specific incident, her conversations with me communicated that in her opinion Ross deserved to be integrated into as many typical situations as possible. Rather then taking what seemed to her as punitive measures, Chrissie defined his behaviors as linked to his disability. Though he might have had some control over them—they derived from typical desires, like attention—his handicap made him unable to achieve them in a socially acceptable manner. Thus, his desires needed to be accommodated as best as possible through the prosthetic work of the family: trying to control his behavior as best they could, but not punish him for wanting what was natural. Both Chrissie and Heather shared with me how difficult there distinct definition of Ross's behavior made their relationship: both women discussed many times the damage it did to their relationship, and the desire to bring it to an end. However, when Ross was a child, it was easier for them to work it out, or at least live with their differences. As Ross got older, he became more difficult to manage, and the normative expectations of society began to weigh more heavily. For example, while Chrissie thought that Ross should be included in all family activities, Heather became more concerned that his presence was disrupting any semblance of a normal life. One of the biggest issues was Heather's increasingly insistent calls to seriously consider placing Ross in a residential setting. Eventually the women separated.

Though Tom, Marge, Anderson, and Jack Vogler agreed that they wanted to keep Brian at home, all members were faced with the cost of what Marge described as "keeping it in the family." Despite the anxiety, work, and injuries associated with Brian's tantrums, Anderson, Tom, and Marge agreed that the most troubling aspect of the violence was the effect it had on Brian's younger brother, Jack. When we first talked about the tough period, Marge told me that Jack was "traumatized" by his brother's attacks. She described how Jack would flee the room if Brian entered, whether or not he was showing signs of aggression. Tom shared a memory in which his brother ran away when Brian tried to hug him. Anderson recalled a family trip to a restaurant when Jack jumped up in his seat at a noise reminiscent of Brian, even though his brother hadn't come along: "it was as if he was back on the battlefield." The possibility of placing Brian in a residential setting was raised several times, and most strongly advocated by Marge's mom. However, Marge and Anderson decided that since Brian was only violent at home and they felt capable of handling his outbursts, the decision would be contingent on the feelings of Jack and Tom. When Marge brought up the option of sending Brian away to her two other sons, both pleaded with her not to: “Mom he is sorry, just let him stay.” Marge and Anderson agreed, despite their differences of opinion, that if only they could keep working on it as a family they would figure out how to stop their son’s aggressive behavior. As time wore on, and Brian’s behavior did indeed get better, Anderson increasingly started to open up to the logic of his wife’s point of view. However, it is possible that their ability to negotiate was contingent on the reality that Brian’s behavior improved.

In the wake of Ross’s crisis, Chrissie and Heather Hamilton increasingly came to see Ross’s self-injurious behavior as evidence of a pathological state. She tells me a story she will never forget. Ross’s crisis began in the aftermath of Chrissie and Heather’s separation. While Chrissie took on primary responsibility for Ross’s care after she separated from Heather, Heather still came to visit her ex-partner and Ross while the latter was being shuttled from one hospital to another. Though both women have complex feelings concerning their relationship, they largely agree that Ross’s behavior during the crisis constituted a sickness. About a year after it started, Ross came out of his crisis and started acting like his old self.

Though both the fire police and the principal framed the deviant behavior of her students differently than Maria Wagner, eventually the teacher’s view largely won out through committed negotiation and despite her own reservations concerning the validity of the handicap frame. Though she disagreed with the frame of deviance the fire police applied to both Zach and Preston when they initiated fire alarms, Maria agreed to allow the police to come to her classroom and make a presentation to her students concerning alarm protocol. When the police came to her classroom they found themselves confronted with a group of students who had special needs, and, unsure how to proceed, looked to Maria for guidance:

> I said to them, I said, 'Okay, I will be Oprah, and I will ask you questions. I'll ask you questions,' and then when I asked them questions, then they would be talking and the kids could hear it [. . .] so instead of we're not talking at them [they could just overhear it] [. . .] the fire police, and the policemen, they were fine, because they felt like they talked to them, and the kids were fine, we certainly did other things before that [to prepare for the police to come talk].

Despite framing some of the students' recent actions as misbehavior, the police required advice from Maria about how best to overcome communication barriers in order to attempt social control. In looking to Maria for help communicating the police responded to her as a "social prosthetic," and in so doing implicitly changed their response to the students from one shaped by the misbehavior frame to one shaped by the handicap frame. Maria decided that rather then talking directly at her students—many of whom had various issues interacting in the typical manner that the fire police might expect when giving a presentation—she would pretend to be a talk show host and interview the fire police. This would allow the fire police to share important safety information to the students in the classroom, and at the same time allow these particular students to get the information in an indirect way that would not be as threatening as a direct lecture. In the case of Darrin—the student who masturbated in public—though the principal of the school was at first incredulous about the boy's attendance, Maria eventually convinced him to let her deal with the situation in her way.

CONCLUSION

This chapter explored how caretakers of adults with autism engaged in conflict and negotiation over the application of popular frames of deviance in the context of the ambiguity and complexity of situations and the stakes surrounding interpretation and social control. The assumptions upon which frames of deviance are built shape the way that social actors interpret and respond to deviant behavior. Actors advancing particular definitions of deviance select from the complex array of social facts to support their preferred definition. The messiness of lived reality challenged the application of available frames of deviance, despite the historical and empirical roots on which these different frames are based. This includes the reality that the same piece of evidence can sometimes be used to support different definitions of deviance. For example, Marge, Tom, and Anderson all interpreted Brian's perseverance when attempting to inflict physical damage through their preferred frame of deviance. Moreover, different definitions of deviance can sometimes be employed to justify similar social control strategies. For example, though Marge and Tom applied different frames of deviance to Brian's tantrums, their strategy of isolating Brian and trying to talk to him were essentially the same. Finally, sometimes individuals advancing the same definition of deviance will end up endorsing opposing social control strategies as necessitated by the particulars of the case in question. For example, though Marge used the sickness frame of deviance to determine that Brian needed to not be restrained when trying to harm others, Chrissie and Heather used the sickness frame of deviance to justify restraining Ross when he was trying to do injure himself. Though this paper is focused on the experiences of stakeholders struggling to interpret and control the maladaptive behaviors exhibited by individuals with autism, the conceptual material it explores is applicable to caretakers struggling with a wide variety of deviant actions.[32]

Though this article deals with a relatively unique form of deviance, previous work has highlighted the social construction that goes into a wide variety of social control efforts. The individuals whose behaviors are the concern of the caretakers in this paper are, because of their autism, unable to offer reflections on their own actions. The analytical upside to this lack of reflexivity is that it allows us to focus on the definitional struggles and negotiations of the audience. The downside is that it raises the question of how generalizable this paper is to cases where caretakers frame the actions of individuals whom can offer analysis of their own deviant behavior. Yet, prior research has demonstrated that individuals who have the ability to frame their own deviance are not necessarily more insistent on or consistent in their definitions (Thoits 1985). Moreover, the frames used by others to define the deviant behavior of an individual can have a profound influence on how that person comes to understand and respond to their own deviance. For example, Susan Sontag (2001) illustrates how popular metaphors of illness can still influence the sick person’s belief about whether they are to blame for their condition or not. The availability of multiple definitions for deviant behavior also

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[32] Though I explored the application of three frames that were most obvious in my data and strongly supported by the literature, other types of “metaphors,” “interpretive packages,” or “historic perceptions” have been suggested for popular social problems (including specific to views of developmentally disabled individuals) (Barry et al. 2009; Gamson and Modigliani 1989; Wolfensberger 1972).

influences the interpretations and social control strategies of caretakers. Family life is often the context for conflict and negotiation over how best to frame and respond to troubling behavior. This remains the case even for caretakers that are faced with deviance from a loved one who is not diagnosed with a biologically based condition (Garfinkel 1967). Thus, in limiting its focus to those who do the framing this paper provides insights into the struggles that beset a diversity of caretakers dealing with deviance. Moreover, in placing the struggles of families and professionals next to one another, this paper also suggests that the dynamics that shape private settings (e.g. a home) and public settings (e.g. a school) are not as different as popular representations would have us believe.

Popular representations of the professions tend to focus on the abstract knowledge of a specialty and the ideal of practice; often brushed over is the pragmatic reality of solving problems that in their complexity, ambiguity, and multivocality share much with the everyday exigencies that animate people's private lives. The academic knowledge or "cognitive structure" that various professions formally endorse is used to shape, through training, the assumptions that individual practitioners use to guide their problem solving in the work place (Abbott 1988). In the sense that these cognitive structures guide definition, interpretation, and response ("diagnosis," "inference," and "treatment" are the terms used by Abbott 1988), they work in ways similar to the frames used by the stakeholders in this paper. Indeed, all of the frames featured in this article draw from the academic knowledge of a variety of influential professions. For example, the sickness frame of deviance is generally associated with the medical profession, while the handicap frame is more closely aligned with the realm of education. That being said, professional institutions are social systems that are not impervious to the variety of ideas and concerns (sometimes characterized as informal, Dalton 1959) that can shape action in ways different from how a given profession's formal academic knowledge might prescribe. For example, in some cases doctors might see a patient's issues as stemming from self-determined misbehavior (e.g. an obese person refusing to diet) as opposed to some underlying pathology. Though the interpretations and social control strategies of educational professionals at North Point were sometimes shaped by the handicap frame (Maria), at other times they were guided by the misbehavior and sickness frames of deviance (Principal, Rachel). Moreover, in relations with other occupational groups (police) and institutions (community businesses), these professionals had to weigh opposing concerns—contexts that shaped and challenged their choice of frames—much in the same way that caretakers do when dealing with developmentally disabled loved ones. Like the conflict and negotiation that occur among families, professionals, through the pragmatism often required to solve issues on the job, often face the limits and ambiguity of different definitions of deviance. This is often the reality whether or not the frame they chose to define a particular case is aligned with or opposes the cognitive structure associated with their profession (Feudtner 2003; Abbott 1988).

Despite the window into the pragmatic nature of professional work afforded by my comparison of framing in private and public settings, families are not like professional institutions to the extent that the deviance they must deal with is personal and invades the most private parts of their lives. The experience of families helps to highlight the ways in which professional problem solving does not always occur in the ideal ways delineated by professional dogma. However, there are very important differences between a professional's and a family's experience of deviance. For one, professionals often have the option of going home at the end of the day. The impact that this temporal control has on the degree of stress and anxiety associated with problem solving is significant. Several of the families in my study pointed out that they are faced with deviance all the time, and that when it is severe it can become all consuming. Another difference is that the personal nature of problem solving in families makes the stakes high. A loved one whose deviance is severe can undermine the functioning of one's family, a social system that for many people is the emotionally defining one in their lives. It is for this reason that the struggles over the definition of deviance that happen in the home are imbued with tensions that are often beyond concerns over whether it is in line with a particular academic dogma. What is of the upmost importance for families is overcoming problems while at the same time protecting individual members and the social system that binds them together.

CHAPTER 4

Purity and Delight: Elements of Innocence and Humor in Interactions with Adults with Autism

INTRODUCTION

In the relatively sparse theoretical landscape specifically relevant to some of the more painful experiences of those caring for adults with autism, “chronic sorrow” has stood as an important framework for thinking about the existential angst that sometimes afflicts people responsible for individuals who are significantly disabled. The concept of chronic sorrow was first introduced by Olshansky (1962) to account for the emotional and psychological reactions of parents who found themselves with an intellectually disabled child. In contrast to the linearity and eventual resolution suggested by the five-stage-model of mourning (i.e. Denial, Anger, Bargaining, Depression, Acceptance), caring for a loved one who continues to exist but with extraordinary needs can lead to a “grief that is ongoing” and “wounds” that are often “unmending” (Roos 2002:XVII; Kubler-Ross 1969). Though originally formulated to describe the experience of those raising a child with a developmental disability, the concept has been applied to the experience of a variety of types of “other-loss” (e.g. parkinson’s, schizophrenia) and even types of self-loss (e.g. multiple sclerosis, spinal cord injury) (Lindgren 1996; Davis and Schultz 1998; Mairs 1989; Reeve 1998). One of Susan Roos’s goals (2002) in writing the first book-length treatment of chronic sorrow was to educate clinicians and the public about the characteristics of mourning that often accompany a “living-loss.” In so doing she wanted to counteract the unfair expectations of time-boundedness associated with popular conceptions of grief, and the further damage that can derive from pathologizing individuals who continue to struggle with conflicted emotions regarding their own or another's impairments (Roos 2002). The emotional struggles of loved ones of children and adults with autism chronicled in the ever expanding number of family memoirs on the topic is a testament to the validity of the concept of chronic sorrow (Greenfeld 1972, 1978, 1986). Despite this value, however, chronic sorrow can be categorized among the large body of academic research and popular representations of autism that define it in relation to what it is not or how it is lacking (Happé, Briskman and Frith 2001; Maynard 2005; Ortega 2009). Though discussions of autism couched in a negative valance have their place, in order to accurately characterize the experience of caring for an individual with the condition it is important to explore both the negative *and* positive aspects of interacting with adults with autism.

Though a crucial component of the experience of many caring for an adult with autism, the concept of chronic sorrow, along with many of the other more negative characterizations of the condition, brush over some of the more positive experiences that caretakers describe in their interactions with the socially atypical. One of the central themes in the concept of chronic sorrow is fantasy, "what could have been or should have been (and maybe will be, after all)" (Roos 2002:27). In the case of autism, grief can derive from a comparison between an atypical adult offspring and his/her typical peers. Such comparisons highlight things that have been missed because of atypicality and dependency (e.g. college, marriage, grandchildren) and things that remain (e.g. caretaking duties, extreme fear of the future) (Roos 2002; Pillemer and Suitor 1991). However, those caring for adults with autism also speak about the lighter moments and interactions that constitute their relationship with them. Despite focusing on how chronic sorrow captures a good deal of the experiences she has had with her adult daughter with autism, even Roos (2002) recognizes aspects of their relationship that words like sorrow and tragedy fail to capture. For example, in the conclusion to her book she states that she is aware of the "wide range of experiences in my life that have occurred as a direct result of being the mother of a child who is 'atypical' [. . .] These experiences have ranged from absurdly funny to tragic [. . .] [and] are reflective samples of a life that matters and of circumstances that are complexly challenging and rewarding" (241). The previous chapter of this dissertation explored the struggles of caretakers to understand and respond to problem behaviors, and features descriptions and analyses of very difficult scenarios. However, to describe such "tragic" scenarios without describing and analyzing "absurdly funny" or positive scenarios would be to do a disservice to the complex experience of caring for those who are atypical. Alongside sorrow and struggle, family memoirs about those with autism are filled with descriptions of wonder, surprise, and joy associated with caring for someone who is atypical (Moore 2004). Among these, descriptions of the humor and innocence (or purity) caretakers associate with individuals with autism feature prominently in stories and discussions (Gilpin 2012).

Due to their atypical psychosocial development and social behavior, many adults with autism undermine normative expectations in ways that have the potential to be experienced by caretakers as innocent and/or humorous. Many adults with autism—

particularly those on the more severe end of the spectrum—often fail to achieve "independent adulthood" (Wing 2001:69). Existing in a state of dependency places those with autism in a large camp peopled by a variety of individuals who rely on the support of others to navigate routine tasks and social situations. However, quite different from many other forms of dependency in which the mind still develops typically, individuals with severe autism often do not understand and do not orient themselves to the norms of typical, everyday social interaction. Taken from a sociological standpoint, the atypical social interaction that is one of the defining aspects of autism derives from a style of thinking that makes the rules of social life, thoughtfully explored by microsociologists, difficult to comprehend (Goffman 1959; Garfinkel 1967). Taken from a biological standpoint, trouble perceiving the social rules that typical people innately perceive and follow is linked to the neurological differences that characterize the brain of someone with autism (Frith 2003). In line with this chapter's goal to explore some of the positive aspects of caring for an individual aging with autism, I will focus on experiences described by caretakers as innocent and humorous and attributable to the atypical development and social behavior of adults with the diagnosis.

Humor is defined as the tendency of certain cognitive experiences to provoke laughter and provide amusement (Polimeni and Reiss 2006). Innocence usually refers to a lack of understanding of the ways of the world stemming from lack of experience with or the inability to understand wrongdoing (Heywood 2001; Midelfort 2000). With respect to the complexity and symbolic weight of both concepts, the social dynamics that lead people to describe phenomena as either humorous or innocent have received relatively little exploration in the sociological literature (for humor see Fine 1984; Francis 1994; Fine and de Soucey 2005; Reay 2011; Nolan 2013; Shifman and Katz 2005; Tavory 2014; for innocence, see Davis 2005). As the results of this chapter will make clear, the innocence of many adults with autism is linked to the ways in which they do not orient themselves to their social environment according to the expectations associated with typical psychosocial development (Erikson 1968). As for humor, one important mechanism are the stark incongruities between the behaviors of those with the condition, and the increasingly rigid social expectations placed upon individuals as they enter into adulthood. In the discussion, I will consider the risk and rewards of exploring aspects of the experience of caring for adults with autism that seem to clash with political correctness and might possibly by viewed as offensive. I will also consider how the positive experiences described by caretakers in this chapter gain further traction when considered alongside the increasing value that modern society places on authenticity and purity in social interactions and relationships.

FAMILIES

The Barclay family consists of Warren (54), Winnie (51), Tyson (19), and Taylor (21). They live in a charming house, with a big back yard, two dogs, a vegetable garden, and an above ground pool, all set in an area that is best described as a rural/suburban mix about an hour outside a large northeast city. Standing at about six feet tall and weighing close to 180 lbs., Tyson is a healthy looking boy with short, light brown hair and hazel green eyes. Diagnosed with Autistic Disorder, Tyson is mostly nonverbal. However, one would be hard-pressed to describe him as quiet. When around the house, he can often be located by listening for the variety of noises that come out of his mouth. The most common is a throaty “Auugghhhh,” or “Eggghhhhhhhh,” but also includes “weah-weah, weah-weah,” (half-way between wee-wee, and wah-wah) and even something approximating “wungah-wungah.” As described by his mom, Tyson is a man of simple pleasures. One of his favorite activities is to sit in a blue canvas collapsible chair, set up next to the kitchen table and in front of a television placed there especially for him, and watch a variety of *Disney* movies. Just as often he will forgo the chair, standing behind it to flap his hands while watching the *Jungle Book*, or rock back and forth with one hand holding down an ear while playing a game of *Wii* Bowling. Tyson is by no means solely focused on the images of the tube, however. He can be quite curious, especially with strangers. I remember my first visit to the Barclay residence in the summer of 2011 when Tyson slowly came out the sliding class door, and hesitatingly stepped towards his mother and me as we talked on the back porch. Eying him with a smile his mother said, “hi their cutey, what to come say hi?” I also remember Tyson’s tendency to look over at me, one hand to his ear, and give a coy smile, the many times I observed him during the course of the week in 2013 that I lived with his family.

When I lived with the Lane family, Evan was 61, Kate was 58, Ziggy was 25, Rebecca was 23, and Arietta (Kate’s mother) was 86. The Lane’s live in a beautiful home tucked away in the woods of a new, gated community in a rural area about two hours north of a large northeastern city. Though the family used to live in a suburb in a neighboring state, they moved to their present location in order to be close to Ziggy who now primarily resides at a large, impressive residential center for individuals with a variety of developmental disabilities. Rebecca lives in the city two hours south of her parent's new home, and was never present for my stays (though I have met her before). Ziggy is a gentle person. He has a good deal of working language, but he rarely if ever initiates social interaction. Though he can often be heard speaking to himself in a variety of understandable and indecipherable language, when spoken to by others his response is usually short. For example, sitting next to him one day in a chair in his room at the residential center, I listen to him as he sings a song to himself, "she'll be coming around the mountain when she comes, she'll be coming around the mountain when she comes…" When I ask him if he likes his room he looks at me and says, "yesssssssssss" in the long drawn out way he does when answering questions in the affirmative. When I ask him another question that can't be answered with a yes or a no, he sits looking at me and after some silence starts speaking to himself again. Though he rarely initiates social interaction, Ziggy does have pretty good receptive language. He can understand a variety of directions and perform a number of tasks. For example, at his residential center and with the oversight of staff, Ziggy packs seeds into cartons in the greenhouse, organizes plastic wrap to be used for the bakery's bread, and funnels tea into organic tea bags sold in the campus store. He is a great singer, having memorized the words to a number of pop songs. On the several occasions I drove him around in my car, I would place a CD in the player—usually Elton John—and enjoy the ride as he sang word for word and on pitch songs like 'tiny dancer' and 'rocket man.' I would also laugh as Ziggy performed a move I call his 'conducting,' twisting his wrist back and forth, fingers to palm, as he bounced his head, breathed to the beat, closed his eyes, smiled, and hummed and sang to the music.

INNOCENCE

While a typically developing child takes concrete steps to pull away from the family unit in adolescence and early adulthood, in these stages of life individuals with autism—though at times difficult, and demonstrating some reluctance to accept adult authority—do not exhibit the same kind of psychosocial transformation. Adolescence has been billed as a period of increased storm and stress in which the developing youth pulls away from parents and family, challenges authority figures, orients themselves to peers, and in so doing starts creating an adult identity (Coleman 1961; Erikson 1968; Milner 2006). Despite taking pains to highlight the variation associated with space, time, place, and personality, the modified "storm and stress" thesis still conceives of adolescence and young adulthood as a period in which conflict with parents, mood disruptions, and risk behavior (e.g. dangerous driving, risky sex, drug abuse) are more likely than at other stages of development (Arnett 1999). Though the puberty of individuals with autism can come with its own significant issues (see previous chapter), breaking away from family and the assertion of independence is noticeably atypical. If increased tantrums and masturbation may be linked to reluctance to accept adult authority and normal physical changes, descriptions of the behavior of adolescents with more severe forms of autism attest to their atypical social and psychosocial development (Wing 2001). Such descriptions include a continuing immaturity, and behaviors akin to that of a "small child" (Wing 2001:141). Of course, with respect to typically developing adolescents, while pulling away from one's family is natural, the phenomenon is still marked by ambivalence on the part of parents (Demo, Small and Savin-Williams 1987; Pickhardt 2013). On the one hand, parents want to encourage youth to move away from the parental nest, knowing that steps taken towards independence are important for future self-sufficiency (Newman, 2012). On the other, the forms that such steps take often come in the guise of rebellion, and it is natural for parents to also secretly (or not so secretly) crave their children to "remain with [them] for as long as possible" (Newman 2012). Though extended adolescence and the effects of the 2007-2009 recession might have put a damper on this desire (especially once an increasing proportion of parents had grown children returning to live with them), neither changed the reality that as a child matures parent's sometimes (or often) experience nostalgia for the past and a desire to return their offspring to innocent state of young childhood. Parenting books and blogs are filled with concerns such as 'my child used to be admiring (even adoring) of me but now is critical and wants more time apart with friends' or 'my child used to like my attention and affection but now is embarrassed to be seen with me or to receive affection' (Cline and Fay 2006; Pickhardt 2013). To the contours of this experience, an interaction I observed one Sunday morning between Winnie Barclay and her son Tyson provide a stark contrast:

> I enter the kitchen to find Tyson walking over to his mother as she stands at the sink washing dishes. He slowly reaches out and places his hand on her arm, and then pulls back as she turns around. She asks, "do you want me to sing to you?" After a couple seconds pause, Tyson pulls his chin into his chest and jerks his head up and down. Winnie starts to sing: "Chim chim-in-ey, chim chim-in-ey, chim chim cher-ee! A sweep is as lucky, as lucky can be…" As Winnie sings, she places her finger on her son's belly and a large smile forms across his mouth. As she arrives at the

> end of the first stanza, she pokes his belly and Tyson belts out a loud "EGGHHHHHHHHHHH" and smiles. When she gets to the end of the song, she says "yayyyy!" At this point, Tyson tenses his upper back and claps his hands furiously. As his mom turns to do dishes again, Tyson stands there smiling and after a couple moments slowly reaches his hand out and taps his mother's arm again. She turns and they repeat the ritual. Then she tells Tyson "that's it!" and he returns to his TV, which, at the moment, is about halfway through the movie *Mary Poppins.*

Tyson loves to have his mother sing to him. Indeed, singing in general is something that he finds to be highly motivational (e.g. as a young child, in-home therapists that worked with Tyson would reward him with songs for tasks well performed). This is not unlike a lot of individuals with autism, who seem particularly inclined to like music and tend to have musical cognition that is pronounced or, at the very least, not impaired (Heaton 2010). While a love of music might be common for many teens, typical adolescents become highly sensitized to behavior that is age appropriate and approved of by their peers (Milner 2006). Conformity and independence being increasingly powerful forces, musical choices and listening rituals are not often engaged with the participation of parents in mind. With many individuals with autism, concerns about age appropriateness are often not on the radar (Moore 2004). Moreover, the common tendency to prefer rituals and objects with which one is familiar means that songs, stories, and movies from childhood often remain of interest (Moore 2004). To some parents, the desire on the part of an atypical offspring to continue to engage in rituals and activities generally associated with youth can be a pleasing attribute of caring for an adult with autism.

Though it clashes with the expectations surrounding typical development, continued engagement in the rituals and paraphernalia of childhood can lend a charming innocence to relationships with an adult with autism. One of the joys of having a child who doesn’t mature out of activities that are often enjoyed by children is that parents can still engage in highly satisfying rituals. Books about raising young children describe in detail the joy that is involved in singing nursery rhymes, sharing cartoons, and connecting to the material culture of youth (Gilman 2011). Indeed, the attraction of the innocence and authenticity of childhood is one of the central themes of a major movement in western poetry and philosophy (Russell 1945). Of course, the behavior of a young child with autism is in many ways different than the behavior of the youth glorified by the romantics. Indeed, some have argued that young children with autism are actually more adult-like then typical individuals their age (Gilman 2011; Moore 2004). However, at the point that typical youth enter into the intense social development of adolescence and begin to fight for independence and an adult identity (Hogan and Astone 1986), the atypical development of many adults with autism makes them seem increasingly more similar to young children than to their peers. To the many parents for whom the world of young children remains a joyful realm, the continued immaturity of aging loved ones with autism can act as a gateway to a seductive, if atypical, form of being. As Winnie Barclay explained to me during an interview:

> There was this guy we knew and he told us about this family he worked with where the dad looked at him once and said, ‘you know, I am the luckiest dad in the world, because my daughter is going to be my little girl for ever’ and I thought, ‘Oh my god, that is so interesting,’ I think that that interaction, I do that all the time, you know. I’m the only one who sings to him anymore, why, because I love that.

In the comment of a parent who delights in the continued innocence of his little girl, Winnie finds something true about caring for an aging child who does not develop typically. Though her son’s atypical psychosocial development will lead to continued dependence in adulthood, it also means Tyson continues to partake in rituals usually reserved for young children. Winnie explains that she thoroughly enjoys such interactions with her son, and that the joy of 'holding on to my [child]' is a sentiment that resonates with her own experience. Other parents have pointed out the disinterest in age appropriate rituals expressed by adolescents and adults with autism (as well as the many "autistic" families "in thrall to the Disney empire") (Moore 2004:231-232). Though Winnie understands that Disney movies and singing are no longer appropriate for a nineteen-year-old male, she finds herself conflicted about clamping down on rituals and objects that both she and her son enjoy. In her back and forth with an aid and family friend who continues to work with Tyson, voice is given to the tension between encouraging age appropriate behavior and letting the individual with autism behave as they desire.

In struggles over the importance of age appropriate behavior, professionals and loved ones of those with autism demonstrate the tension between social norms and the idiosyncrasies of parent relationships with aging children with autism. Parents of adults with autism usually appreciate the benefits of age appropriate behavior. However, when the joy and innocence of a loved one with autism is associated with age-inappropriate behavior, parents are faced with conflicted feelings about the value of conformity. In the early years of Tyson's life, teachers who conducted Applied Behavioral Analysis[33] sessions with him often rewarded him with songs when he performed well. This reward was linked to Tyson's own requests, as evidence by his sticking the picture of a person

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[33] ABA is a method of behavior modification used for both educational and social purposes in which an instructor or therapist shapes an individual's actions by rewarding what is desired and ignoring/punishing what is undesired (Feinstein 2010).

singing on his PECS[34] board when he finished an assignment and one of his teachers asked, “what have you earned?” Winnie explains that her main requirement for professionals working with Tyson when he was young was that they would be able to sing songs to him. However, as he got older, Tyson’s staff decided that they needed to limit singing in order to find more age-appropriate reinforcers. At present, the professional who continues to work with Tyson outside of school is Claire Smalls. Claire is a habilitation expert who has worked with the Barclay family for years and in various capacities. Generally, habilitation constitutes services to help a person learn, keep, or improve skills and functional abilities that may not be developing normally. In the case of adults with autism, habilitation out in the community includes encouraging behavior that supports independence and social appropriateness. Given her responsibility to teach and encourage Tyson’s integration into the community, Claire continues to work on shaping his behavior to be more age appropriate. When I joined her on one of her outings with Tyson, Claire told me about her efforts to try and shape his habits and impression management:

> Now you will see the difference between my music and their music. I try to make Tyson very age appropriate. No we don’t listen to *Disney* Music [. . .] I also tried to introduce him to *Glee*. Cause he really likes music, I’m like, you know what [. . .] let’s not sit and watch *Disney* Movies, let’s watch age appropriate things.
>
> *While we are walking across the parking lot to a thrift store—a place that Claire often brings Tyson to on their outings—she tells me that when he*

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[34] Picture Exchange Communication System is a form of augmentative and alternative communication for individuals with a variety of communication, cognitive, and physical impairments. Often used by those with autism, the system involves the use of picture symbols (e.g. photographic, graphic) in order to communicate with partners through the exchange of said symbols (Schwartz, Garfinkle and Bauer 1998; c.f. Banda 2005).

> *was younger Tyson used to carry around a book about a little princess or Disney magazines. As he got older, Claire decided that she was no longer going to let him carry such items around. She tells me, "people see a boy his age carry around a princess book, or a pink magazine and they will think some pretty bad things about him."*

One of Claire's main goals when she spends time with Tyson is to shape his behavior so that it is more age appropriate. Claire also introduces gender inappropriate behavior as another type of conformity that is little on the minds of many individuals with autism (Moore 2004). In his memoir of his teenage son, Robert Hughes (2003) describes how Walker's favorite Disney movies included *The Little Mermaid*, *Cinderella*, and *Alice and Wonderland*. Though Claire is aware of Tyson's indifference to conformity, she views a more typical presentation of self as important to her general goal of promoting his social skills. While Claire and Winnie have a strong and trusting relationship (they easily qualify for the designation of fictive kin [Stack 1974]), the former describes what she views as a subtle struggle to convince the latter of the importance of age appropriate behavior. And though Winnie appreciates Claire's point of view, she still feels torn by her desire to let Tyson do what he enjoys. She also admits that his enjoyment of childlike activities is something that she takes pleasure in as well.

Though parents of adults with autism appreciate the value of continuing to encourage social development, they are often faced with the reality that their joy and the joy of their child is partly linked to the child's continued innocence. Even if parents understand the importance of a child developing normally, it is not uncommon for parents to fantasize about a child remaining young and innocent forever. As one mother describes in a book about parenting, "[my daughter] cried about growing up [. . .] she wanted to stay little, and, to be honest, I wished she would too" (Ruiz 2013:272). In her description of her son's desire to have her sing to him, Winnie expresses both an understanding that such behavior is no longer age appropriate and that, despite this, she continues to engage in the interaction, social norms be damned:

> [Ben: And he'll ask you to sing?] Yes, he'll say 'sing.' [Ben: Oh he says sing?] 'A-sing, A-sing.' And then I sit there and I'm thinking 'he's actually saying the word, how can I not do it.' [Ben: yeah, it's impressive] It is! And it is so highly reinforcing for him, but they, I'm the only one, and I know it's wrong, like I know it's inappropriate, but, so I'm really trying to taper that off [. . .] He's nineteen and I am singing him Disney songs.
>
> *A few moments after I observe Winnie singing to Tyson, Winnie takes another opportunity to compare her opinions to Claire's: "you see, Claire tells me 'I never sing to him' and I understand what she is saying, but I am his mother. And that is the challenge, is that I don't always want to be so stuck on him being appropriate. Sometimes I just want to be his mom. And, you know, no one else lets me sing to them."*

In describing her struggle with Claire, Winnie admits that she understands where her friend is coming from. However, being Tyson's mother—a role that she partly associates with valuing his happiness, in whatever guise it may come—Winnie doesn't want to always choose "being appropriate" over giving him joy. This is echoed in the comments of other parents of children with autism who explain that "their joy is my joy" and "as long as [they] are happy, I'm happy" (Jones 2011:126; Moore 2004:274). Of course, Winnie demonstrates that her desire to sing to Tyson doesn't simply derive from his and her own joy. Indeed, in describing the degree to which her son desires to be sung to—"he's actually saying the word"—Winnie also highlights the complexity and contradictions of the project of encouraging more 'socially appropriate' behavior in adults with autism.

Though childlike rituals between parents and adult children with autism might challenge both age and gender appropriateness, when they initiate an interaction that is enjoyed by all parties involved those with autism suggest a general sociality that goes against classic definitions of the disorder. The desire on the part of a nineteen-year old boy to have his mother sing *Disney* songs to him would seem to many people an inappropriate or, at the very least, highly odd request. Claire surely believes so, and gives it as her reason for discouraging Winnie from sing-a-longs with Tyson. However, when he initiates a social interaction that is mutually enjoyable to both him and his mother, Tyson is behaving in a way that is generally at odds with popular conceptions of autism. One of the two characteristics that Kanner (1943) emphasized above all others when he wrote the first scientific description of autism was an "extreme aloneness, from the earliest days" (242). This is particularly true of those with more severe forms of autism, many of whom are non-verbal or struggle to use language (Wing 2001). In noting that "he's actually saying the word," Winnie is commenting on the degree to which Tyson desires the interaction, given that her son rarely uses language in an appropriate manner. However, in remarking on Tyson's use of words to initiate their singing ritual, Winnie also implicitly suggests that her son is performing a feet that is "impressive," given his condition, and should, at least sometimes, be rewarded with her songs. While the heterogeneity of the autism spectrum has long been noted, continuing evidence that avoidance of social interaction often remains one of the disorders defining characteristics means there is an argument to be made that it should be encouraged in all its forms. Though they do agree with professionals about the importance of age and gender appropriateness, parents often find some justification for enjoying innocent interactions with adult children given that it goes against the 'aloneness' that is one of the major defining aspects of the disorder.

As individuals who have themselves developed in a typical manner, parents who experience joy in the innocence of an adult child with the diagnosis usually express conflicting views about the value of age and gender-appropriateness. Interactions with professionals represent one scenario in which parents struggle to determine their opinions of the relative importance of reinforcing age and gender appropriateness. However, parents do not require the intervention of professionals to find themselves in a conversation over values. As individuals who have themselves developed typically and likely never imagined the future that lay in store for them, they have plenty of past experiences against which to judge their present ones. Thus, parents often find themselves ruminating on the behavior of their adult child with respect to how it might look to outsiders—outsiders who they once were themselves. Take Kate Lane's description of her twenty-five year old son's habit of routinely kissing her on the cheek:

> Ziggy's a piece of cake. My big problem with Ziggy is that he loves to kiss me too much and what do I do about that. Do I let him or is it inappropriate. It's his way of communicating with me and he doesn't do it to anyone else. It's not like he is indiscriminate and does it to grandma and does it to dad and does it to Rebecca. It's just me, but I've been his primary caregiver. So it's complicated, but in the scheme of having a child on the spectrum, Ziggy's been a total delight. You just have to love this kid to pieces.
>
> *At various points during the day I observe Ziggy walk over to his mother, bend down, and kiss her on the cheek. For example, last night when Evan and Kate sat down with their son to have him show me his Hebrew reading skills, at the end of reciting one paragraph, Ziggy got up several*

> *times, leaned over his dad, and kissed his mom on the cheek. A couple times when he did this, Kate said, gently, "ok, Ziggy, that's enough."*
>
> *I am having a conversation with Kate after dinner, and in association with a discussion about Ziggy kissing her in public she tells me a story about an experience she had years back. "I was at a conference for one of the autism organizations, and Ziggy was still very young—maybe six or seven. At one of the forums I saw a mother with an adult child with autism who looked like he was in his mid to late twenties. The son was lying across his mom's lap. It reminded me of Michelangelo's Pieta, a full-grown man being cradled by his mother. Maybe she felt more comfortable allowing him to do that given the social context we were in, but I remember my reaction as being a little repulsed. I thought, at his age that is no longer appropriate. I reflect on that now because my twenty-five-year old son often kisses me in public.*

Among the multitude of rituals with parents that aging youth are apt to discourage, physical signs of affection—particularly kissing—rank among the top. This is not to say that adolescents don't like affection—quite to the contrary, they are still dependent on their parents and still want to be cared for by them. However, given the increasing value of independence and peer approval, the affection of and dependency on parents is associated with mounting stigma (Milner 2006). The adolescent who gets a ride from parents to school, but asks them not to drop her off directly in front of the building, illustrates weariness about being seen as childlike or too close to her parents. In another example, Pickhardt (2013) describes the need of the adolescent male to increasingly avoid physical affection from mom, not because he doesn't love his mother, but because he is working on developing a "growing maleness" (97). While they should and often do view this rejection as a part of natural development, parents also complain about the once adoring and affectionate child avoiding contact (Pickhardt 2013). Against the heightened sensitivity to appearances expressed by a typical teen and young adult, Ziggy's continued kissing of his mother—both in and outside of the home—strikes a significant contrast. Though Kate describes her son as someone "you just have to love to pieces," she is very conscious that his kissing is, to some degree, an issue. Indeed, as a reflection of how inappropriate the behavior might look to others, Kate references her own repulsion at seeing a young man lay in his mother's lap at an autism conference in a manner that she describes as "no longer appropriate." Though her evocative comparison to the sexually neutral scene of the Madonna and child might suggest otherwise, it is likely that Kate also understands the nuances of gender that might further add to the seeming in-appropriateness of her son's continued kissing. Despite this awareness, Kate also finds herself faced with the tradeoff of discouraging age and gender inappropriateness or encouraging a joyful innocence and generally social behavior.

Though affection—particularly in public—might be viewed as increasingly inappropriate among adult children and their parents, on another level the reality that the deficits of autism include such affection makes it difficult for parents to want to punish what some might argue should be encouraged. As she expressed above, Kate understands how off Ziggy's displays of affection might look to others, particularly to strangers out in public. However, in talking to me about the differences in behavior that characterize her two children, she highlights the contradictions that she faces in deciding how to respond to her son's kissing:

> Rebecca, my normal, typical kid, is very rational, very cool kid. She's not a lovey-dovey type [. . .] She's kind of an independent, self-contained type person. She always has been. Well not always, from about the age of 12. I always joked with Evan, I said, 'I need the autistic kid who kisses me, tells me he loves me.'

> It’s a very complicated emotion. I recognize that a lot. A very complicated emotional equation, because you know that you have to let them be more appropriate and help them, because they get stuck on this stuff, and at the same time, they’re childlike. Ziggy’s twenty-five. He’s going to be older sometimes than his staff. I have to play that in my mind. Lately, when he sings *Old MacDonald Had a Farm*, I say, ‘Ziggy, you know, that’s a baby song, why don’t we sing a Beatles song or why don’t we sing Elton John,’ and try and just gently redirect him. I’ll start with a couple of lines of another song and he’ll usually pick up and about ten minutes later he goes back to Old MacDonald. It’s harder I think for the mother to make that, because usually the mothers been the one to put them to bed, to shower them.

In comparing the behavior of her typically developing daughter and her son with autism, Kate provides another example of the tension between discouraging age-inappropriateness and encouraging sociality. Just as in the case of Winnie singing to Tyson, Kate finds in her son’s behavior a desire for affection that her typically developing daughter avoids. While few would argue that it is off that Rebecca is an “independent” and “self-contained type,” Kate still finds it humorous that her son with autism is the one that provides the affection that she enjoys. Of course, despite finding her son’s innocence enjoyable, Kate experiences conflicted emotions concerning his kissing. In what she describes as a very complicated “emotional equation,” Kate notes that her enjoyment of Ziggy’s affection is often undermined by a sense that she should encourage more age and gender appropriate behavior. Kate observes that though Ziggy still kisses her and sings children’s songs, he is older than some of the aids that work with him at the residential campus at which he resides. This further compels her to want to promote age-appropriate behavior, a goal she is ‘gently’ trying to introduce despite the joy that her son’s innocence sometimes brings. And yet, Kate continues to allow Ziggy to kiss her without too much reproach, since she loves him dearly and desires to let him be who he is. In highlighting the humor see sees in the incongruity of a parent looking to a child with autism for affection, Kate suggests one of the other dimensions of the disorder that allows caretakers to experience joy.

HUMOR

One characteristic of the behavior of those with autism that can contribute to the humorous quality of their actions is the tendency to follow specific guidelines concerning socially appropriate behavior as enforced by others while at the same time demonstrating a lack of awareness of the larger social convention these guidelines are meant to convey. Researchers across various disciplines have agreed that one of the basic components of humor is incongruity (Fry 2002). As expanded upon by Paulos (1980) “incongruity is intended in a wide sense, comprising the following oppositions: expectation vs. surprise, the mechanical vs. the spiritual, superiority vs. incompetence, balance vs. exaggeration, and propriety vs. vulgarity” (p.102). As one of the hallmarks of the condition, literalness of interpretation often leads to scenarios in which the behavior of an individual with autism reflects stark incongruities. For example, in her book *The Funny Side of Autism* Lisa Masters (2010) shares an anecdote in which a ten-year old with the diagnosis was given turkey bacon, and then explained that at his house they get their bacon “from America!” (40). In this comment a child with autism shows the incongruity of a mind that grasps a relatively sophisticated geographical knowledge, while at the same time struggling to understand the contextual nature of words and their usage. Another form that literalness of interpretation can take is the difficulty with generalization that is common to autism. Trouble generalizing can be classified under “weak central coherence," put forth by Happé (1996) and Frith (2003) as one of the cognitive atypicalities characteristic of those on the spectrum. While weak central coherence is responsible for several of the comparative strengths of the "cognitive style" of autism (Happé 1999), the ways in which it leads to trouble integrating diverse information at different levels of abstraction contributes to some crucial incongruities in the behavior of those diagnosed. Such incongruities, in turn, create the potential for experiencing the behavior of those with autism as funny. Take the following example relayed by Kate Lane concerning her son Ziggy:

> Now what does privacy mean? Privacy is a very abstract concept. I had to bring it down to something very concrete, so for him, privacy means he's in his room alone without mom or dad or anyone else interfering in his space.
>
> Now Ziggy's a stitch sometimes [. . .] he makes us [Evan and I] laugh so much. He will not—I taught him, and he's learned the lesson well, he won't get into his pajamas with me in the room. So he'll say, "I need privacy." I'll say, "absolutely." I go out and he closes the door and then he'll go buck-naked to the bathroom. He doesn't really get it. I'm allowed to be with him when he's naked in the shower, but not when he's changing into his pajamas, because I taught him that, but I still needed to be in the shower with him, so it's just so inconsistent.
>
> You know, you laugh and it's very healthy to laugh, to be able to see just some of the humor in it and you're laughing with love [. . .] He's just so funny, you've got to love this kid.

Here Ziggy illustrates weak central coherence by following closely his mother's application of the social rule of privacy to changing alone in his bedroom while at the same time failing to extrapolate that specific application of privacy to the underlying concept and other contexts in which it applies. In highlighting that it is hard to explain what exactly privacy is, Kate demonstrates how the typical human brain intuitively grasps complex social ideas and then applies them to a variety of specific cases. To someone with autism, these abstractions are often very difficult to grasp or remain entirely mysterious (Grandin 2006). In relating Ziggy's inability to translate the lesson about changing to the concept of privacy, Kate also demonstrates how the behavior of someone with autism can lead to stark incongruities. In this case we see the incongruity being propriety (i.e. please let me change in private) and impropriety (i.e. I am going to walk buck naked to the bathroom). Given the relationship between incongruity and humor, it is not surprising that Ziggy's behavior could be viewed by both his mother and father as funny. Of course, the definition of humor also has important relational components. Humor involves reciprocity, or the sharing of laughter with others in relation to the object that is deemed humorous (Lyons and Fitzgerald 2004). While Evan and his wife share laughter with respect to the incongruities of their son's behavior, the reality that Ziggy does not laugh, nor seems to understand the incongruities of his behavior, why it might be funny, or even that his parents are laughing, might lead observers to question whether this is humorous and whether laughter is appropriate. To this implication, Kate responds that it is very healthy to laugh, and that she and her husband laugh with love. Through their laughter, Kate argues that they express an appreciation of their son's uniqueness, and in so doing view their atypical relationship with him as one possessing joy and affection.

Despite creating the potential for embarrassment, consternation, and even social ostracism, to those who care for individuals with autism the incongruities of behavior that persist into adulthood can be viewed as moments of hilarity in which to express appreciation and love. During the process of socialization, typically developing individuals naturally extrapolate the contours of social norms from specific cases in which those norms are applied. For example, when an adolescent is teased for, say, being physically disabled, they tend to understand the expectations against which they are being judged (Goffman 1963). Individuals with autism, however, struggle to understand the norms surrounding behavior in a given context, and thus find themselves the target of hostility for actions whose norm-breaking characteristics are a mystery (Koegel and LaZebnik 2009). Even when an individual with autism learns that a certain behavior is unacceptable (e.g. you should change in private), they can easily miss the larger implications this has for impression management (e.g. one should avoid nudity with others present, except in very specific situations). As attested to by those with autism who can describe their experience, this weak central coherence can lead to the sense that consequences happen but for reasons that are unclear. In a telling quote, Gunilla Guijan states "I always felt that there was something I didn't really understand [. . .] even when I understood quite a lot, there was always something left—the actual way it all hung together. I made a huge effort [. . .] the world was an ever changing mystery, things happened suddenly. How? Why?" (Gerland 1997). If this lack of social understanding can be baffling to those with autism, it can also lead to upsetting situations for typically developing individuals who are close to them:

> *During one of our conversations, Kate tells me another story about Ziggy's difficulty with the concept of privacy in connection with his sister Rebecca. One time she was home babysitting her brother, and he came out of his room naked because there was no underwear in his drawer. Though he knew how to put on underwear, Kate had forgotten to fold his recently washed underwear and put it into his dresser. This was very upsetting to*

> *Rebecca, who called her mother to report the behavior. Kate told me that she herself wasn't very upset by her son's trouble understanding.*
>
> *I am sitting with Kate, and she is telling me about some of the funny incidents that have occurred in her determination to teach Ziggy about the concept of privacy. One example she gives is she and Evan's efforts to convey to their son the importance of knocking before entering someone's bedroom. They taught Ziggy that he should always knock on the door and wait for someone to say "come in" before going in. One time when Kate was in her bedroom changing, Ziggy barged in without warning and without knocking. Kate gave her son a look of surprise and told him to "go back out and knock." In response, Ziggy left the room, knocked on the door, said "come in," and then went back into the room before Kate had a chance to finish getting dressed.*

Besides leading to upsetting scenarios for loved ones in public situations (Gray 2002a), failures to follow the rules of impression management can leave family members' sense of social propriety challenged even in the context of the home. As Rebecca's negative response to her brother's nudity illustrates, the potential for upset seems particularly heightened when the proprieties around opposite-sex sibling interactions are undermined. In approaching his sister in the nude because he didn't have underwear in his draw, Ziggy threatened the code of conduct through which people defend against the sexual possibilities implicit in social interaction, particularly those where sexuality is highly taboo (Goffman 1959). Though Kate appreciated her daughter's upset at Ziggy's nudity, she described her own feelings as to her son's inability to understand privacy in relation to his sister as "not very" upsetting. Indeed, when Ziggy placed Kate in the uncomfortable position of being seen nude by her twenty-five-year old son, rather than become upset at the social impropriety the scenario suggested she saw the situation as humorous. In relaying the incident, Kate took particular delight in Ziggy's creative work-around of waiting for someone to say "come in" by saying "come in" himself. In so doing, Ziggy once again demonstrates the incongruity of a mind that follows explicit guidelines to the letter while missing the social concept the guidelines are meant to convey. Finding hilarity in Ziggy's behavior is not meant to say that this reaction is inherently better, but rather to demonstrate that it is one of the situational possibilities open to those who care for adults with autism. While these cases of incongruity have been used to illustrate the humorous potential of the behavior of those with autism, in not expressing embarrassment at either his own nudity in front of his sister or his mother's nudity when he barges into her bedroom, Ziggy's actions also fit with the theme of innocence explored earlier in the chapter. The mingling of innocence and hilarity that can be viewed in the socially atypical behavior of adults with autism demonstrates how the themes of this chapter often run hand in hand.

The innocent valence of the funny actions of those with autism demonstrates the joy that can be experienced in the behavior of an aging child who disregards social expectations. Much of Goffman's work shows how individual concerns over the judgments of an audience shape individual efforts to align behavior to situational definitions, the flow of interaction, and the whims of social approval (Goffman 1959; Collins 2004). The pressures of conformity that increasingly orient adolescents to their peer group can be analyzed as lending a developmental angle to Goffman's focus on impression management (Kinney 1993). While the behavior of young children often demonstrates that they see their families as their most important reference group, adolescents and young adults increasingly orient themselves to the judgments of their peers (Milner 2006). While this development is related to the rejection that parents sometimes find painful, it is also an important step in pushing an individual to enter the wider world and one day create a family of their own. In comparison to the overwhelming interest a teen will take in their peers (particularly those of the opposite sex), consider the following story that Winnie Barclay told me involving her son Tyson (19yrs old):

> *At dinner this evening, Winnie tells me a story in order to illustrate her son's attractiveness. The family had taken a trip to the beach, and they were walking down the boardwalk. Tyson was in his bathing suit, but had his shirt off and was walking ahead of his mom, dad, and brother. Winnie tells me that at first look you wouldn't know Tyson has autism, unless you saw him doing some of his odd behaviors. There were these two girls walking towards them, a little younger than Tyson, and they were smiling at him and whispering to each other. Just as they were about to pass him, Tyson lifted his hand, put it close to his face, and belted out one of his "EGHHHHHHHH" noises. Winnie tells me, laughing, that both girls were in shock. Their jaws dropped, and they just looked at her son wide eyed. She tells me that "it was hilarious." Continuing to laugh, Winnie explains that when it happened she was thinking "teaches you girls for thinking dirty thoughts about my son!" She goes on to argue that she is sure that, to this day, those two girls haven't forgotten the experience.*

In failing to register the attentions of two similarly aged females, Tyson engages in behavior that is quite different from the average adolescent male. Whispering to one another and smiling at him, the two teenage girls tried to attract Tyson's attention and instigate in him some recognition of the sexual possibilities of the situation. In lifting up his hand, holding it to his face, and expelling a non-communicative noise into his palm, Tyson entirely undermined the definition of the situation the two girls were trying to establish and left both of them "in shock." He also demonstrated how the ability (though unknown to them) of those with autism to be mistaken as typical enhances the possibility for situational incongruities.[35] For Winnie, the incongruities of the moment were "hilarious." Moreover, in undermining the aims of these two women whose "dirty thoughts" tried to ensnare her son's attention, Winnie suggests that her son's innocence at the attention of individuals of the opposite sex is something she enjoys. Rather than focus increasing attention on the judgments of those his age, Tyson remains impervious to the social pressures of his peer group. He remains ever her baby. Moreover, though Tyson's behavior in this instance seems easily characterized as innocent, even instances in which his behavior has more potential to be defined as devious carry the potential to be viewed as humorous.

Though some forms of norm-breaking behavior seem shocking enough to undermine viewing them as either innocent or funny, both are still options on the part of the caretakers of those with autism tasked with their control. Aggression and inappropriate behavior rank among those actions that the developmental disabilities literature categorizes as maladaptive or problematic (Clarke 1996; Shattuck et. al. 2007). Many, though not all, of the more severely disabled on the autism spectrum exhibit an increase in difficult behaviors in adolescence and young adulthood (Wing 2001). Sociological research has demonstrated the challenge such behaviors pose to caretakers when they are engaged by adolescents and adults with autism, focusing specifically on the conflict and negotiation that surround the framing and social control of such actions (DiCicco-Bloom 2014). One reality that makes the problem behaviors of adults with autism particularly challenging is that as adults they are more strictly held to the

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[35] Passing as typical is not possible for someone with, for example, Down's Syndrome.

standards of impression management against which all adults are judged. And yet, the danger and negative attention that can potentially be attracted by—for example—public displays of nudity not withstanding, parents and other caretakers in my study still noted the potential for hilarity at the inappropriate acts of adults with the condition. Take the example of the comments below, in which Winnie describes her reaction to Tyson's proclivity to take his penis out of his pants in order to avoid activities in which he didn't want to participate:

> No, he doesn't take his pants off. He would pop his penis right over the top of his pants. We can't quite figure out how that worked. I'm not a man; I don't know, but people told me it was quite an amazing feat what he was doing, and then you're trying to stuff it back in and he'd take it out.
>
> We were able to isolate the fact that he did it basically for two reasons. One was for the shock value of it, so if this were a year ago, when he saw you, he would walk up to you and give you deadly good eye contact with it out and shake it at you [. . .] Then the other was he knew that that was how he could get out of a situation [. . .] I said to them [some staff at Tyson's school] because they really thought that it was something very sexual and I'm like, "I don't think this is sexual. He knows that if he wants to have a moment, he can go up to his room. He understands that whole situation." So I said, "it's not that. Look at what he's doing. Look at his face." It was like this, it was really, I'm sorry that we went through it but it was a fascinating thing to look at and he stopped if you gave him no feedback. So if you could just put it on extinction[36], he would just stuff it back in and walk away like, humph! [. . .] And so I was able to get it under control at home and Claire got it under control, but it was very interesting, every time new staff came in the room at school, there it was [. . .] Then, he also learned that, okay, well, I get no feedback in this environment, but what about if I'm in the community and so that became a real, you know, obviously— So we got it under control in all these different environments and then what do we do about this. We went to the zoo one day and this

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[36] An extinction procedure occurs "when reinforcement of a previously reinforced behavior is discontinued; as a result, the frequency of that behavior decreases in the future" (Cooper, Herron and Heward 2007:457). In this case, the extinction procedure consisted of ignoring Tyson's self-exposure in order to undermine the function the behavior was believed to be serving (i.e. getting attention, getting out of activities).

> was so funny. It wasn't funny, but [. . .] We had had this kind of wonderful day and Warren and I are sitting there kind of just feeling like we're the best parents in the whole world. Taylor was down there with his friend Max, and Tyson had been with us. We met them at the gate and Taylor said, "I saved the gorillas just for you guys. We can all go together." And we're like, "okay," and Tyson was expecting to leave and all of a sudden we turn back in the zoo, and it was as though just the genie was out of the bottle as it were. It was awful, and Taylor is wanting to do this with us and so I looked at Warren and I said, "take Tyson back to the car." If you know where the zoo is, you know you go down the road there to get to the parking lot and of course there are police everywhere, everywhere.
>
> Turner [a teacher at Tyson's school] has known him since he was this big [. . .] he said "hey, no way. I'm going to come and observe him and I'm going to look at the context,' and that's when he just said "this has nothing to do with sexuality. This is definitively attention-seeking."

Winnie along with some of the staff she viewed as more supportive at Tyson's school determined that he was taking his penis out of his pants in order to get attention or in order to get out of activities he wanted to avoid. Both motives are described as some of the common drivers of inappropriate behavior among adolescents and adults with autism (Wing 2001). Though the analysis of conflicts over framing explored in the previous chapter would likely apply to this scenario, it also demonstrates the potential to find humor in some of the more transgressive acts of those on the spectrum. While the zoo debacle was definitely "not funny," it was also, according to Winnie, "so funny." Here we see another property of humor that is both intensely sociological and particularly applicable to caring for an adult with autism. As explained by Reay (2011), "the highlighting of incongruities [. . .] makes humor ideal for exploring [. . .] risky topics [. . .] when people react to incongruity with smiles, laughter, and/or elevated mood, they are managing a potentially disruptive experience: that of the world not making as much sense as typically assumed" (1). Above we saw how an adult who closely follows the application of a rule in one scenario but is unable to extrapolate that rule to other scenarios provides an opening for loved ones to experience humor. In another example of a world making less sense than is typically assumed, a behavior that on its face seems significantly deviant—an adult male taking out his penis and shaking it at people—can be viewed as both highly attuned to other people's behavior (i.e. "he'd give you deadly good eye contact and shake it at you" "for the shock value of it") while at the same time being totally innocent of the larger implications (e.g. "they really thought it was something very sexual," and "of course there are police everywhere, everywhere"). As Winnie explains, Tyson's ability to get his penis out of his pants and use it in such an effective way was "fascinating." It demonstrated real creativity and observational powers. Yet, in likely missing the larger implications of such behavior—for example, how dangerous it was to do so in public with police around—Tyson also demonstrated innocence as to the broader social effects and possible consequences of his actions. Wing (2001) has explained that adults with autism have a "lack of appreciation of social taboos" that can often lead them to, for example, remove their clothes or urinate in public "in all innocence" (108). What Winnie shows us is that in being so cunning, on one level, and so innocent, on another, the inappropriate behaviors of adults with autism provide another zone in which incongruities—though often troubling—can also lead to situations that are humorous.

CONCLUSION

This chapter has explored the innocence and humor that caretakers sometimes read into the atypical and incongruous behavior of adults with autism. Caretakers associated innocence with things like an adult with autism's failure to align their behavior with age and gender appropriateness, norms that typically developing peers increasingly see as very important. Caretakers associated humor with some of the behaviors associated with the cognitive style of autism known as weak central coherence, in which individuals with the condition will—for example—follow guidelines taught in relation to specific scenarios while failing to extrapolate these to underlying social concepts and their application elsewhere. It is also clear from caretaker comments that humor and innocence often run together. This was illustrated by an adult with autism who entirely missed the cues of two individuals of the opposite sex on a boardwalk, and then yelled into his hand in a manner that both shocked his audience and undermined the definition of the situation that had guided that audience's behavior. It was also illustrated in the incongruity of the effective (if vulgar) technique of flashing one's penis to get out of unwanted activities, while at the same time demonstrating a profound innocence of the more dire implications of such behavior if done in the wrong place and at the wrong time.

Some might argue that the topic or presentation of the themes of this chapter are offensive, in that they might be viewed as romanticizing or making jokes out of something as serious as life-long dependency and severe disability. However, one of the issues of the literature on autism is that it tends to ignore the complexity of the experience of those who care for individuals with the condition. In his book on politics, Michael Lewis (1998) remarked that politicians who mix seriousness and humor on the public stage tend to be written off as wacky or troubling. He laments the way in which this leads the most sincere and complex individuals to be defined as phony, while the sound bites of phonies tend to gain traction as representative of serious and respectful minds. I would like to suggest that autism—being a disorder that is as politicized as it is complex—sometimes falls into the same realm. It is a serious thing that can only be discussed in hushed tones, even though we know that in real life the things we care about most are often experienced with mixed and complex emotions (Ellis 1991). However, given the reality that the data of this study is built on the words and experiences of those who most would argue have a right to speak about autism, the significant presence of humor and innocence in my fieldnotes, interviews, and observations seems to overwhelm the potential political incorrectness of discussing these themes.

Parents have been remarking for decades about the joyous, fascinating, and funny side of individuals with autism. In addition to my data a variety of memoirs were used in this chapter in order to show the relevance of innocence and humor to the experience of caring for individuals with autism. Though they describe everything from the significant burden of care to the relatively paltry services for those with autism after they turn twenty-one (Greenfeld 2009a), families have also remarked and remarked often about the more enjoyable though less explored aspects of loving someone so atypical. In the introduction to her recent publication *The Funny Side of Autism*, Masters (2010) puts it thusly:

> For one, I think it is important to show a side of autism that is hardly, if ever, portrayed [. . .] As hard and exhausting as it is, there are moments that catch you off guard—funny moments that show you how sweet and innocent autistic children are, and how they are just as desperately trying

> to comprehend our world as we are trying to comprehend theirs. Often, they make you 'see' things you would otherwise take for granted. I've found that these moments are what fuel me to go on, and I sincerely hope they will do the same for you (ix-x).

Masters describes the difficulty and exhaustion that are associated with the care of an individual with autism. However, she also remarks on the funny moments and the innocence of children with the condition. This chapter demonstrates that the same is true for experiences with adolescents and adults with the condition. It is possible that the shift away, in the point of view of families, from the significance of problem behaviors and towards, for example, anxiety about the future (Gray 2002b), might be partly connected to loved ones changing their understanding of atypical behavior. As one mother states in response to the idea of seeing someone with autism being funny, "there have been so many days—especially those immediately following my son's diagnosis—when if someone had mentioned the 'funny side of autism' to me, I might have punched them in the nose. But now, a few years into the journey, I'd be glad to talk about the lighter side of autism to anyone who wants to listen" (Katherine 2011). As she and her husband have aged, they have learned that if they "don't laugh" they might "cry instead." While this perspective on laughing defines it more as a coping method, I would argue that some of the laughter reviewed in this chapter is unadulterated—in moments, or in years—by pain underneath. As one mother in my study explained, "listen, autism is not funny, but people with autism are!" Of course, the complexity of emotions—like humor in the midst of sorrow—is one avenue for future research among those caring for developmentally disabled individuals and others in relationships whose challenges would at least make them eligible for the "living-loss" explored by Roos (2002).

Then again, autism can be very sad and stressful for those caring for individuals with the condition. As one father of a son with complex comorbidities (e.g. severe epilepsy) explained to me, “since I am the one who works I get a break, but my wife doesn’t; she has talked about the possibility that one solution for her son’s future, which terrifies her and she constantly thinks about it, is that she would take her son’s life and her own.” Lest these possibilities be viewed as only an exaggeration, there are reports of cases in which parents of individuals with autism have killed them (and sometimes themselves) to protect them from a dark future (Wood 2006; McGovern 2006; c.f. Silverman 2012). The Chronic Sorrow literature does a good job exploring some of the larger social factors that lead to the pain associated with relationships with individuals who develop atypically. Despite the sorrowful parts of the experience of caring for someone with autism, my data also attests to the reality that innocence and humor are part of the picture as well. In order to put those elements into the context of a larger social narrative, I end the chapter with a short discussion of the relationship between innocence and humor in interactions with those with autism, and the search for purity and authenticity in everyday modern life.

In failing to orient themselves to the strictures and codes of everyday social interaction, individuals with autism can be seen as acting out an authenticity and purity that remains attractive to typical individuals who are highly aware of the pressures of social life. In descriptions of autism, scholars have noted the enchantment that surrounds those with the disorder, both in current descriptions and historical anecdotes (Frith 2003). A variety of analogies and narratives seem to speak to the “chilling and fascinating combination of childhood innocence" and "disturbance" in autism that "cry out for symbolic elaboration" (Frith 2003:18). Despite the danger of romanticizing autism or divorcing it from its lived reality, the words of those responsible for individuals with autism also give voice to the fascinating and mesmerizing aspects of people with the diagnosis. In her book about her two sons with autism, Moore (2004) states, "I suppose some people find it sad that a child with a perfect face is not 'normal.' I don't; for me, their angelic faces perfectly express their innocence and strange integrity." In remarking on her son's innocence and strange integrity, Moore hints that their way of being skirts the pressures of social norms and in so doing can be viewed as representing an attractive if atypical authenticity. Her comments suggest a way in which to understand the role of innocence and humor in the relationships between caretakers and those with autism. In a book on identity in modern times, Giddens (1991) argues that the emergence of "pure relationships"—bonds "in which external criteria have become dissolved" such as "kinship, social duty or traditional obligation"—are one of the hallmarks of modernity (6). In another book on identity, Davis (2005) comments that "the moral ideal of authenticity is a powerful force in modern culture and a crucial element of modern identity" (259). While it is open to debate whether authenticity and purity are more achievable in modern times, Goffman's work shows that the rigors of social norms and impression management still have the power to orient our behavior towards approval and the success of interactions rather than the "pure" connection described by Giddens. Though this points to the more cynical implications of Goffman's work, to whatever degree this reading is true it demonstrates one way in which the behavior of those with autism might be seen as refreshing and liberating. The potential to experience their behavior as innocent and/or humorous is built into the ways in which individuals with autism do not follow the strictures of social expectations. In loving them, one opens their heart up to people who are deeply authentic, people who can “only be themselves” (*People* Magazine, Review of Moore, 2004). And given the exploratory and creative character of humor (Reay 2011), we can glimpse how in their interactions with those with autism caretakers laughing are both showing love and exploring the possibilities afforded by different ways of being.

CHAPTER 5

The Language of Pathology and the Looming Future: Growth in the Context of Atypicality and Dependency

INTRODUCTION

Autism is seen as belonging among the increasing number of human conditions that western society has defined as clinical entities, to be diagnosed and conceptualized through the language and concepts of modern medicine. The forces that drive a condition to be seen as belonging to the medical arena are diverse and complex (Conrad 2007). Though this belonging can only ever be partial, to be viewed as a clinical entity to any significant degree is associated with powerful effects on the way that a condition is interpreted and responded to. For example, Jane Mercer (1973) argues that individuals working in the helping professions—medicine, psychology, social work, and even education—often take a "clinical perspective" on clients with an intellectual disability (ID) (2; see also Carrier 1983). This means that those tasked with studying and managing the care of individuals with an intellectual disability believe that the best way to define ID is as a form of biological abnormality that can be measured by standardized assessment techniques and addressed through changes to that person's functionality (Mercer 1973). Though intellectual disability is a fundamentally different condition than autism, in many instances the two overlap.[37] Moreover, at present both are defined as

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[37] Intellectual disability is assessed by scoring a 70 or below on a basic Intelligence Quotient test. Autism, on the other hand, is fundamentally based on criteria concerned with social interaction (e.g. issues with eye contact, trouble interpreting emotions), communication (e.g. trouble with figurative language, or complex requests), and repetitive behaviors (e.g. hand-flapping, echolalia). That being said, the proportion of

developmental disabilities, and Mercer's comments about the clinical perspective apply just as readily to autism as to ID (Sullivan 1979). Of course, understanding and trying to address autism with the assumptions and techniques of the clinical perspective is not without merit. Indeed, a variety of stakeholders (professionals, families, even individuals with the diagnosis) have described the value autism's current conceptualization in giving them answers and access to services, supports, and empathy (Newschaffer and Curran 2003; Grinker 2007; Robison 2008).[38] However and despite the benefits, there are also costs associated with looking at and speaking about individuals whose behavior fits the criteria for autism from the viewpoint of the clinical perspective.

Though in theory the clinical perspective is applied to two fundamentally different types of "abnormality," its real world application to both pathological and statistical conditions encourages the tendency to speak about the later as if they actually represented those of the former. Though the clinical perspective is applied to entities that are believed to derive primarily from an individual's atypical biology, the perspective

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individuals who have autism and co-occurring intellectual disability is high. Dated literature found that 75% of individuals with autism also had intellectual disability (with half of these functioning in the severe range [Rutter & Lockyer 1967]). More recent literature has the rate of co-occurrence dropping (likely due to the integration of Aspergers and high-functioning autism into the spectrum), with a recent meta-review by Fombonne (2001) finding that 19.4% of individuals with autism functioned within the normal range, 29.4% had mild to moderate learning disability (verbal and performance IQ scores in 50-70 range), and 49.9% had severe to profound learning disability (below 50 – although, the difficulty of testing individuals with autism using language based exams is important to note [see Charmin et al. 2011]) (c.f. O'Brien and Pearson 2004).

[38] For example, the ascendance of autism to the rank of "celebrity" social problem in the public sphere has—as with other equally ranked issues—brought awareness and resources to those with the label and those with whom they are associated (for the term "celebrity" social problem, see Hilgartner and Bosk 1988:57).

actually encompasses two very different forms of abnormality. The first, "pathological abnormality," describes conditions in which "symptoms" stem from biological processes in the body that carry the potential to "destroy the biological organism as a living system" (Mercer 1973:3; Mercer 1965). The second, "statistical abnormality," describes conditions that lead appearance or behavior to deviate enough from some population norm that it gets defined as a problem, but a problem which—though linked to biology—will not directly threaten the fundamental operation of the organism in question (Mercer 1973). Both of these categories represent ideal types, to which real cases conform to varying degrees.[39] Ignoring the conceptual messiness for now, Mercer (1973) suggests that one of the issues in housing both pathological and statistical abnormality under the clinical gaze is that we run the risk of thinking "in terms of one model while operating with the other" (5). In practice, this would mean, for example, describing and responding to individuals with a developmental disability like autism (a form of statistical abnormality) as if they had a form of pathological abnormality that could fundamentally destroy them "as a biological organism." Of course, severe autism and intellectual disability (unlike, say, left-handedness and eye-

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[39] For example, while an extremely dangerous illness like Ebola clearly fits the pathological model, is the common cold really a danger to life? And, though individuals with intellectual disability continue to live and develop over time, can the same not be said of individuals who live with cancer for decades? In addition and adding another level of ambiguity, individuals who are left handed, for example, have a statistical atypicality based in biology that could theoretically be labeled as a problem and be brought under the clinical gaze (and has, see Coren 1993). So where do we draw the line between something that is of clinical-statistical relevance and something that is just "normal variation" (Ortega 2009:430).

color)[40] represent cases of statistical abnormality whose characteristics lead to considerable challenges (difficulty navigating social situations, the need for intensive supervision and support) (Mercer 1973).[41] However, describing autism with words like "etiology, symptom, syndrome, diagnosis, prognosis, and prevalence" means perceiving those with autism as having something "somewhat akin to the disease processes to which these terms are usually applied"—disease entities that are life threatening (Mercer 1973:17).

Though developmental disabilities are generally neither fatal nor stop development, the language used to talk about autism in the public sphere (e.g. in the media) often suggests—even if only figuratively—that autism is akin to a degenerative or deadly disease. Some of the major tensions between a number of the most popular representations of autism and the experience of those caring for individuals with the disorder are the result of public discussions and conceptualizations of the condition that have spoken about it with the language of the pathological model (Silverman 2012). This language has been used to describe autism even though, in the words of one sibling and writer, the condition is "nondegenerative and nonterminal" and "the boys and girls" with

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[40] The distinction between left-handedness and eye color suggests which forms of statistical abnormality more easily fall under the clinical gaze. Specifically, those whose biological differences more clearly come into conflict the operations and assumptions of particular societies and cultures. While eye color seems entirely unrelated to many forms of activity, left-handedness (a mechanical reality that gets in the way of, for example, using three rings binders, scissors, right-sided desks, can openers, etc.) does not. Of course, the reality that race has been turned into a clinical entity on many occasions entirely undermines this argument (Zuberi 2001).

[41] This is one of the main reasons that autism has been described as a "public health emergency," and why caretakers and activists have sought to attract the attention of the clinical gaze or, at the very least, not fought it off (Newschaffer and Curran 2003; Eyal et al. 2010; Eyal 2013; Feinstein 2010; Silverman 2012; Valentine 2010).

the diagnosis "grow up" (Greenfeld 2009b:32). Thus, descriptions of autism that suggest—even metaphorically—that it threatens the fundamental operation of those with the condition have the potential to conflict with the lived experience of those caring for adults with the diagnosis. Moreover, suggestions of non-development and death demonstrate the power and sometimes-unintended consequences of professional, media, and activist representations of significant atypicality that shape public perceptions and policy on autism (Broderick 2011; *The New York Times* 2009; Scully 2008; for a study of how the media shapes popular views on mental illness, see Wahl 1999).[42] The first half of this chapter will explore the ways in which the experiences of caretakers of adults with autism come into conflict with representations of autism associated with the language of pathology. The application of the clinical model and the language of pathology likely serve to represent the fear and angst of caretakers concerned about what will happen to an individual with autism who will need care throughout their lives. It is likely also fed by the hope that the language of pathology will energize individuals with the right knowledge and techniques to set about finding a cure for autism (a magic bullet that would solve the problem of future care). However, the reality remains that many individuals with autism grow, develop, and learn, remain alive and present in the social networks in which they are embedded, and yet continue to qualify for a diagnosis of autism and remain atypical and dependent. In order to accurately represent the experience of adults with autism and their caretakers it is crucial to recognize just how important

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[42] As one writer put it, the dichotomous assumption behind the pathological model—that either you are treated or you will eventually die (what one author describes as the "cure or die" mentality, Waltz 2013)—does not accurately describe the reality of autism.

planning for the future is for those who remain atypical and dependent. The second part of this chapter will seek to draw on sociological theory of the future in order to clarify how the reality of statistical abnormality is different from pathological abnormality precisely because conceptualization of the future plays such an important role in care.

Given my focus on how caretakers of adults with autism interact with and plan for the reality that those with the condition generally have a normal life expectancy, it seems serendipitous that there has recently arisen in sociology an interest in theorizing how people conceptualize and anticipate the future. Recent work in sociology has begun to push for more concrete theoretical tools through which to understand how people imagine their relationship with the future and how that conceptualization shapes subsequent behavior (DiCicco-Bloom and Gibson 2010; Cerulo 2006; Mische 2009; Gibson 2011a; Gibson 2011b). One article in particular suggests a theoretical structure with which to explore the tensions involved in the multiple levels on which the future unfolds. While past theoretical work has conflated shorter- and longer-term horizons into an amorphous mass (Heritage 1984; Bourdieu 2000; Schutz 1967), Tavory and Eliasoph (2013) argue that the future is shaped by layers of temporal structure which, though often unfolding in tandem, can also exist in tension with one another. They introduce us to three abstract modes of "future making"—protensions, trajectories, and what I will call 'temporal structures'—through which people conceptualize and towards which they coordinate everyday interaction as they make sense of what comes ahead (Eliasoph and Tavory 2013).

The term “protention” is used to describe the “moment-by-moment anticipations” through which individuals “constantly calibrate” themselves to the immediate future (Tavory and Eliasoph 2013:909, 913; Husserl 1960). Though the social “skills” required to bring about the immediate future are usually taken for granted, the complexities within protentional dynamics become starkly apparent when, for example, the smooth flow of micro-interaction breaks down (Tavory and Eliasoph, 2013:909, 913; Garfinkel 1967). The term “trajectories” refers to the longer-term paths along which actors envision themselves moving, and tend to proceed in ways that “are more or less culturally predicable” (Tavory and Eliasoph 2013:909). Trajectories can be broken down into two sub-concepts: “narratives,” or shared stories about how specific events relate to one another, and “projects,” or individual goals towards which people see their everyday actions building (Tavory and Eliasoph 2013:914, 915; Mische 2009).[43] The final conceptual level of future coordination—what I call temporal structure—feels to actors as if it unfolds “automatically and would keep going with or without anyone’s actions” (Tavory and Eliasoph 2013: 916). Though they do not provide a name for the master-concept (my reason for providing temporal structure), Tavory and Eliasoph (2013) describe two sub-concepts: “plans,” or assumed and well trodden paths (e.g. ranks in the military hierarchy, or grades in high school), and “temporal landscapes,” or things people take for granted so deeply (e.g. the seven day week) that they seem natural, universal, and very hard to change.

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[43] The authors recognize the continued struggle to understand how narratives and projects interrelate, cautious not to assign too much power to either “culture” or “individual psychology” (Tavory and Eliasoph 2013; Mische 2009; Fligstein 2001).

The reality that people's anticipation of and coordination with the future can unfold on multiple levels provides a useful analytical tool to start conceptualizing how caretakers of adults with autism orient themselves continued existence and future needs of those with the condition. Despite the little sociological work that has explicitly delved into the ways in which modes of future-coordination both intersect and diverge from one-another, past empirical studies do provide some clues as to how the strains and contradictions surrounding the conceptualization of future might be analyzed. In the introduction to their paper, Tavory and Eliasoph (2013) explain that "in contrast to those" who argue that modes of "future orientation operate in tandem or can be reduced to one basic form," the reality is that these modes merge, detach, and directly contradict each other when, for example, "actors place similar protentions on different narratives [. . .] similar trajectories on different temporal landscapes" or "ambivalently orient themselves to multiple futures at once" (909). Past studies into phenomena like flirtation and marriage show how different future orientations can starkly or subtly conflict with one another. For example, during flirtation, two people might easily coordinate (protention) what appear to be behaviors that represent an equal interest in one another, while at the same time imagining these behaviors fitting into very different trajectories (one viewing the behaviors as a preamble to a sexual encounter, the other viewing it as harmless fun that will lead no where) (Tavory 2009; on ambiguity in momentary interaction, see Leifer 1988). In another example, the recent rise in divorce, multiple marriages, and long-term relationships outside the context of marriage shows how the increase in multiple trajectories actually undermines the "naturalized plan" or temporal structure of marriage as an inevitable part of adulthood (Tavory and Eliasoph 2013:928; Beck-Gernsheim 1999; Hackstaff 1999).

In the case of autism, the challenges of future care are considerable, with the major concern of aging caretakers turning to who will take care of the individual with autism after they die (Donvan and Zucker 2010; Naseef 2013). Answering this question with certainty always remains challenging, with families and professionals working to cobble together funding for places to live, transportation needs, health needs, and a whole variety of necessities that the individual with autism is unable to organize for themselves. While the first part of this chapter will explore how the popular language of autism misrepresents the reality and challenges represented by the condition and the available responses and solutions to those challenges, the second part will address the role that temporality plays in caretaker's efforts to address the most pressing challenge presented by autism—the need for life long care and significant support considerably beyond what a typical adult requires. The importance of appreciating how people's orientation to the future can unfold in commensurate and conflicting ways is that it opens up a theoretical angle through which to discover how caretakers think about and respond to a difficult (logistically, emotionally, socially) reality that rarely has a clear answer, magic bullet, or "cure." In the conclusion, I return to ways in which the pathological model does a disservice to representations of other statistical and chronic illnesses, and how the reality of planning for future needs is an important component of the lived experience of such conditions.

AUTISM AND THE LANGUAGE OF PATHOLOGY

Though descriptions of autism that employ the language of pathology have aided in the push for scientific research and educational services, pathological terms and imagery have characterized individuals with the condition in ways that conflict with the experience of those caring for people aging with the disorder. Language is “essential”: it associates meanings and labels with the categories created by abstraction, dividing the complexity of reality into concrete units so that experiences may be contemplated and manipulated intellectually (Mercer 1973:256). Despite the utility of this process, language also has its costs: once we categorize an empirical phenomena as belonging to some class, associated meanings and labels get treated as “given,” “natural,” or “right” and place obstructions in the way of more “creative,” “useful,” or, at the very least, relevant ways of organizing the empirical world (Mercer 1973:256; Bowker and Star 1999). Autism has been characterized by the meanings associated with the pathological model of abnormality for some time: descriptors like “disease” and “severe pathology” have been common for decades, and ones like “epidemic” have become more popular as rates of diagnosis have increased (Bettelheim 1967:396; Henry 1971:278; Silverman 2012; Harris and O’Conner 2005; Kirby 2005:23; Fombonne 2001; *Wall Street Journal* 2003). There are a number of compelling reasons for lumping autism—which, on closer inspection, more easily qualifies for the statistical model of abnormality—with phenomena whose characteristics largely qualify them for the pathological model of abnormality (Grinker 2007). For example, speaking about the behavior of those with autism as “symptoms” gives individuals from the helping professions and the clients they serve (e.g. families) a targeted language through which to conceptualize behavioral issues and create therapeutic goals (an author and father notes that calling autism an "epidemic" has been "good" because it means that we are seeing "more research, more philanthropy, and more understanding of how families struggle," [Grinker 2007:5]). On a logistical note, the pathological model also supplies a language familiar to third party payers (i.e. insurance companies) who seek to impart homogeneity, accountability, and temporality to the relatively heterogeneous and continually expanding diagnostic and therapeutic methods applied to autism (Leslie and Martin 2007; Bouder, Spielman and Mandell 2009; for discussion of same issue with mental illness, see Horwitz 2002:75). From the perspective of epidemiologists, the pathological model of autism keys people into the reality that—while much of the increase in diagnosis is due to changes in clinician behavior, the official definition of autism, and general awareness—autism is based in real, if complex, biological irregularities, and some of the increase may actually be secular (i.e. not due entirely to measurement changes) (Croen at al. 2002; Newschafer et al. 2007; Lawler et al. 2004; King and Bearman 2008). And in what one sibling describes as "marketing" autism, it can even be argued that part of the motivation of applying the concepts of the pathological model to the disorder might be to try and energize—though arguably an act of magical thinking—some kind of treatment success equal to the major innovations (e.g. antibiotics, vaccines, the eradication of smallpox) of America's golden age of public health and medicine (Greenfeld 2009b:32; Starr 1982; Rogers 2014; for the danger of this thinking, see Offit 2008). However, the experience of those who interact with and care for individuals with autism—particularly adults with the condition—attests to some of the costs of characterizing autism through the language of the pathological model.

Through such mischaracterizations as the suggestion that individuals with the disorder do not continue to grow and develop throughout their lives, the language of the pathological model of abnormality does a disservice to the lived reality of caring for adults with autism. Though the fit between reality and the abstract categories of language are never perfect, there are basic criteria that guide our use of various concepts when applied to our lived experience. The pathological model of abnormality is ideally suited to phenomena—usually described as diseases—which threaten the development and basic operation of the biological organisms with which they interact. Thus, the language of the pathological model tends to affix to the conditions to which and individuals to whom it is applied the suggestion that because of some abnormality (1) their existence is threatened, and thus (2) if they continue to be abnormal will eventually cease to develop and survive. A demonstration of the power of the language of pathology is given by the reality that suggestions of non-development and what might be described as metaphors of death pervade the way that we talk about autism in the public sphere (Fitzpatrick 2009; Morrice 2005; Broderick and Ne'eman 2008).

In speaking about their everyday experience, however, caretakers of adults with autism explicitly and implicitly buck against the ways in which pathological language mischaracterizes individuals who have the diagnosis. For example, despite a noticeably atypical developmental course, the suggestion that individuals with autism do not continue to develop, learn, and grow as they age—physically, socially, emotionally—

does not accord with the experience of those who interact with and care for them (Sicile-Kira 2012; Biklen et al. 2005). Talks with and observations of Ross and Molly Zago demonstrate how their experience of their son, Martin, demonstrates that he continues grow and learn as he ages:

> *Standing next to his wife as she washes dishes at the sink, Ross tells me, "you know, we recently had friends for dinner, and Martin handed the lady something and she said 'thank you.'" After saying this, Ross looks at me—his voice slowing for effect—and says with pride and wonder, "and Martin said 'you're welcome.'" He laughs, scrutinizing me for a response. Then Ross goes on to describe another recent incident in which Martin brought him a shirt, and told him "this is your shirt." After telling me this, he exclaims, "that's the first time!" [referring to his son's correct use of the pronoun "your" in his statement].*[44] *After another pause, Ross explains to me that while these things might seem like small successes, they are really big for him and Molly.*
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> Ben: Can you tell me a time that Martin did something that surprised you with his insight into something? [. . .]
> Molly: He was lying down. And I went in and I covered him up, and I said, 'how are you feeling?' He had to be upset [earlier that day, Martin had been in a van that was involved in an accident]. He said, 'Martin will die someday.' Golly, he was really scared.
> Ben: What did you say?
> Molly: There was nothing I could say. I said, 'yeah, but not now. You're okay.'
>
> *I am sitting out on the front porch of the Zago residence with Ross. Together we watch as Martin pushes the lawn mower across the green grass that covers the expansive lawn sloping down towards the road below. Ross tells me how he still remembers when his son turned twenty-one, and he told him "Ok, now you're a man and you can mow the grass." Martin was the "happiest guy in the world," and from that point he started mowing the lawn on his own. He puts the gas in the mower, takes care of it, cleans it, and puts it away and locks the shed when he is done (though his technique could still use some improvement: Ross points out to me that rather than going in a circle, so as to throw cuttings where the mower has already cut, Martin's path sometimes throws cuttings onto parts of the lawn he*

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[44] Using correct pronouns—"I" and "You"—was one of the fundamental issues that Kanner (1943) said distinguished the syndrome in the first scientific paper to describe autism.

> *won't cut). As I sit and talk with Ross, the mower stops for a moment. I watch as Martin bends down and tampers with the machine. Ross gets up to go and assist his son. When Ross comes back he tells me that the mower has trouble starting sometimes. We talk on and Ross tells me about a cousin of his that does lawn mower repair. He tells me that his cousin, Roger, is a bit of an introvert and actively avoids interaction with his family.*[45] *He then explains that in the past, when something was broken, Martin will ask him (Ross) to fix it. However recently, when the mower's screws vibrated loose, Martin went to Ross and said, "mower broke; take it to Roger Webster." After telling me this, Ross laughs and says, "he knows what he's talking about!"*
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> Ross: But basically he would just talk about stuff now more and more, [and he'll] ask you questions about anything, but they're simple, just to-the-point, blunt, three-four word, why is this [. . .] I don't know how to put a finger on it, just the interest, just asking questions about things. That was just the other day; I told you about the weeds, the fact that he walked along and helped me. He would never come with me and do something [in the past], and the fact that [the weeds I was carrying] started to fall and he just on his own pushed them back and then he held on until I got up through here and we went in the woods to dump them [. . .] He asked [my brother-in-law, the last time we saw him] something about either something on TV? I forget what he said he asked him about but [my brother-in-law] said, "he was actually trying to have a conversation with me," and that's the first time, the first time ever. [. . .] Sometimes I think he needs more but I don't know what would be available, especially when I see him developing, like he's developed in the last two or three years. It's unfortunate there's no funding or anything for any kind of formal education. After 21, they're done and he is just changing.[46] But I don't know, there again, what would he achieve?"

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[45] On one occasion, Ross wondered allowed to me whether his cousin might not qualify for a diagnosis of autism.

[46] The end of formal education is widely cited as a shock to families caring for individuals with developmental disabilities like autism. In one article, a parent states: " 'It's a big shock to the system when they graduate,' Smetona said. 'Their schooling was everything to them. It met their social and extracurricular needs. It's hard to find something in the community for Michael and Megan to do.' [. . .] 'Kids have been getting $60,000 a year minimum worth of school services. Then it's gone,' [. . .] 'A percentage will go on to college. Others can't be home alone'" (Henry 2009). An 'appropriate education' for all is an entitlement. Adult services for those with a developmental disability are based on 'what's available,' and is almost always associated with waiting lists (e.g. you can't sue the state for adult services, unless they break a previously made contract; you can sue the school district for not providing an "appropriate education," and, as many parents explained, just the name of the right lawyer can make the case).

Ross and Molly suggest some of the social advances that have characterized their son's aging. Saying you're welcome when a guest thanks him; helping his father as he carries weeds from the garden; using the correct pronoun when notifying his father about a shirt; demonstrating some awareness of death and his own mortality; using body language to signal to his uncle the desire to engage in conversation. All represent things that Martin rarely or "has never done before" in his interactions with his parents and others in his social network. Together, these experiences attest to the reality that, despite the imagery of pathology, adults with autism are "not done" but keep "developing" and "changing." In the words of another father of an adult with autism, "development delayed does not mean development denied" (Naseef 2013:213).

Of course, it is easy to find caretakers agreeing at times with the pathological model's suggestion of non-development. For example, in Ross's question as to what further education "would achieve" he suggests ambivalence about the potential for growth. Such statements attest to the reality that, despite their growth, the development of individuals with autism as they age is abnormal compared to the rest of the population. However, no matter the degree of disability, one is hard pressed to find cases of individuals with autism who do not grow and change. Just as powerful and potentially damaging as the suggestion of non-development is the suggestion of non-existence. Though the official definition of autism does not characterize it as a fatal condition, popular descriptions of autism that use words associated with pathology can intimate the opposite. While these descriptors do not necessarily suggest that autism leads to death, describing individuals with the condition as absent, lost, or even "dead souls" can be interpreted as transforming autism into a metaphor of death (Fitzpatrick 2009: 44; Seroussi 2002:201; Sarrett 2011; Waltz 2013). These metaphors sit in contrast with the complex experiences of caretakers, who, in their daily interactions with adults with autism, are faced with the irrefutable presence, even if abnormal, of those with the condition.

In their interactions with adults with the disorder, caretakers demonstrate that the metaphors of death that attach themselves to pathological descriptions of autism brush over the ways in which those with the condition are both present and active participants in the social milieus in which they are situated. Though individuals with autism have been classified by one scholar and parent as among those sorrowful events that she describes as a "living loss," the issue with using the language of pathology to describe those with the disorder is to go as far as to suggest that caring for individuals with developmental disability is the same as reacting to a child that has died (Roos 2002). While some may argue that the focus on children with autism shows how in the public conscience they are viewed as anything but dead, the language used to describe people with the condition—exotic terms like "absent," "lost," and "dead souls"—involve descriptions that "slip out of imaginary discourse to shape the perception and reception of real individuals" and leave little room for the reality of adults with the condition (Goehner 2011; Johnson and Van Rensselaer 2008; Murray 2008:117; Fitzpatrick 2009:44; Truchan-Tatryn 2003:207). The power of this language becomes more extreme once a child with autism becomes an adult with autism, and thus demonstrates by his or her continued presence that they might be difficult to integrate socially but they are certainly not dead (Greenfeld 2009b). Grappling with the implicit suggestions of the pathological model that pervade popular representations of autism, the sibling of a twenty-year old with the condition who participated in my study stated on his blog that: "Autism Spectrum Disorder is *not* a disease. Cancer is a disease. Alzheimer's is a disease.[47] Diseases kill you. Last I checked, autism does not kill you." In so stating, this sibling was arguing against language that suggests that autism qualifies for the pathological model of abnormality ("autism does not kill you") as opposed to the reality that it is a form of statistical abnormality (once again, Mercer 1973). In their interactions with and stories about Bianca Lee, friends, family, and co-workers demonstrate how she is neither dead nor absent, but rather is a present and active element of the social settings she inhabits:

> Jack: [Bianca's] an introvert and does not, you know, doesn't get energy from being with people. The bigger the crowd sometimes, the more energy it takes for her to maintain herself in that setting [. . .] Bianca's actually a clear cut case of that [someone who wanted her own place, and to live independently from her parents]. We bought [her brother] his house and we were going over to look at it, and she didn't say, "well when do I get mine?" But we went and looked at the place that was for sale over here. And at that point she kind of clicked into, oh, okay. So then she said, "I need a new house." [. . .] Bianca has seemed to me to be capable of development, I mean, from the time she was a little girl. I perceive that, I think I said I can see that she goes on in the developmental ladder and that she would, you know [. . .] Recently, it was really like a breakthrough. She was really upset and I ask her to tell me why she was upset and she did and I'm not remembering the specifics of that now. And that was, I mean, that was a new thing [. . .] So with respect to Bianca, she's contributing

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[47] Despite the general point of this statement, it unwittingly attests to the difficulty of classifying today's chronic conditions—like autism—because Alzeheimer's is often not directly responsible for killing people. Rather, the behavior characteristic of Alzheimer's (e.g. issues swallowing, walking, controlling bladder and bowel) can lead to comorbidities (e.g. infections, blood clots, pneumonia) which themselves cause death.

her share of the groceries, she's buying clothes and she's buying some recreation with her own money.

I am shadowing Bianca for the day at her job, at the offices of Helping Hands (HH). HH specializes in behavioral health, including services for individuals with Autism and/or an Intellectual Disability. Some of HH's staff manages the house that Bianca and her roommate live in. Bianca works four days a week for about four hours a day. Her responsibilities include (in order of the amount of time she spends doing each) passing confidential health documents through a paper shredder, placing paper in the office printer and copy machines, taking mail from people's boxes and delivering it to their offices, watering the potted plants on her floor (on Thursdays), and, if the shredder is down, organizing the administrative closets (her boss, Carolyn, tells me, "she is great at that!"). Throughout the day, Bianca is monitored by her job coach, Julia, who also spends time with Bianca at the home she lives in. Julia tells me that Bianca is "so smart" and "inquisitive," and interested in all kinds of things. For example, she once took her automatic coin operator entirely apart—unscrewing all the small pieces—and then put the whole thing back together. More recently, when her TV stopped working, Bianca wanted to open it up. She applied a butter knife to the back of the monitor in an effort to achieve this.

I spend an hour sitting next to Bianca at work, watching her as she methodically takes paper from a pile to her right and runs it through the shredder. When Bianca comes upon stapled packets of paper, she gets a stapler remover and pulls the staples out. Sometimes she pauses to slowly scan the pieces of paper, and I wonder if she can read them. I ask her at one point, "what does it say on that top line" and she tells me, "pe…peer…revia…peer review…[then, after placing her finger on the first word]…inve…investigation…reccomen…recommendations…peer review and investigation recommendations." Though she is often quiet, at times she suddenly initiates conversation, saying, for example, "Ben…I want a new HD TV, and a Video Recorder…" (Earlier in the day, Julia told me that I should have joined them in the car, because Bianca was talking non-stop about getting a new TV [her old one still broken]). Less than an hour before the end of the day, I talk to Carolyn about the work Bianca does. She tells me that there is a company that comes and shreds the paper that Bianca doesn't get to—because there is so much to do. She tells me that during the time she has overseen Bianca, she has had the pleasure of watching her grow and develop in her position. For example, she tells me how she has an easier time now negotiating with Bianca about which days to work: "if we don't have, uhm, work for a certain day, I'll write her a note, and say, 'there is no work tomorrow, can you switch,

> *take off tomorrow, and come in on Friday. Put yes or no' and she tells me. And then she takes the note home, and then she knows that her work schedule has changed. Which was, uhm, not always comfortable in the very beginning. For her to come in on a Friday, she was, ah, initially resistant to that, and she has gotten much better, much more flexible with that."*

> Jack: "I got an e-mail that says, 'I want to go to Puerto Rico.'"
> Ben: "From Bianca? Really?"
> Jack: "Uh-hum. 'I want to go for six days. When can I go to Puerto Rico?'" [. . .]
> Jack: "She and Joan[48], she's been, and so now…" [. . .]
> Joan: "Oh, it's totally time! I totally agree with her [. . .] We stayed outside San Juan [last time we went], I think Jack had used his points for a hotel, right on the water. And it was right on the water, and it had a pool. Because Bianca likes a pool. And so we would go, we would get up and rent one of those little things ["a cabana?" I ask]. Yeah, and I would set it all up, and Bianca would be in the water, and then I would go out and we would go out into the water, and then we would hang out in the little cabana thingy, and then she would go back into the pool, and then as soon as she could she would swim up to the swim up bar [everyone laughs] and then I had to have a conversation with the bartender that you can not just give Bianca anything she asks for, she can have one drink, one! [. . .] She was really fun! [. . .] We went, we went to go see the lighthouse, and it was closed on the day that we went. And I was like, 'huh, I should have checked that.' So then we had to drive back. And then I thought to myself, 'why do we have to drive all the way around the island, why don't we just drive through the island.' [. . .] [we] are driving along and Bianca's looking out the window, and says, 'there's an Indian,' 'there's a native person.' [laughing] And then we stop in this tiny little town, cause it is lunchtime and she wants lunch, they only speak Spanish, so I said, 'ok

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[48] Joan has been a friend of the Lee family ever since Jack met her at his congregation decades ago. At the time she was dating another woman, and the Lees invited both women to move into their home (the congregation did not accept their relationship). Both Joan and her girlfriend were some of the most pivotal of the several young teachers (many of them undergraduates at a near by college) who were given room and board in the Lee residence in return for working with Miller and Bianca. Like others who become close to individuals with autism and their families, Joan (and, at the time, her girlfriend) no doubt qualify as "fictive kin" for the Lees (Stack 1974). Indeed, Jack and Vale both informed me of how Joan's parents expressed some discomfort with how close Joan seemed to the Lees—possibly surpassing the closeness of her relationship with her biological parents. This settled down when the Lees and Joan's parents spent time together recently and hit it off.

> Bianca, what does this say?' [. . .] She knew enough Spanish (from watching Placo del Sesimo on TV) I told her what I wanted, and she ordered it, said 'Gracias' to the people."

These extended interview and field note excerpts demonstrate that, like Martin Zago, Bianca Lee continues to grow and develop. They also attest to the reality that in the experience of family, friends, employers, and service staff, she is a vibrant member of the social situations in which she is embedded. Those who know her describe Bianca as a hard-working employee whose constant pace of activity is much appreciated by her boss, and whose labors help her to buy various necessities and luxuries (for a review of the value of integrating individuals with autism into the workplace, see Bornstein 2011). Bianca's boss also describes her as a person who has evolved in her employment (having an easier time now negotiating work hours with her employer), just as family and friends describe her as having evolved through her personal hobbies and relationships (e.g. learning Spanish, and recently demonstrating an ability to use words to communicate her feelings—"that was a new thing"). Of course, there is a good deal of experiential evidence that attests to the reality that Bianca is atypical: she is described and observed to be an introvert, someone who needs extra support in the context of work, a person who obsessively focuses on items that she desires, and someone—to take a specific case in point—who does not recognize the tensions that might be aroused by describing the citizens of Puerto Rico as "natives" or "Indians."[49] The contours of her atypicality

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[49] In another example that demonstrates difficulty comprehending social distinctions, Joan told me a story about Bianca in which the later worked at a sock factory at which most of the workers were Cambodian. To the dismay of her then job coach, Bianca would speak to her Cambodian co-workers in Spanish. The reasoning, as Joan explained,

qualified Bianca for a diagnosis of autism; the label signifies to those around her that her behavior is significantly different than a typical member of the general population (though the statistical nature of this normality is more assumed than measured, see Mercer 1973). However, suggestions of absence or death conveyed by the popular use of pathological language to describe autism does a disservice to the reality that Bianca is a living person embedded in a social network. Moreover, in suggesting that death is an integral part of the condition—an outcome that is relatively unmovable, no matter the social context—descriptions of autism ignore the degree to which the experience of atypicality and the degree of a person's functionality are determined by social surroundings. For example, Bianca has no problem doing quite typical things—going on vacation with a family friend, swimming with her in a pool, and making her way over to the pool bar to order a pina colada. While seemingly mundane observations, in their very mundanity they highlight the damage that the language of pathology exerts on those with autism. Moving beyond the ways in which the language of pathology performs a disservice to the development and presence of individuals with the condition, we find that the pathologizing of autism can attach stigma both to those it describes and those with whom they are associated.

Pathological descriptions of autism not only attach suggestions of non-development and metaphors of death to those with the disorder, but also impute to their families and other caretakers a form of honorary pathology that subtly (or not so subtly) undermines the nuanced experience of living alongside autism. Scholars of the anti-

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seemed to be: "she noticed that they were speaking a foreign language, so she spoke the only foreign language that she knew."

psychiatry movement argued that one of the issues with medicalizing "madness" was that in so doing you stigmatize those so labeled, communicating to others that there is something fundamentally bad, scary, or sad about them (Conrad & Schneider 1992; Szasz 1961; Scheff 1966; Goffman 1961). Though autism is no longer defined as a mental illness, describing those with the condition as non-developers or "dead souls" can be viewed as a process of stigmatization. In a classic work on the nature of stigma, Goffman (1963) argued that those who are stigmatized often confer onto those with whom they are connected a level of associational stigma—suggesting that they, too, are bad, scary, and/or sad (also, see Milner 1994). A powerful historical example of honorary stigma in action is presented by the so-called "menace of the feebleminded," in which early eugenicists argued that the "mentally deficient"[50] and their kin constituted a "social menace," a "drain on society," a "national calamity," and linked them to social problems like "crime," "abuse of charity," "drunkenness," and other threats to America and its "future generations" (Trent 1994:141, 160, 165, 166, 178; Wray 2006). It is possible to see in these theories of "degeneration" suggestions of how the language of pathology spreads the threat of non-development and death from those who are significantly atypical to their families and caretakers. Despite being a largely historical concept (though, further below, we will see how the idea of "degeneracy" sometimes rears its ugly head), describing autism with the language of pathology still has the power to subtly communicate that there is something fundamentally tragic, sad, or "broken," about those

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[50] Though labeled with now out-of-date and offensive labels like "idiots," "morons," and "imbeciles," the 19th century population of individuals with developmental disabilities no doubt included people who would today be diagnosed with autism.

diagnosed and those with whom they are associated (Sarrett 2011:147; Sinclair 1993; Fitzpatrick 2009). And while caretakers of adults with autism are quick to point out the challenges associated with atypicality, their words and experiences, at the very least, complicate the moral suggestions made by stakeholders in the press and public about the quality of their everyday lives. To demonstrate this, we return once again to Ross and Molly Zago's descriptions of daily life with their son Martin:

> *At dinner, Ross talks to me about some of the newspaper articles he reads about individuals with autism and the families that care for them. He tells me that these articles are all about "the suffering child with autism" and their "suffering families." Ross recounts that recently, after reading one of these articles, he looked up at his wife and said, "we're not suffering." As he gets up to make coffee, he explains that he doesn't worry about whether Martin will get married, or have children. Molly follows this by telling me that they "don't think about it."*[51]
>
> Ross: Oh yes. He's pretty strong because we ride bikes a lot. See, we do that with our free time. Two years ago, we rode 2,000 miles and last year we rode 1,000 [a couple of their trips have been written about in a local newspaper] [. . .] He talks to girls. Oh yes! And they can be 13 or 40, it don't matter. That's how he introduces himself. "What's your name? What month, day and year were you born?" Then he tells them what day of the week it was and they're always fascinated [. . .] He goes to therapeutic riding. We go there with him and I'm on the Board of Directors for that now, so I'm involved with that [. . .] (speaking of therapeutic riding) I mean, nothing is better, I say to anybody, 'if you think you need a psychiatrist, just come with me on Thursday. I'll give you an hour.' [. . .] [In the evening] we usually have dinner and clean up and everything and we watch TV and eight o'clock or something we'll have dessert.

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[51] In the interest of full disclosure, it would be inaccurate to say that the language of brokenness, for example, never entered Molly or Ross's descriptions of their son. For example, in describing a tantrum his son was having in a Mall once when he was ten years old, Ross told me that a woman came up to him and said, "what kind of father are you?" Ross responded, "lady, if you can fix him, I'll make you a millionaire." This comment was effective in getting the woman to "realize that he had a problem, and swallow her tongue," but also shows how despite taking umbrage with media portrayals, families also, at times, use the language of pathology to describe the atypicality of their loved ones.

> Molly: The thing with Martin is, he's just a part of our lives. We have one friend that said to Ross, 'Can we go do adult stuff?' Martin's an adult. What are you going to do? We're not going to a strip club, because that's not what we do anyway. It's like, you go to a restaurant, Martin will go to any restaurant, he's perfectly good at a restaurant [. . .] Our lives would be completely different without him, but that's not necessarily meaning it would be any better.[52]

In their descriptions of Martin, the dynamics of their relationship with him, and the impact that autism has had on their lives, Ross and Molly Zago explicitly and implicitly challenge suggestions of brokenness and sorrow often associated with the language of pathology. While it is true that they have struggled at times and to varying degrees, Martin's caretakers speak about and demonstrate the elements of joy and vitality that animate their lives. Through the distinct (biking hundreds of miles) and the mundane (the ritual of evening TV and dessert); walking around the community (Martin's quirks attracting the attention of women) and participating in special services (therapeutic riding, about which Ross contends "nothing is better"); even through engaging in hobbies and chores (Martin's mowing represents both)—the Zagos contest the stigmas of pathology often attributed to those with autism and those who care for them. Or, as put by Ross, the complexity of their experience is shortchanged by descriptions of the "suffering child with autism" and his "suffering family." Despite the troubles they have faced, other

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[52] Though I was never given a chance to interview him, the Zago's other son might disagree with his parents about the effect of his brother. Both parents explained their strained relationship with him, particularly Ross who "hasn't been able to talk to him since a year ago" because of a fight they had when Ross made some suggestions about his future. Molly described the relationship between her two sons as "empty," but did not give me enough information to determine whether he might agree with descriptions of autism like that made by Kartzinel (2007) who states that the condition sucks "life's marrow out of the family members one by one" (xvi).

families and individuals with autism have sought to contest the description of the condition in terms like “tragedy” (Fitzpatrick 2009). While such descriptors are not always rejected (see chapter 3), they don’t encompass the nuanced lived experience of many with autism and those caring for them. A final example of the ways in which the pathological model mischaracterizes the experience of those who care for individuals with autism is in the language used to describe things like growth, change, and development when it is significant enough to be recognized.

In another example of how the pathological model bends the lived reality of autism to its own logic, many events that are more realistically described as learning or growth get described as “treatment,” “recovery,” and even “cure.” When applied to conditions like autism—in which people do not die and continue to develop—suggestions of non-development, metaphors of death, and reductionist characterizations demonstrate how the language of pathology can do a disservice to the lived experience of statistical abnormality. Some have argued that one of the reasons autism has been described as a pathological condition is to energize research into finding a cause and a cure (Fitzpatrick 2009). Despite the benefits that this research produces, one of the downsides is to suggest that autism is or will soon be curable (Eyal et al. 2010). Another more subtle downside is to encourage descriptions of processes that are most realistically described by words like development and learning with words like “treatment,” “recovery,” and even “cure” (Pellicano and Stears 2011; Davis 2009; Robertson 2009; Helt et al. 2008; for discussion of this with ID, see Mercer 1973:71; Waltz 2013). One of the main issues in speaking about methods for bringing about change or growth as “treatments” or “cures” is the risk of brushing over the ways in which many individuals with autism—though helped by interventions—remain atypical and dependent as they age (for examples of this, see Edelson and Rimland 2003; McCarthy and Kartzinel 2010; Johnson and Van Rensselaer 2008).

Facilitated communication—a method in which a helper gives physical support to someone with autism as they communicate through typing—is one of the controversial interventions that have been pitched in the past as a "treatment" for autism (Berger 1994). Though the controversy around facilitated communication has cooled down since it was first brought to the attention of the newspaper reading public, it still serves as a useful analogy for the complexity that surrounds other interventions that have since come to be described as treatments for autism (e.g. diets).[53] While these various techniques can be used to bring about a degree of improvement, to describe them as treatments—language

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[53] A very sophisticated discussion of the complex effects associated with diets and other interventions is provided by Charlotte Moore (2004) in her fabulous book *George & Sam*: "A year later, when Sam was seven, a lot of publicity was given to secretin injections [. . .] I wouldn't feel justified in injecting them with anything about which so little was known. But Sam's condition at that time had deteriorated so much that I'd have tried almost anything [. . .] And though no miracle was worked, Sam did improve after secretin. It's hard to be very clear about its effects, because I'd removed the gluten from his diet a few weeks before, so I'm not sure which improvement to attribute to which treatment [. . .] After secretin (and gluten removal) Sam immediately started sleeping through the night [. . .] It's hard to discuss treatments we tried without sounding evangelical, either for or against. I can only reiterate that every autistic child is different, and that what suits one may do little for another [. . .] Speaking entirely from my own experience, if I had my time with the boys again, I would put them on the diet, and start an ABA or Verbal Behavior program as early as possible. Autistic children get set in their ways; it's best if you can point them in desirable directions. The later you leave the intervention, the harder your struggle will be" (120, 121, 126, 127). While Moore's comments clearly demonstrate the help and improvement that can be supplied by interventions like diets and education, her work is also very clear about the reality that despite the improvements, learning, and growth, both her boys continue to have autism.

associated with the pathological model of abnormality—can easily shade into suggesting that they lead to a dissipation of all challenges associated with the diagnosis, in short a cure. The experience of Miller Lee and his family with Facilitated Communication (FC) is a powerful example of the complexity that characterizes something which some commentators might jump to describe as a miracle:

> Jack: And so I think, you know, I had, I think I had said to her 'I would love to try this [facilitated communication] with Miller,' and so she [representative from a state sponsored cooperative whose mission is to create favorable opportunities for people with developmental disabilities] just let us know that he [another representative] was coming. Well, I saw Miller focused and into it [. . .] He wanted to do it and that's kind of mindboggling [. . .] And so they first were having him just point to like pictures like day and night and that sort of thing because they wanted to see can he respond to symbols or whatever [. . .] It was the first campaign, the first election of Bill Clinton and they asked him who are you going to vote for, for president and he typed "I don,' d-o-n, and then he hit the eight. Well, on a lot of keyboards in the old days, above the eight was the apostrophe and so I don't know and then he stopped and then the guy who was with him said 'are you finished,' and he [. . .] I mean, for a kid like Miller who has plenty of self-stimulatory behaviors and all of that, even more then than I think he does now, he just was so focused and so happy to, and so that's how it started [. . .] he resists lying on his belly and the OT [occupational therapist] person uses facilitated communication with him and he basically said, "I have to see where I am, and so I don't like lying down cause then I don't know where I am." And, I mean, he's never slept on his belly [. . .] One of the things Miller will do is we'll get to the end of a sentence or we'll take a break and my computer, well you can set it up different ways, but it'll say each word and then you hit the period and it'll read the sentence and speak the sentence. And if I drop my hand away or if Miller pulls back, he'll reach to the keyboard and he'll hit a letter and the interesting thing is it turns out to be the first letter of the next word [. . .] You know, where I resolved that there's the academic controversy in the research and that's fine, well and good, but facilitated communication is a grassroots phenomenon and in some sense it almost doesn't matter where the academic conversation comes out because it is so practically useful to know that Miller would prefer beer or wine and, you know, you can ask

him questions and you can get an answer and you can act on it and it floats.[54]

Jack and Vale have decided to invite their son Miller to join us for dinner; this will give Jack and Miller the opportunity to show me FC, and allow me to ask Miller some questions. Before Miller arrives I tell Jack that I am skeptical, and so will be closely observing the FC communication in order to find evidence that the words being typed are actually derived from Miller's efforts. We set up in Jack's office on the second floor, Miller sitting to my right, and Jack to the right of his son. I watch as Jack supports Miller's right wrist in the nook between index finger and thumb, allowing his son's pointer finger to bob up and down above the keyboard tapping away at letters. The Macintosh desktop is opened to a program that speaks out words typed once they are completed, and as his finger pokes the keys, Miller's left hand braces the edge of the desk. At times he licks the finger he types with, and/or rubs his eyes with it, his head rocking back and forth, just as often as not looking at the keyboard, as a stream of light noises emanate from his mouth (a flutter of a sound from his throat that sounds like a light wheezing mixed with tongue taps against the pallet). While I watch I think of reasons that make me question whether this conversation is controlled by Jack: 1) why earlier in the day when FCing with a staff person did miller only say "hello"; 2) why, if it is Miller composing these sentences, does he need so much support from others to write; 3) why, if he can communicate so clearly, does he still act so atypical in public settings (e.g. when I watched him grab soda from a refrigerator at a fast food restaurant, spilling it all over the floor, even though his staff person said not to.). But then again, I realize many things that seem to support it: 1) Though I struggle with Miller when he allows me to FC with him, it makes sense that such an intimate interaction would require some practice; 2) I learned from interactions with students in a school for autism and documentaries (e.g. the film Autism is a World*) that people who behave just like Miller have learned to type first through FC, and later learned to type independently; 3) Many of the things that Miller says to his father are embarrassing, controversial, and surprising to Jack in a way that seriously undermine his being the one to pose the question (several times Jack says things like, "huh!" or "oh, that's interesting"; 4) The intensity with which Miller looks at me directly in the eyes for periods while he was typing (something he did not do at any other time on our visit) suggests he is focused on communicating with me; 5) the reality that Miller got up during the typing, went to the bathroom, and then quickly*

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[54] Jack and other parents I talked to who use Facilitated Communication did share examples with me of other cases of FC where they questioned whether the disabled individual was actually responsible for the text being produced.

> *returned to his seat as if he had more to say (if he wasn't in control, why come back?)*
>
> Vale: Well there's another whole category of things in terms of FC, is stuff that the person wouldn't, the facilitator wouldn't want to bring up or they wouldn't want to use in a context. Well I remember, I'm thinking of Maggie (a family friend). Maggie is a lesbian and one of the things Miller said with her was, "is God okay with your lesbianism?" [. . .] And another time he said, "why don't you have sex with me?" [. . .] Maggie says, "well, I'm a lesbian and lesbians don't have sex with men. It's nothing personal." [I am also told of an incident in which the parents of a roommate of Miller's were disabused of their doubts concerning FC when their son reported that his ear was aching, and then a visit to his primary care specialist confirmed it to be true].
>
> Ben: Can you tell me what it was like when you started to type?]
> Miller: bbg it was like getting out of jail. it was freedom. it was like finally exiised.
> Ben: Tell me something you were very happy to share with your parents.
> Miller: that i loved them and was sorry we hadn't been able to be ffriends, only ddisabled kid and caaregivers.
> Ben: Tell me something people would be surprised to know about you?
> Miller: that i follow the news espevcialkly politics. i know what the parties mean and that tthe president and governor and legislators can do to make my life possible in the community.
>
> Jack: And he did say to me, I mean, I asked him about, you know, did you understand what, did you understand people's speech and what people were saying and he said 'no, when I was younger, I didn't. I could not make much sense out of what they said' [. . .] And he says he learned to read by watching television.

Learning to type out his thoughts with the help of a facilitator represented for Miller and his family a pretty stark transformation. Before he was able to do this, his parents and others around him had no idea how much of his environment he was aware of. Once he began to communicate, it helped shape the way that those around him acted, serving instrumental (we know if he wants wine or beer), social (I follow the news), and emotional (it felt like I existed) needs.[55] And it might be seen as miraculous: here is an individual who comes across as very atypical who, all of a sudden, is speaking about things that no one ever suspected he understood. Indeed, for those who find the transformation questionable, my own notes and the work of others who began as doubters attest to the reality that doubt is normal *and* that, despite pushing credulity, there is considerable evidence that many who do FC are in control of it (Biklen and Cardinal 1997; Wells 2006). And yet, what can get lost in discussions of whether or not FC is real and how miraculous it seems is the reality that someone like Miller remains considerably disabled (indeed, the degree of his atypicality significantly contributes to the seeming miraculousness of his communication). A line in a 1994 *New York Times* article demonstrates: "But Jenny had become the study of a new treatment for autism that, depending on one's point of view, is either a miraculous way to lift the silence in which most autistic children live or an 'emperor's new clothes' delusion" (Berger 1994). While this article is careful to note the controversy surrounding FC, in using the language of pathology—FC as a "treatment"—it also represents what Mercer describes as "referring to one with the model of the other." Treatment fits FC into the death vs. cure dichotomy, suggesting the question "does it work, or doesn't it." At the same time, it undermines asking the question "even if it does work, how atypical does someone like Miller remain after learning to do it?" One might argue that this focus comes from talking about autism as a pathological condition as opposed to a statistical difference. The issue with this is

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[55] Miller's comments suggest why metaphors of death are so attractive: he describes feeling like he was in jail or non-existent. However, it is important to note that there is a difference between feeling this way and describing autism in the public sphere in ways that characterize those with autism as if they don't develop and don't exist.

encouraging us to ignore the fact that—though FC has been very helpful for Miller—it has not meant that his atypicality and dependency have just gone away. And this is a reality that his caretakers—like all those in my study—will continue to face as they focus on what the future holds.

PREPARING FOR DEPENDENCY

Though the language of pathology often mischaracterizes the complexity of the lived experience of caretakers of adults with autism, the challenges that are faced when trying to care for someone who remains significantly atypical and dependent are considerable. The language of pathology can suggest that individuals with autism do not develop and do not grow up. It can also suggest that they and their families are fundamentally tragic, broken, or sad. However, individuals with autism do develop and do grow into adult men and women. Moreover, as opposed to behaving in ways that suggest pathology (as older psychodynamic theories of autism suggest, see Bettelheim 1967: 69), families are vital to the social integration of those with autism and remain central to their outcomes—as "caregivers, advocates and, too often, the only party with the autistic adult's best interests in mind" (Greenfeld 2009b:32). Of course, any critique of the pathological model of abnormality must make note of its many uses and valid points. Beyond scientific research that attests to the degree to which autism is based in biological difference (e.g. distinct cognitive patterns, neurological and genetic abnormalities), is the reality that families of individuals with autism admit to the complex and challenging experience of caring for those who are significantly atypical and dependent (Frith 2003**;** Grandin 2006; Greenfeld

1972, 1978, 1986; DiCicco-Bloom et al. 2006**;** Silverman 2012). For example, repetitive behaviors, communication issues, challenges with social interaction, and a variety of maladaptive behaviors—in other words, significant atypicality or deviance (see Chapter 3)—can all suggest at least some validity to describing autism as a clinical entity. And yet, caretakers also lament the ways in which the pathologizing of those with autism in their lives causes public discourse to brush over genuine development and learning.[56]

As we saw above, another cost of the language of pathology is to convert what is often better described as development, growth, and change into treatment, recovery, and cure. In her critique of this move, Park (2001) states that the issue with giving people the "success story everybody wants to hear" is that you can start to lose grip on the challenges of the lived experience of continued atypicality and dependency. For this, Park (2001) provides a relevant antidote in a section of a memoir about her daughter with autism's adult years:

> A description of autism must be anecdotal; without anecdotes there are words but not experience. Anecdotes must temper our yen for the miraculous, keep the account honest. Without them, Jessy's slow progress takes on too much of the aura of the success story everybody wants to hear. Suppose I say what is entirely true: that she has worked, rapidly and efficiently, for twenty years [. . .] that she is hardly ever absent and never late; that she pays taxes; that she keeps her bank account accurately to the penny [. . .] That she is a contributing member of her community and of her family. Who wouldn't hear, behind those words, others: "miracle," "recovery," "cure"? Reality escapes between the lines. Anecdotes must recapture it, as many as I can cram into these pages, not for decoration or liveliness, but for truth (25).

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[56] For a great example of a parent writing off as a "repetitious monologue of meaningless speech" one specific act that actually represented learning can be found in Hart (1989:191).

Though Jessy Park has done considerably well in comparison to many who have significant forms of autism, her mother points to the reality of continued atypicality and dependency despite her vital presence and growth.[57] Thus far, this paper has sought to demonstrate the damage done to the lived experience of atypicality rendered by the pathological model of abnormality. However, it is possible that caretakers would agree that the biggest issue with the language of pathology is the simple reality that it brushes over the degree to which conceptualizing the future is a fundamental part of what it is like to be responsible for someone who will likely remain atypical and dependent for the rest of their lives (Johnson and Van Rensselaer 2008; Frankland 1995). Or, as summed up by a simple question: “who is going to take care of this person after I am gone?” (Donvan and Zucker 2010; Naseef 2013). At first glance it might seem a bit ironic that for all of the concern drummed up by the language of pathology, the reality of continued needs throughout adulthood is covered up by the suggestion that those with autism do not develop and do not continue to exist. Statements by some parents hint at the psychological realities behind some family members being the stakeholders partly responsible for talking about autism as if it cleanly fit the pathological model of abnormality (Fitzpatrick 2009). For example, speaking about finding a strong conviction to recover her child from autism, Karen Seroussi states (2002): “the most difficult and trying thing in my life was no longer fear about Mile’s future, but the daily question of what he should eat” (106). In a memoir, Josh Greenfeld (1986) states the psychological

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[57] Since she doesn’t and will never live independently and continues to have a diagnosis of autism, Jesse does not qualify for the “optimal outcome” described in recent research, (Feign et al. 2009).

and emotional dynamics more clearly when he says: “Foumi still talks of starting a school, establishing a group residence [. . .] I guess all that’s down the line [. . .] meanwhile I live in my Peter Pan dream, enjoying the Noah who will never grow up” (124).[58] However, as we know, individuals like Noah do grow up, and do have a future. In order to explore the challenge of continued atypicality and dependency for those caring for individuals with autism without relying on the language of pathology, the rest of this chapter will explore how the pain associated with the future is linked to significant tension between modes of future orientation.

In the tug of war between potential and the likelihood of continued and significant abnormality, we see how the conceptualization of alternate trajectories animates the lived experience of caretakers of adults with autism. Despite being couched in the language of pathology (e.g. “symptomatic improvements,” “symptom abatement”), recent scientific work has expressed the reality that most individuals with autism develop and learn as they age (Levy and Perry 2011:1272; Seltzer et al. 2004:234). This work has given credibility to the idea that development in autism is not a mirage, but a valid—if complex, and uncertain—reality. Though this growth usually occurs in seemingly less romantic form, examples of stark breakthroughs, enticing cases demonstrating the potential for growth, are hard to ignore for the possibilities they suggest (Fountain, Winter and Bearman 2012; Helt et al. 2008).[59] Yet, the reality that continued atypicality

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[58] Greenfeld (1986) goes on to say “I mentioned the whole business of living without a future to a friend. ‘But you have to have hope,’ he said. I’m not so sure. I think you have to have guts” (124).

[59] Recent research has chronicled a sub-group of individuals with autism who—though diagnosed as having the condition when young—age out of the diagnosis (often into

and dependency are relatively common—even when such breakthroughs occur—is partly responsible for the empirical patterns that allow caretakers of individuals with autism to experience tension between alternate trajectories. As reviewed earlier, Miller Lee's performance with FC was a revelation to his parents. Their surprise was similar to others who have learned that some people whose behavior suggests otherwise are actually quite self-reflexive and, with the right support, able to communicate (for example, Mukhopadhyay 2011; Hacking 2009). In the aftermath of Miller's newfound abilities, Jack started to talk to his son about a variety of different issues. However, the mismatch between the desires now being communicated and the reality of Miller's continuing atypicality and dependency in the future introduce more complex tensions for his parents and other caretakers:

> Ben: Tell me what you'd change about your life if you could?
> Miller[60]: I wish the state would stop fucking with my supports. but he can't read [speaking about the governor] i would likke to get ba new job and have girlfriends. I don't know how to find a girl friend. i can't hang out in bars with aastaff person unless they can help me type. i'd love to vconnect with a woman who wouldd fc [facilitated communication] with me. i have enjoyedd kelly who use to work with me and did fc. and shed is gone I woulld to have a non staaff friend. maybe i could do something online, but i'm hesitant. i don't do email that much. it takes a lot of energy yo use thje computer. maybe ben the pvrn who helps me do email could help me do some bloggging or something. i know this is up to me, but I get cold feet. maybe i should get some kind of goal to make this part

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other clinical categories, like ADHD, OCD, or generalized anxiety) (Helt et al. 2008). It remains to be seen whether the best way to describe this group—as Helt et al. do—is as a "recovery" group. Others have described the "optimal outcome" as those who eventually 1) live independently, 2) work full-time, 3) get married, and 4) have friends.

[60] Conversations with Miller were typed by him with his father (Jack) acting as facilitator. Specifically, Jack sat next to Miller and supported his wrist according to the Facilitated Communication method. My questions were asked out-loud by me, and then typed into the computer by Jack so that there would be a record of them along with Miller's answers.

of my daily life. very glad you asked. i am going to send alison an email. tonight

Vale: He wants a girlfriend.
Jack: At our last [services] meeting, they were asking some formal questions, and one of them was 'are you satisfied with your services?' [laughing] and he typed, he typed 'yes, everything but a girl friend.' [. . .] [the service provider responded] 'well you're on your own for that.' [. . .]
Vale: but Miller doesn't even masturbate. So I don't even know what the poor guy.
Jack: Yeah, well, I don't think his, ah, wiring is, is, typical? [. . .] and, when he was adolescent, and he would get erections in the shower, and ah it's like he would, ah, stimulate himself a little, but then it was like, maybe it's too much [. . .]
Vale: He thinks he would like to have sex with people he is attracted to, it's just that I'm not sure that he [. . .] well he knows what's involved, you asked him.
Jack: No, I did that. Yes, the man puts his penis in the woman's vagina, and then he takes it out [laughing] [. . .] I, uhm, we did, we hired a sex worker, or a sex therapist I guess she would be considered [. . .] to see if he could learn to masturbate, because we thought that this might be [. . .] uhm, yeah, she, it, there wasn't, we didn't have enough money to hire her for long enough for her to learn to communicate with Miller [. . .] I mean, it just, just practically, we couldn't, we couldn't do it, and, and her first attempts, uhm, just didn't go [. . .] and realizing that unless she would learn to, to, FC with him, or, you know, develop some way to communicate with him.

Ben: Can you tell me how people like your staff learn to do fc correctly with you?
Miller: they have to trust me to be high functioning enough and be willing to[practice with me. i get a rythm after some time with a person. you did well for a first time. edverybody end up with a different style with me. i try to tune in to them and good partners tune into me. i'm not sure but maybe relax more. that's harder at the beginning partly because i'm tenser too and feel like I have to try hardeer and i'm not yet familiar with your touch. some times i can tell they are tired or upset about something. it helped tonight tha you act like a fridend and not a staff who is worried aaboutt being evaluated forr how well we do. yes we are.
Ben: besides dad who is most in tune with you doing fc.
Miller: grace whitney, then bill oaks thhen on staff now barnes then alfred then vanessa. she has great promise. i ghave tried with alison and maybe we'll maake it. she is not that comfortable getting close. there is a bonding in the best partnerships. i'd like that. yes. i know it is late and

> mom promised dessert. so let's quit and maybe you can visit me again. i hope so. talking with you has been a blast.cool. now dessert.
>
> Miller: have him typing my wilder ideas like watching naked ladies on the web. noot as much as i hoped. only in magazines. bess w. got me a hustler to distract me giving bloodf at the hospitasl. It worked. I enjoyyed looking at the women for sometime. i bought another one. but not recently [*I ask him whether he would want to have sex with someone*] i guess so but i don't know what that looks like or how it really works. i can't really connect that to me [. . .] there was a woman who trierto help me but i ddidn't get whazt she wanted me to do and she couldn't ttype withe me. i don't think staff wants to touch this topic].
>
> Jack: I would love for him to find a [. . .] typical female who would get off on the intimacy of an FC relationship with Miller.
> Ben: And can you imagine that realistically?
> Jack: I can imagine it but…I can imagine another human being finding him interesting and [. . .]
> Ben: But, I mean, I was going to ask whether that could…
> Jack: Could be a sexual relationship or something [. . .] or a romantic relationship, I don't think Miller can go there[61] [. . .]

Over the couple sessions I attend in which Jack facilitated his son's typing while I asked questions, Miller expressed a variety of reactions to his daily life: disappointment with recent cuts in service funding, and the politician who brought them about; the individual characteristics of service staff that FC with him on a daily basis; who was best at facilitating, and the importance of interpersonal dynamics to successful FCing. While FCing, Miller also shared a variety of desires he has for the future: to get a new "job and girlfriends,"; to integrate "e-mail" and "blogging" into his daily routine; to FC with people other than his support staff. Focusing on the most challenging, Miller's desire to

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[61] While Bianca has expressed interest in other people having babies (she wanted Joan to have a baby, saying "you have baby now"), to the best of their knowledge she is not interested in having a baby herself or a serious relationship. Of course, though she is verbal, Bianca does not answer direct questions with the degree of reflexivity that Miller does through FC.

have a girlfriend fits with what many might describe as a cultural narrative or even something as naturalized as a plan (a temporal structure). Though not unaware of the external ("Staff would need to FC with me in the bar") and internal ("I get cold feet") hurtles involved in finding a romantic companion, the way that Miller talks about it ("I would like to have girlfriends") still puts it forth as a desire that he has thought about and, at least in conversation, a project that he believes is achievable. While Jack describes the possibility that some people "would be interested in a human like him," he speaks about the many ways that the degree of Miller's atypicality and dependency will complicate achieving his son's goal. Though Jack has learned the interpersonal and protensorial (given the anticipation required) skills required to FC with his son, the imagined trajectory that Miller puts forth seems to conflict with the trajectory believed to be more realistic by his mother, father, and support staff. This is not to say that Jack and Vale don't want to support the trajectory that Miller envisions (as Jack's comment, "it would be great for him," shows); but rather that the financial and temporal resources required to accommodate his atypical communication, and questions as to his sexual functionality (of which Miller is not unaware) make coordinating a relationship difficult. Though the particularities of this case allow us to compare an individual with significant autism's own thoughts about trajectory with those of his parents, in most of the other cases I explored—since individuals with autism were unable to comment in depth—thoughts on competing trajectories were played out entirely in the anticipations and conceptualizations of caretakers. This limitation did not dampen the reality that tension between competing trajectories was usually the norm.

By organizing the experience of autism around tensions between and within modes of future orientation, we find that one obstacle facing family projects seeking to provision care for those with profound and constant needs is cultural narratives concerning what we owe the atypical and the dependent. Despite the development that characterizes those with autism and the gains associated with some interventions, most people diagnosed with the disorder as children continue to qualify for the diagnosis as adults. Moreover, "childhood IQ" and "early language development" are still predictive of the degree of adult impairment (Levy and Perry 2011:1273). Thus, the reality faced by most caretakers is that individuals with severe forms of autism will remain atypical and dependent, and finding people and organizations to provide the supports they need is a goal that is as pressing as it is challenging. Though Miller and Bianca Lee have experienced important development over the course of their lives, they both have significant cases of autism and are dependent on others for a variety of things (e.g. housing) and activities (i.e. navigating the social and physical landscape). While at present there exist a variety of options (albeit, in high demand, with long waiting lists, and in the context of diminishing public funding) open to families trying to provide shelter and care for adults with autism (e.g. group homes, large residential settings, adult foster care, nursing homes), Jack and Vale took it upon themselves—in cooperation with several other families—to buy a pair of houses in a residential neighborhood where their adult children could reside independent of their families (Miller lives with two other men, and Bianca has one female room mate). A precedent forming action on the part of Vale, Jack, and these several other families decades ago allowed for their children's services to be funded by a program originally designed for individuals with severe brain injuries whose needs are determined to be at the "institutional level." It is part of a larger family of programs (available in many states) that provides community-based supports funded through a combination of state and federal funds. This program is called the "waiver program" because it allows the state to waive some Medicaid rules (e.g. placing persons in settings that qualify as "institutional") so that individuals and caretakers can have more choices about the services received and how they are provided.[62] Despite the early success and decades of state support secured by the Lees and the other families involved in the project, a recent decision by the state to cut back on services has put the project in jeopardy. Though Jack, Vale and the other families (and, as we saw from his typing, Miller as well) lay much of the blame at the feet of the new governor and his advisors, they are acutely aware (as are all caretakers of those with significant needs) of the dangers posed by the government cutbacks that have and continue to occur in the wake of the 2007-2008 recession. Calling themselves the "Phillipstown Four" after the neighborhood in which the two residences are located, the Lees and the other families have filed a lawsuit in order to preserve what they believe to be, despite other options, the right trajectory for their children:

> Vale: Well I think you have to work with individuals situations, but I wouldn't want to be advocating to create any more (secluded residential settings) [. . .]
> Jack: There are people who want farms [. . .] and are developing farms and maybe, certainly somebody who's grown up in a rural area might…
> Vale: Well I think though there's a feeling that with many families their feelings is this kid's just going to embarrass themselves in public and they

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[62] Securing waiver funding and just how difficult it is now becoming was a popular topic of conversation among many of the families I spent time with.

just need to be in the environment where they're sort of shielded from all that [. . .] Well that's a very tempting belief but I think it's a mistake because I think you really are safer [. . .] in a typical setting and I, because it's in isolated situations where weird stuff can happen and the public or generally people don't know about that [. . .] And I think we had some pretty tough run-ins in terms of our kids in terms of stuff that was happening where the provider wasn't doing a very good job, in terms of police getting called, hospitalizations, things of that nature, uhm, and my poster child for that would be the people who live right next store to Bianca. It's a little, tiny twin house and while we tried to enforce the wall, you can still hear what goes on if people get really loud, you know. And they ended up pulling their hair out, in fact I think they ended up calling the police, and they tried to document Bianca's screaming and they said she was breaking the peace and all this stuff and cited her and we had this meeting with the police chief and all this stuff [. . .] [the neighbors were at their wits end] and if the previous provider didn't know what to do, they just kind of ignored it. So in connection with this meeting with the police chief, Jack said, "well if she's screaming, you call me. Here's my phone number," and Paul said, "oh well you're not going to answer the phone." And [Jack] said, "no, I'll hear it. I'll hear it, you know. It's in the other room but I'll hear it." And so he called him a couple times when she was screaming and Jack picked up the phone and then talk to Bianca and kind of intersected it [. . .]

Jack: The Nantels [Bianca's neighbors] are now advocates for those two women [Bianca and her roommate]. They will tell you if a staff person treats them disrespectfully, I mean [. . .] Roxy will say "that staff doesn't treat them with respect."
Vale: She's always known who was good and who wasn't [. . .] They're a good example of normal community people but when they're unhappy and are really pissed off it's because things are b-a-d, bad and if things get better [. . .] they'll be happy [. . .] She's safer and there's people who are watching [. . .]
Jack: There was a fire at Bianca's house and how did that happen [. . .] The fire department in Phillipstown basically said "well, we think this was, you know, it started out," it was an outside house fire on the back deck and so they said it was accidental probably smoking and staff basically said oh no, no, no, nobody's smoking here [. . .] Actually Paul Nantel has told him [the fire chief] that. He didn't want to rat him out so

> they just waited. In other words the neighbors said yes staff smoke on the back porch and they put their cigarettes out.[63]
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> *Over the course of my time living with the Lees they lay out to me some of the challenges they have faced because of the cuts in funding that have recently gone into effect across the state. As Vale explains to me in reference to some struggles her son has had at his supported employment: "At that point, the house manager was just not up to the job and there was just, it was just, it was part, it was all part of this after the service cuts took effect, everything at the boys' house kind of melted down because people that needed to be involved, that had some skills, weren't there anymore and the supervisory people were stretched thinner and it just all kind of came to a bad outcome. Anyway, sometime in the fall, Miller had a wetting accident and Carolyn did a kind of intervention [. . .] Miller says, 'I want to do the job my way,' and he described what that was [. . .] Rather than doing the part he appeared not to be able to do, which is often the typical job coach shtick, Kelly had discovered that what he liked to do was sort of like stomp on the boxes and break the, and break the tape [. . .] And so, it would appear in hindsight that [the job coach] didn't get the message or couldn't figure out, you know, I don't know. Anyway, there was another incident I think involved soiling as well as wetting, and I think it was a combination of him not realizing he needed to go to the bathroom plus Miller saying, well shit on you essentially, because that is a strategy that people with severe disabilities use to get out of things that they really don't like." The Lees also tell me in detail about the lawsuit that they are bringing against the state, since the level of funding that is being cut is undermining the operation of the homes. They explain to me that the homes have been a model that they have tried to spread to others—through their participation in several advocacy organizations—and they've "done all this work, and no one is paying any attention to it. Other parents want their kids to live on a farm in east jesus, [state] [. . .] there have not been a lot of people, parents who have said, 'this is what we want to do, show us how to do it…'"*

Vale and Jack have worked hard to secure funding from the state for their children's services, buy homes for them to live in, and all in a situation that allows their kids to reside in the community—an outcome that is central to their beliefs about what is best for

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[63] Though Jane Jacob's (1989) concept of "eyes on the street" was theorized in relation to urban settings, these comments would seem to suggest that this is one of the potential values of placing the atypical and dependent into suburban settings as well.

Miller and Bianca. This is a project that they have worked hard to accomplish, and for a long time they envisioned it as a model that others could and should pick up on. However, despite feeling that their model is superior to other options[64], they have struggled to get other families interested. Moreover, challenges to the model have always existed ("screaming, hopsitalizations, police getting called"), and, as Miller's recent soiling incidents demonstrate (caused either because of frustration, motor control issues, or a combination of both), continue to emerge. Finally, despite the success they have in instituting and supporting their model in the past, fiscal tensions in recent years have created a new narrative around state support for the atypical and dependent (Edsall 2012**;** Leland 2010). Thus, despite the trajectory that the Lee's have envisioned, contingencies continue to emerge that suggest that other trajectories for their children (being placed in more restrictive settings, as per the state's wishes; returning home to live with Vale and Jack) may still become a reality. The lawsuit has only made more clear the reality that the Lee family exists in a protensorial state that uncomfortably flits around a variety of different trajectories: which of those trajectories will ultimately prevail is a question that nags all members of the Philliptown four. While other families have not taken the same route as the Lees, all have experienced what it is like to live with a level of tangible uncertainty that is part and parcel of the challenges of imagining and creating a future for adults with autism.

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[64] I should be pointed out that others in my study had children on farms, or created these programs; others also had individuals in residential settings, or classic group homes. And there are examples of all of these that people were very happy with. I also know of examples that were less than admirable.

While battles between family projects and the narratives of the state are most easily described as tensions between trajectories, at other times the issues that families face are more rightly described as tensions between trajectories and the larger temporal structures which suggest where the atypical and dependent belong. Starting in the mid-1800s, individuals with developmental disabilities like autism were placed in institutions. These institutions were often situated in rural areas, away from large populations. It was common for doctors, family, and friends to suggest upon the birth of an atypical child that the child be place in "an institution that can care for them" (Trent 1994: 233; Donvan and Zucker 2010). During the 1960s things changes: deinstitutionalization and the "community mental health movement" brought about the idea that individuals with mental illness and developmental disabilities should be moved back home and into the community (Grob 1994; Eyal et al. 2010). However, the promise of community mental health and the reality have been quite different. While this change helped create special education (since children were moved from institutions back home [see Eyal et al. 2010; Eyal 2013]), the move also brought about the challenge of integrating the significantly atypical. Though this population was around before large institutions starting housing them in the 19th century, by the time they began to be closed in the 1970s the changes to American society were considerable. Finding jobs, a place to live, and people to care for them is a challenge that all those responsible for adults with autism continue to face. In their experience with this, the Zago family demonstrates through stories and interviews the challenges:

> *When Martin was 21 (right after graduating high school) he got a job at a big-box store "fronting" shelves (a task in which an employee arranges*

merchandise into appealing rows, making sure that products are positioned as close to the front of shelves as possible with labels facing forward). Molly explains to me that Martin loves this activity, having first learned to do it in a vocational program connected to school. Indeed, when accompanying his mother shopping Martin will front shelves for free – Molly tells me with pride that, on busy days, a local clerk at a store they frequent will ask "I am really busy today, can Martin help me?" Soon after beginning at the big box chain, he was offered a job at a small, local grocery store by the store's manager. Though he did relatively well at this job for a while, one day he approached a customer and asked her when her birthday was. In response the customer went to the owner of the store (who happened to be in that day), and said, "people like that shouldn't be out in public" and the owner fired Martin on the spot. Though they were upset (he didn't even call to let us know until Monday; and left us wondering all weekend why Martin was saying "needs new job, doesn't work here anymore."), both Ross and Molly expressed some ambivalence about whether it was such a bad thing. Molly tells me that Ross struggled with down time ("he would start pacing and getting in people's way, and they would call and be like 'he's pacing' and I would say 'he probably doesn't have anything to do'") and with anxiety around pleasing people ("that is what he works for" and "he just calmed right down after losing that job"). For his part, Ross thought about suing the owner, but appreciated that at least "they were giving handicapped people opportunities." Moreover, Ross expressed ambivalence about the public money spent on supporting a job coach to work with his son all day ("there again, for him to work, they had a coach, the coach stood there, so that's kind of counterproductive to society, to whatever he produced") but also feels ambivalent about wanting more for his son.

Ross: My mother was afraid of him. Her idea was put him in an institution and go along with your life, but that was thirty years ago and she was older too. What did blind people do? The blind girl I knew when we were growing up, weaved carpets. That's what blind people did. That's how it was. Downs was nothing. It was just considered totally retarded and useless. Look what Down's kids do today. It's fabulous what they do. It's just amazing [. . .]
Ben: Can you tell me a little bit about how you think about the future?
Ross: I'm in la-la land. We haven't faced it. We haven't. We're just going to wait until one of us gets sick or who knows what. I think part of it is from watching in [last state they lived in], but I understand here it's as bad, the waiting lists are so long that it's almost irrelevant anyhow. They take them when the second parent's unable to care [. . .] I don't know. I'm not ready to not be with him. I like him too much. We enjoy him. To me, he's pleasant. He's funny. I don't know that I'd want to sit here and think,

is he sitting somewhere, what kind of dinner did he have. They're not going to let him run the mower. I know they're not because no matter where he is, the risk for liability would be too high. Seriously, I haven't thought about it but I've even been toying with the idea of giving this property to the state as a group home for him because I know a lady in [last state they were in] did that [. . .] I've also toyed with the idea of buying another house, a little house somewhere or maybe a little two bedroom modular for us to move into when we're elderly and let him stay here. [. . .] [One lady I know placed her son in a group home, and she said to me] "I raised him to twenty-one; I'm done with him. I did my job. Let the state take him." Now, [this woman] will come to horseback riding and visit [her son]. She comes and gets him and takes him to dinner but she had, I think, nine children, but she felt they should make that break, and some ways, it would be better if we did it now or when we're seventy so we would still be alive that we could do that, we could go get him, take him to dinner and he could get adjusted to not living in our home. Because of that, I lean toward putting him in a home at some time, but like I said, now, as long as we're able to ride the bicycles together and he loves to mow the grass and shovel the snow and all this stuff, I'll see.

Ross shares a story with me about his involvement in a local dispute concerning a group home for adults with autism. Several weeks before I visited, a private for profit organization announced its plans to build a house in a nearby residential neighborhood. At a township supervisors meeting, some residents expressed upset at the plans. Days later, one of these resident published an article in a local newspaper in which he stated that: "I have never thought that two autistic young men living under professional supervision next door would adversely affect my property value by much if by any at all, but I do have a serious concern that the commercial operation of a for-profit organization like [company] could. Interestingly, our neighborhood covenant states that the 'premises may not be used for commercial enterprise,' but this issue was never raised in the meeting [. . .] Since federal and state legislation mandates this type of accommodation for individuals with a disability, if I do suffer financial loss from this real estate transaction, I will then be one property owner randomly singled out and indirectly forced to pay an additional penalty for a problem I did not create simply because I bought my house before this situation arose and could not there for do anything to avoid it." Martin was outraged after reading this. He explained to me that of all people, this professor, who, by his job title, he believed should have been more enlightened, was organizing this smear campaign. Particularly infuriating to Martin was the fact that the professor actually rented rooms in his house to others, enough so that "he was, technically, breaking the same law that he was supposed to be enforcing." One of the individuals

> *that was to live in this house was a young man that Martin knew. Another thing that shocked him was some of the other comments that came out around the issue. One individual—on an online forum where people could write in about any local topic—had stated something to the order of 'who cares about people with autism, they are nothing more than the result of drug dealers and alcoholics"* [this would be degenerative thinking rearing its ugly head]. *In a response letter written by Martin and printed in the paper, he wrote "These are not drug addicts and child molesters. Autism is not contagious. The neighbors of this home will most likely never have their house shot with paint balls or their mailbox jammed full of snow [. . .] Two unrelated people cannot occupy a home in [town]. No unmarried couples? No gay couples? Seriously? [. . .] My son is severely autistic. He said his first words at age 9 and three-word sentences by 11. He did have his share of tantrums. We were informed by one professional that around puberty, he would either become uncontrollable or he would start to become a gentle man. That he is. Happy, loving, compassionate, obedient, curious, intelligent, a joy to all who meet him."*

Contained in this long string of field-notes and interview excerpts is the story of two parents grappling with the challenges of integrating an individual who is atypical and dependent into a society whose response to them is—at the very best—ambivalent. Throughout we see hints as to the alternate trajectories they juggle for Martin, and the ways in which they find themselves contending with the larger temporal structures that are most easily described as plans (Tavory and Eliasoph 2013). Ross and Molly were both very proud of Martin's work at the grocery store, and were grateful to the store manager who gave him a job. They viewed their son's work in the store as fulfilling a personal project, and in line with the cultural narrative (or even temporal structure) of a paid occupation that, particularly in American Society, is a normative outcome for young adults. When a customer came into the store and complained to the owner that "people like that shouldn't work here," she was tapping into what might be described as another plan: that individuals who are severely atypical should not be placed in typical settings.

This mentality fit more directly with an older way of doing things—the age of institutionalization (that oriented Ross's mother's view)—when the atypical were expected to be placed in institutional settings (or hidden from public site). Martin and Molly were furious at this; they felt their son was a great worker, and, though it went against their larger beliefs about the money spent on social programs, placed him on SSDI (because, as Martin explains, "he deserved it."). Moreover, while his son was not directly linked to the ruckus in the neighboring town, Ross felt that people like his son had every right to be in residential neighborhoods. Martin made his feelings known by publishing an article to air his feelings.

And yet, unlike the Lees, who set up an independent living situation and work for their children, the Zagos have kept Martin at home. Ross and Molly Zago give various reasons for keeping Martin at home: "he is happy being here," "we haven't wanted to think about it," "he is just a part of our lives." Molly goes on to explain that, while they were happy with his work, they both have to admit that he seems more relaxed now that he doesn't have the pressure of fitting into a job. While Ross liked his son working, he also likes the program he is now in. And yet he wonders whether there might not be anything more for his son; he also wonders whether the cost of this to society is worth the benefit. It is important to describe these thoughts and feelings as belonging to the Zagos. Other families in my study might disagree strongly with some of these assertions, and in their hard work, activism, and personal examples, have tried to shape the trajectories of individuals with autism—and the narratives and plans for the disabled in society—around differing assumptions. However, sharing both strong feelings and ambivalence, the Zagos give voice to the underlying questions that animate (or haunt, depending on how you look at it) our society's struggle to integrate and respond to atypicality and dependency. While the language of the medical model focuses on pathology and treatment, focusing on the future of adults with autism raises a list of longer more complicated questions. As the professor Michael Bérubé stated while writing about his son with Down Syndrome "For Jamie came into the world asking us a question more basic than any I've dealt with, in this book or in life: Assuming that we can even imagine a form of social organization in which citizens like Jamie are nourished, supported, encouraged to reach their full potential, why might we seek to create it at all?" (Bérubé 1998; c.f. Nussbaum 2006).

CONCLUSION

Despite suggestions and characterizations associated with applications of the pathological model of abnormality, individuals with autism continue to live and develop into adulthood; as opposed to having no future, tensions associated with conceptualizing the future are a central component of the experiences of caretakers. When applied to conditions like autism—in which people do not die and continue to develop—suggestions of non-development, metaphors of death, and reductionist characterizations demonstrate how the language of pathology can do a disservice to the lived experience of statistical abnormality and the caretakers associated with it. In focusing on caretakers coordinating care while struggling to conceive of and shape the future, we see how the experience of those responsible for adults with autism generalizes out to other conditions in which individuals continue to survive albeit atypical and dependent. One such example that immediately jumps to mind is mental illness, a category of statistical abnormality that has been the target of heated classificatory battles over the course of the 20th century. Like Autism, severe mental illness has been the target of both pathological language and utopian ideas of how various techniques offer a cure or magic bullet. While severe mental illness does create considerable challenges, to speak about those with the diagnosis as if they were not going to survive or wouldn't require life long support and care is to do a disservice to them and their caretakers (Grob 1994). While medication, for example, can be of great help, it requires sustained intake, and thus is a long-term management technique as opposed to a cure (Shorter 1997; Johnson 1990; Estroff 1985). Viewing mental illness differently than this is to perform the same type of subtle transformation from statistical abnormality to pathological abnormality that are demonstrated by the experiences of caretakers of adults with autism.

Applications of the pathological model of abnormality mischaracterize a variety of conditions that share at least some of the qualities of what it is like to care for an adult with autism. The anti-psychiatry movement had a profound influence on how Americans think about and respond to mental illness. Writers like Szasz, Scheff, and Goffman all questioned—explicitly or implicitly—whether the medical model of mental illness held water (Szasz 1961; Scheff 1966; Goffman 1961). Of course, the rhetoric they used was sometimes as extreme as that used by the psychiatrists they sought to challenge—going as far as to call mental illness a myth, undermining the experience of those who care for and work with the mentally ill (Johnson 1990). What these authors did was to seemingly question the biological bases of all mental illness, including the more extreme forms.

This was a mistake: interacting with individuals with severe autism (or schizophrenia, or severe intellectual disability, or manic depression) precludes one from thinking that there isn't a strong biological basis to these conditions (whether or not we understand that biology). Indeed, when Goffman was personally touched by mental illness—his first wife was mentally ill, and committed suicide—he described feeling bad about seeming to portray mental illness as solely based in the relations of an institution (though, and this is often ignored, Goffman does differentiate in *Asylums* (1961) between "organics" and others, though talking little about the former).[65] The dichotomy between pathological abnormality and statistical abnormality is a more nuanced way of distinguishing between the costs of applying the "medical model" to the realities of what caretakers of conditions like autism experience than to say that those diagnosed represent merely individuals that have "problems with living" (Szasz 1961). Though autism is not defined as a mental illness (it is defined as a developmental disability), the management required for many individuals with mental illness shares some similarities with caring for those with autism (preoccupation with the future topping the list). The disservice done by the anti-psychiatry movement has not been rectified as the struggles faced by individuals caring for the significantly atypical continue to be written about (Earley 2006; Davenport 2010; Jamison 1995). For as we have seen, though the language of pathology does a

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[65] "In *Asylums* Goffman usually places 'mental illness' in quotes [. . .] but once his wife committed suicide, he drops the quotation marks and refers to a possible organic roots of mental illness. David Mechanic, with whom I corresponded, wrote that after his wife's suicide, Erving told somebody that had he written it again, his book would be different" (See Dmitri Shalin interview with Samuel Heilman, http://cdclv.unlv.edu//archives/interactionism/goffman/heilman_08.html).

disservice to the reality of autism (and mental illness), so to does the idea that like classic pathological conditions autism (and, once again, mental illness) can be easily treated and cured. Instead, a large part of the work is better described as management in the context of social networks, and it is these social networks—caretakers working together—that determine whether and to what degree care and support will be provided.

Interestingly, it is in describing what has been relayed above as long-term management and care that we see how the case of autism generalizes beyond immediately clear forms of statistical abnormality. In her book on illness metaphors, Sontag (2001) complains about the ways that metaphors of illness frame those with sickness as if they were, for example, fundamentally sad or already dead. What is important to note is that the conditions that Sontag chose to look at have long periods in which the individual can be expected to continuing living (and even thriving). Heart Disease, Cancer, AIDS: all of these, as opposed to conditions that spread and kill quickly (the classic examples of the pathological model), are illnesses that manifest in more complex ways; moreover, for those who contract them, the advent of new interventions, has led to increased life expectancies to the point that pathological abnormality starts to look more and more chronic or even statistical in nature. The fusing of modern medicine, science, and technology has created changes in other conditions as well—while childhood diabetes used to kill individuals quickly, the introduction of insulin drastically changed the condition (Feudtner 2003). Other conditions include severe abnormalities, or babies born with conditions that we would not have been able to deal with before. Besides the ethical issues and complications that arise (Bosk 1992), these examples blur the boundary between statistical and pathological abnormality. We also have more clearly statistical forms of abnormality like cerebral palsy. In one example, a mother of an individual with CP states: “my child has cerebral palsy, and there are not enough programs out there. People always look at the children but never the adults. We could save so many more people with all sorts of problems, but when families can no longer care for them, where do they go? What kind of life do they have? I do not want to think of the day when I can no longer care for my child. We must learn to see the whole picture for all these people” (Fallon 2009). This mother notes the issues faced by those who continue to live and develop in the context of atypicality and dependency. Seeing the whole picture requires looking at the way our language obscures the reality of what such a life looks like. It also requires acknowledging—personally, morally, politically—that conceptualizing the future is not just an academic exercise, but a deeply personal reality for those who care for and are responsible for the atypical and the dependent.

CHAPTER 6

Conclusion

The reality that autism is neither a deadly condition nor one for which we have a generally effective cure means that descriptions of it that employ the language, concepts, and assumptions of modern medicine discourage recognition and discussion of the needs and experiences of the many adults with autism and caretakers for whom talk of cause and cure is very much besides the point. Over the course of the 20th century, medical historians, anthropologists, and sociologists began to highlight two generally different ways through which disease entities have been conceptualized.[66] The first conceptualization, the physiological, views disease as something to be primarily understood through its expression in the individual, with the cause, symptoms, course, and outcome of a specific condition predominantly determined by individual idiosyncrasy in the context of a particular environment (Aronowitz 1998; Temkin 1977; Rosenberg 2007b). The birth of modern scientific medicine in the late 19th century further energized (though did not create, as both were around since antiquity) the other, increasingly popular conceptualization of disease, the ontological. This orientation views diseases as entities that are autonomous, exist "in some platonic sense outside their manifestation in the individual," and "unfold in characteristic ways in the typical person" (Aronowitz 1998:8; Temkin 1977). The popularity of the ontological view was helped by the germ

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[66] Though this dissertation has expended a considerable amount of space problematizing descriptions of autism that try to pigeonhole it into the worldview of modern medicine, the reality that so many people—including some in this study—sometimes speak about their experience using the assumptions and terms of that worldview drives this conclusion's engagement with its concepts and language.

theory of disease, and an increasing number of relatively effective treatments for several major infectious conditions (e.g. smallpox, tuberculosis). That we have been able to discover a relatively standard cause and cure for these conditions has provided a persuasive argument that, no matter the quirks of the individual patient and their social location, the nature of disease and our response to it can, at least in theory, rely on the assumption that clear and significant autonomous characteristics are an actionable reality (Christakis 1997; Christakis 1999). The increasing routinization and bureaucracy that surround modern medicine have both relied on and further reinforced the ontological view, or the idea of a perfect correspondence between "pathological mechanisms, diagnostic categories, and disease-specific treatments" (Silverman 2012: 13). Indeed, the assumption that disease entities have standard properties is[67] one upon which insurance billing, laboratory science, medical and pharmaceutical research, and evidenced based practice all rely (Daly 2005; Horwitz 2002; Starr 1982; Timmermans and Berg 2003).

And yet, there have been many studies that have shown that even with conditions that fit most easily with the assumptions of the ontological view—those diagnoses that have a clear etiology, pathology, and treatment—if we look closely enough, contextual and sociological reality has a tendency to undermine the neat assumptions of ontology (Aronowitz 1998; Bowker and Star 2000; Rosenberg 2007a). Speaking about a historical

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[67] The distinction between ontological and physiological can be related to other scholastic distinctions like rational vs. empirical, or conventional vs. natural. In the sociology and anthropology of medicine, a very influential formulation has been that between illness—"the innately human experience of symptoms of suffering"—and disease—"what the practitioner creates in the recasting of illness in terms of disorder" (Klienman 1988:3; c.f. Aronowitz 1998; Mol 2002). The distinction is made between individual experience and the knowledge developed by biomedicine.

incident featuring a condition that easily fits the ontological view of disease, Rosenberg (2007a) states, “even frightening epidemics, such as the yellow fever that visited Philadelphia in 1793, could be construed as the consequence of a peculiarly tainted microenvironment [. . .] coupled with idiosyncrasy, which explained why some succumbed, some recovered, and others never fell ill” (3). For conditions like autism—a diagnosis that we conceptualize with the language of ontology[68], but which has no clear treatment, is (in most cases) not infectious[69], has a complex and only partially understood etiology, and is associated with a relatively typical life expectancy—individual variation presents such a stubborn barrier to finding a standard cause and cure, that our desire to do so has led to popular discussions around autism that are at best confused and at worst dishonest.

Of course, there are benefits that derive from associating autism with the language, concepts, and, most importantly, the optimism of modern medicine. These include attention from powerful actors, momentum for advocates to draw in resources, justifications for insurance coverage and educational services, and the platform and marketing for funding scientific and clinical research which, if it doesn’t find a cause and cure, does provide a better understanding of the biology behind autism (Bouder, Spielman and Mandell 2009; Eyal 2013; Grinker 2007; King and Bearman 2011; Singh et

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[68] For example, one of the reasons DSM-5 got rid of Autism subtypes, to be replaced with a severity scale, was that “the science” of autism diagnosis “failed” to support the validity of subtypes (i.e. Autistic Disoder vs. PDD-NOS vs. Aspergers) (Personal Communication, David S. Mandell).

[69] This qualification only because some cases of autism might be linked to an infectious illness in the mother (e.g. rubella) (Libbey et al. 2005).

al. 2009).[70] However, the language and concepts of modern medicine have also encouraged many stakeholders to speak about autism as if it is a condition that only children have, that it somehow stops development, that it is a threat to life, that it can or will soon be miraculously cured, or that individuals like those in my study won't need intensive support throughout their lives (see previous chapter; Greenfeld 2009b). Such conceptualizations have the potential to do a disservice to adults with the condition and their caretakers for whom terms like care, management, and support, are much more relevant to lived experience than etiology, pathology, and treatment.

Though the assumptions and goals of ontologically-focused modern medicine are the foundation upon which much of the language we use to speak about autism is built, the life-long atypicality and dependency that are a significant attribute of the lives of many with the diagnosis suggest the importance of attending to the social-contextual factors that the physiological view values. In their review of the sociological factors that contribute to the "autism epidemic," Eyal et al. (2010) provide a compelling description of how the ontological view of autism is out of sync with the physiological reality of those with the condition, particularly as they and their families age:

> With a great deal of resources and effort now dedicated to early diagnosis and early intervention in autism, those with other diagnoses (specifically mental retardation), those who are deemed too impaired, and also those

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[70] According to King and Bearman (2011): "Autism was the first specific disorder to have a Senate hearing focused exclusively on it [. . .] Between 1997 and 2006, funding for autism research by the National Institutes of Health increased five-fold from $22 million to $108 million [. . .] The Centers for Disease Control and Prevention's funding of autism activities increased from $2.1 million in 2000 to about $16.7 million in 2005 [. . .] And an additional $1 billion was committed to autism with the signing of the Combating Autism Act in 2006. The increase in resources devoted to autism research and treatment has far outpaced increasing prevalence rates" (325).

> who are too old, are marginalized [. . .] And since nobody is in the position to assume the mantle of medical diagnosis of social destiny, the fateful decision as to this allocation of categories, resources, and destinies is preempted by arbitrary forces such as the differential clout of parents, place of residence, social proximity to other affected families, differential access to services, and more. Moreover, even if we had in place an objective and rational assignment and allocation, what would happen to these very same children when they grow up into adolescents and adults with autism, in likelihood not "cured" or sufficiently improved to lead fully independent lives? Prevention, early intervention and improvement of diagnosis would no longer be relevant to them. As many parents can testify, there is a stark discontinuity in the lives of their children as they grow up. Sometime around early adolescence, the intensive therapeutic regime they underwent as toddlers and youngsters is gradually whittled down, replaced by very little that is targeted, and they and their parents are left to their own devices (Eyal et al. 2010: 262).

One of the hot topics of autism has been around "intensive therapeutic regimes," which, in an interesting melding of medical and educational standardization, have been described as treatments and "gold standard" interventions.[71] Though such programs can have a profound influence on those with autism, once individuals have aged out of the education system they are no longer qualified for these services and their families are "left to their own devices." The experience of adults with autism and those who care for them not only becomes increasingly 'physiological' in nature, but also falls largely outside the rhetoric of modern medicine with its focus on discovering therapies that bring about fundamental change (Eyal et al. 2010: 29; Gadamer 1996). This dissertation has focused on families and other caretakers dealing with the complex, physiological, lived experience of

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[71] In a striking case of what we might describe as the medicalization of education, applied behavior analysis—which is arguably a form of education, as much as it is a form of therapy—gets called a "treatment." I thank Jason Schnittker who once asked in a sociology colloquium (whose speaker was David S. Mandell) why ABA, an education program in schools, was often described as a "treatment." It is an example of how medical language spreads, and possibly encourages confusion about the potential and reality of medical and educational techniques.

atypicality and dependency. Despite the variation that characterizes this small sample, the questions, concerns, and reflections that animate their experience is shared by many others who are connected to adults with the condition. Moreover, their interpretations and responses to atypicality and dependency provide insights into other forms of "abnormality" associated with experiences and challenges not easily addressed with the language of biomedicine. These include those with disabilities, those of old age, and others with a variety of conditions that have come to make up a larger part of the mortality and morbidity load of the American population (Rosenberg 2009).

Though much of the mystique of modern medicine has been built around the profound innovations surrounding our understanding and treatment of infectious disease, the changes in mortality and morbidity that are associated with the second half of the 20th century in the U.S. means that the larger themes of this dissertation have become ever more important and applicable. Up until the mid-20th century, the major shaper of morbidity and mortality in many human populations was infectious disease (McNeil 1977). In what, since Omran's (1971) article, has popularly come to be called the "epidemiological transition", mortality and morbidity, at least in wealthy countries like the U.S., has increasingly been shaped by chronic illnesses like cancer and heart disease. A recent article entitled "what do people in the U.S. die from," argued that tobacco, poor diet and physical inactivity, and alcohol consumption were the leading causes of death in the year 2000 (Mokdad et al. 2004). The authors contend that, though the transition is uneven and complex, the suggestion still remains that "these findings, along with escalating healthcare costs" and "an aging population" argue for a reorientation of U.S.

health care and public health systems (Mokdad et al. 2004: 1238; McKeown 2009) It also suggests that the job of medicine—to perform miraculous, multiplying saves—will become increasingly expensive and difficult to achieve, and will need to be supplemented with the often less miraculous job of management, care, support, and behavioral health.

Obviously, autism is very different than cancer, but the themes of this dissertation resonate with and have relevance for the increasing number of chronic and life-long conditions that fall under the clinical view and yet evade easy answers. Most obviously, these include other forms of developmental and physical disability, and significant mental illness: down's syndrome, cerebral palsy, fragile X, schizophrenia, manic-depression (on the ideology of "recovery" in mental health policy, see Grob and Goldman 2000; Braslow 2013). It also includes conditions that, though they might threaten life, allow a person to live for a long enough period of time while ill that their atypicality and dependency arguably qualify, to a point, as statistical abnormality: quadriplegia, multiple sclerosis, Parkinson's disease, Alzeheimer's. It also includes a number of conditions that Feudtner (2003: 17) describes as "transmuted disease," or disease entities that, because of modern medical techniques, are transformed from acute to chronic conditions, not cured but managed for extended periods of time: AIDS, Cancer, Type 1 Diabetes, Heart Conditions. It also includes the care and dependency that come to define us all as we move into old age (a designation that will describe an increasing proportion of the U.S. population in the coming decades) (Hochschild 1978; Gubrium 1997; Levitsky 2014). An exploration of the complex interpretations, responses, and reflections of families and other caretakers of adults with autism provides a picture of one kind of atypicality and dependency, the themes of which resonate, to varying degrees, with many of the others kinds listed above. In what follows I cite some sources whose reflections demonstrate how the themes of each chapter resonate with those associated with other forms of atypicality and/or dependency.

The conflict and negotiation that animated caretaker applications of popular frames of deviance to complex situations of deviance (i.e. the maladaptive behavior of adults with autism) are similar to the dynamics that characterize applications of these frames to other forms of deviant behavior. Chapter three used the case of maladaptive behaviors in adults with autism to explore how caretakers interpret and respond to deviant behavior—actions that undermine role performance and the functioning of social systems. Drawing on concepts from the sociology of deviance, medicalization, social problems, and Goffmanian structuralism, the chapter shows how caretakers do use historical, widely accessible definitions or frames of deviance to understand and socially control maladaptive behavior. However, the conflict, negotiation, and residual ambiguity left over from these applications demonstrates that in understanding abnormality we are always faced with the uncomfortable relationship between neat frames and the messy situations of everyday life. It doesn't take much searching to find these same three meaning-structures being applied to various forms of deviance (some associated with other medicalized conditions, e.g. mental illness) in ways that show caretakers struggling to fit the coherence of these frames with the ambiguity of lived reality. The three cases below recount, respectively, a conversation between a brother of an adult with autism and a mental health staff worker; the thoughts of a father of a boy with manic-depressive disorder on a woman who is charging his son for breaking and entering into a private residence; and the response of parents to a non-disabled, adult offspring behaving in a troubling manner:

> During the morning coffee break, Sumner had attacked another employee at the workshop, someone who was physically disabled. He had forced the weaker person to the ground and began banging his victim's head on the floor. When the staff separated them, Sumner had nervously repeated, 'I'm being good, I'm being good,' in his throaty monotone. The curious staff person asked me what he meant. She thought that in his disturbed way, Sumner must have a confused notion of right and wrong, and perhaps some delusion or perversion of the mind compelled him to believe he should molest a weaker person. 'The answer is probably a lot simpler than that,' I replied. 'When did he say, 'I'm being good?' She explained that he began chanting the phrase after he had been separated from his victim. I recalled similar events I had seen as a child when Sumner would cower if he heard that my father might beat him after similar outbursts, times I had seen my older brother tremble and heard him say, 'I'm being good,' in an attempt to say, 'I'm sorry, it's over, I won't do it again, don't hit me!' 'You have to remember,' I explained, 'Sumner's problem isn't mental illness or delusions. It's a communication problem. He doesn't have the ability to explain his behavior, or even to offer an apology. He can't express himself through new phrases; he can only repeat a few echolalic statements he has learned in the past.' 'You mean he didn't mean it's good to beat other people?' she asked, still confused. 'No, I'm sure he meant that stopping was 'being good.' I reassured her. We talked a little while longer, and I took the opportunity to explain what 'communication disorder,' meant and why we had to remember that Sumner's feelings and thought patterns were not as abnormal as they appeared. It was simply his inability to express himself that separated him from other people, creating these periods of frustration that erupted into inappropriate behavior and echolalia (Hart 1989: 153-154).

> A tall, thin uniformed officer was waiting outside when I pulled up to the center. Police Officer Vern Albert said Mike had gotten up early at his mother's house and had walked to a nearby Starbucks coffee shop. He'd removed a glass water bottle from a shelf there, hoisted it up into the air, and announced to the store's customers that it wouldn't break if he dropped it because he had supernatural powers. He had let the bottle fall, and it had shattered at his feet [. . .] From Starbucks, he'd run into a residential area, entered the backyard of a house, climbed onto its wooden deck, and hurled a patio chair through the plate-glass door, setting off the

alarm. Ignoring the piercing sound, Mike had ducked inside the house, switched on a stereo CD player to drown out the racket, and begun rummaging through the kitchen cabinets. He'd then made his way upstairs, where he'd gone from bathroom to bathroom, turning on the taps. After checking the bedrooms and discovering no one was around, Mike had stripped and taken a bubble bath [. . .] The officers burst in after releasing the dog. Mike had finished his bath and had dressed. He was stepping into a bedroom when the animal sprang. As trained, the dog locked its teeth into Mike's upper arm. Even though the dog was biting him, Mike hadn't surrendered. He'd wrestled with the officers, and it had taken five of them to finally handcuff him [. . .] A few minutes later, Kersey reappeared and explained that the husband didn't care if Mike pleaded guilty to two misdemeanors or to a single felony. "But his wife wants him punished. She's saying he did sixty thousand dollars' worth of damage to their house." "Sixty Thousand!" I exclaimed. That was more than twice what she'd originally said. "That's ridiculous!" Kersey said she was afraid Mike might come back. "What she really wants is for him to be put in prison, but that's just not going to happen." "I was in their house," I said. "I saw the damage. She's making this much worse than it is!" Kersey shrugged. "She is the victim." I didn't feel that way. As far as I was concerned, Mike was the victim. He'd not asked to become mentally ill. He'd thought he was dreaming when he broke into their house [. . .] As we left the courtroom, I thought about the victims, especially the wife. Before this moment, I had honestly come to despise her. As a reporter, I had been trained to put myself into someone else's shoes. And if my son had not been the one who had broken into their house, I'm certain I could have easily slipped into that role. But I hadn't been able to do that. Now that Mike's case was over, I tried. I wondered how I would have felt if I had come home and discovered a madman had thrown a lawn chair through my plate-glass patio door. How would I have reacted if I'd suspected that he had urinated on my carpet and had taken a bubble bath in my teenage daughter's tub? If it had been my life that had been intruded on, if I had been so distraught that I had felt compelled to put my house on the market, would I have demanded a pound of flesh, as they had done? Or would I have understood that mental illness was a chemical brain malfunction? Would I have shown mercy? Because it was Mike who was psychotic, the answer had seemed obvious. But sadly, when I stripped away his face and replaced it with the hollow look of a deranged stranger, I was forced to admit that I might have reacted much as they had. I felt conflicted (Earley 2006:20-22, 127, 215-216).

In another procedure students were asked to spend from fifteen minutes to an hour in their homes imagining that they were boarders and acting out this assumption. They were instructed to conduct themselves in a

> circumspect and polite fashion. They were to avoid getting personal, to use formal address, to speak only when spoken to [. . .] In the remaining four-fifths of the cases family members were stupefied. They vigorously sought to make the strange actions intelligible and to restore the situation to normal appearances [. . .] Many accounts reported versions of the following confrontation. A father followed his son into their bedroom. "Your mother is right. You don't look well and you're not talking sense. You had better get another job that doesn't require such late hours." To this the student replied that he appreciated the consideration, but that he felt fine and only wanted a little privacy. The father responded in a high rage, "I don't want any more of *that* out of *you* and if you can't treat your mother decently you'd better move out!" (Garfinkel 1967:47, 48).

All of the above cases represent caretakers of individuals behaving in an atypical or deviant fashion (the first two because of neurological conditions) drawing on and negotiating with others the application of the frames explored in chapter three in the context of the ambiguity of lived reality. In the first, the brother of an aging adult male with autism tries to negotiate with a mental health staff person the handicap frame of deviance, though she is at first convinced that the misbehavior frame is best suited to the situation. The brother explains that Sumner's aggression stems from a communication issue, and pleads for a response that is about support, social prosthesis, and not punishment for seeming to want to hurt people. The second case is in connection with atypical behavior linked to a diagnosis of manic depression, in which an individual broke into and entered the home of a stranger. The father believes his son to be the victim of forces that were beyond his control (a neurological condition based on brain science), but must face some of the reality (and merits) behind the reaction of those whose home was broken into and who view his son as bad and deserving of punishment. [72] The final case

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[72] Recent research by Jason Schnittker shows how the change to a genetic conception of mental illness has not decreased the stigma associated with those conditions that are

demonstrates an example of atypical behavior not stemming from neurological difference, but rather a predetermined “breaching experiment” to see how caretakers and loved ones might react to deviance in the home. A father is faced with a son behaving differently, and finds himself struggling to apply different frames of deviance (i.e. “you don’t look well,” “you can’t treat your mother decently”) and the social control strategies with which they are associated (i.e. “get another job that doesn’t require such late hours,” “you’d better move out!”). All three cases demonstrate how the framing of deviance is conducted through the use of readily available frames that people use to understand and respond to deviant behavior. However, the use of these frames is always complicated by the ambiguity of situations, and contested by the perceptions and positions of other stakeholders in the setting.

Despite the characterizations of sorrow and tragedy that often attend popular representations of disability and chronic illness, the experiences of those who have or care for those with incurable medical conditions are anything but monochromatic. In her study of “chronic sorrow,” Roos explains that the reality of loving and being responsible for someone who can be characterized as a “living loss” brings with it experiences and struggles that are quite different than the grief associated with death (so often the worst prognosis of those classic conditions that most easily fit the ontological model of disease). Though Roos’s insights clearly fit some of the findings of my own study, the families and other caretakers with whom I spent time demonstrated that there were also

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popularly linked with violent behavior, even though we might expect that the science behind the illness would encourage people to see such violence as out of people’s control (Schnittker 2008).

more positive experiences associated with caring for someone who remains atypical and dependent. Chapter four explored how humor and innocence are two aspects of the experience of caretaking for an individual with autism that likely apply to the experiences of others with or caring for people with conditions associated with continued atypicality and dependency. The two cases below recount the experience of a mother of two males with autism, and a woman with Multiple Sclerosis:

> If I were a firm believer, would their imperviousness to religion worry me? I don't think so. Autists present a fascinating challenge to the theologically inclined. Their absence of altruism, their underdeveloped moral sense, is balanced by an absence of malice, an almost prelapsarian innocence. George once said to baby Jake, who was crying, "Jake, Tinky-Winky created you for good, but you've turned out evil." This sounds profound, but it is in fact an adaption of a line from *Wallace and Gromit*. George does not truly understand the meaning of good and evil, nor is he (as yet) capable of implementing either. Most of the Ten Commandments are easy for the boys to keep. The Seven Deadly Sins are largely an irrelevance. The boys might covet their neighbor's ox—or their neighbor's ice pop—but the desire would be purely for the ox or ice lolly itself, unaccompanied by any desire to get one over on the neighbor. Any temptations they feel arise from their overriding private preoccupations, not from the kinds of torments that neurotypical flesh is heir to. I met a very intelligent Asperger's boy in his late teens, who was a fanatical Lib Dem (if that's not a contradiction in terms) and followed the workings of Parliament with close attention. At the time, a number of sexual scandals among politicians of the Chelsea-strip variety were coming to light. This boy, who wanted to become a politician himself, had the answer: "I know how to avoid a sexual scandal!" he announced. "If somebody said they wanted to suck my toes, I'd just say, 'No, thank you'" (258) [. . .] Perhaps this life would be hellish if I riled against it. Hell—my definition, anyway—is a place where you don't want to be, and from which you can't get out. When you have autistic children, there is no respite, either for them or for you [. . .] But I've long since settled into a fairly calm acceptance. They are what they are. That's all there is to it. Our family life has its own rhythms, its own compensations. Every day, the boys make me feel bored and irritated; equally, every day they provide me with delight, amusement, and joy. The sight of them at supper last night, for instance. They all sat down at the table together: good. Time was when that would have been an impossibility. But still I can't serve them with the same

> meal. Last night, Jake had pizza, carrots, sugar snap peas, grapes, a plum, and a mug of milk. Sam had a bowl of Day-Glo-colored cereal called Rainbow Drops, most of which lived up to their name and dropped to the floor. George has the carcass of Sunday's roast duck. He hauled this out of the pantry himself, and tore at it with his teeth, like Obelix devouring a wild boar. The duck was still on its serving dish. George chomped on the skin and licked up the fat. To many, this would not have been a pretty sight, but I found it funny. Of course, on one level I wish that George and Sam would eat the carrots and the sugar snaps, but I can't worry about that all the time. What makes me smile is the way that every single thing they do is so utterly characteristic. Never imagine that a child who doesn't talk or play much lacks character. "Autism" is an umbrella term; the condition in no way reduces individuality. The boys express their characters in their every tiny action, and individuality is something I'm inclined to celebrate. When George finished slavering over his dead duck, he said to me, "Thanks, mademoiselle" (273-274).

> "Oh, shit," I yell as, catching my toe on the front edge of the elevator, I pitch toward the concrete floor of the garage in my new apartment building. "Do you realize," George [her husband] will ask me later, "that you might have died in that fall, and then your very last words would have been, 'Oh, shit'?" "Ignominious," I'll giggle [. . .] Despite its inauspicious opening, I like this new life. I find the city, sprawled under its gaseous haze, beautiful. I have come to a point in my life where I can find almost anything beautiful. My aesthetic sense, instead of growing more refined and discriminating, has become catholic and egalitarian. Perhaps this effect arises from my increasing immobility. I can't dash through my sorroundings. I can scarcely drag my feet along, and even in the wheelchair I've been relying on increasingly over the past six years I can't go faster than three miles an hour. Much of the time I don't move at all. Stilled, I gaze and gaze. And, looked at deliberately for long moments, the world always yields up some delight. Really [. . .] I sense that [in the past] I was really scrambling out from under the projections of others. I wanted to find the space in which I could become my own creature. Here it is, at last. "And I shall be well," wrote the medieval anchoress Dame Julian of Norwich, another woman alone, "and all manner of thing shall be well." I begin to feel some of her confidence: not that only good things happen—that's not what she's saying—but that all that happens can be accepted, incorporated, celebrated (Mairs 1995: 265, 266, 267).

In speaking about autism, Moore gives us compelling descriptions of the humor and innocence that are central to her experience of the atypicality of her sons. Appreciating that these lighter characteristics are an important part of the texture of her experience and relationship with atypciality is important, even if not easily contained in the language and concepts often used by the medical model. While Mrs. Mairs, a woman with MS who wrote about her experience, does not have a developmental disorder, her experience with the complexity of another form of disability demonstrate that similar characteristics animate her experience of atypicality and dependency. Pain and grief are part of her story, but so too are humor, innocence, wisdom, and joy. In writing "all that happens can be accepted, incorporated, celebrated," words are placed to a form of idealism (quite different than the utopianism of modern medicine) to which many caretakers in my study aspired.

While the power of modern medicine to define difference can be seen in the application of the clinical view to a wide variety of problems in social life, the reality that this view is applied to both pathological and statistical forms of abnormality (and a variety of cases that fall somewhere in between) means that the assumptions of the pathological model that misrepresent the reality of autism may also misrepresent the reality of other forms of atypicality and dependency. While the assumptions and methods of modern medicine are best suited for those conditions that easily qualify for the pathological model of abnormality, the reality is that our success at dealing with pathology has left us applying the pathological model to conditions that are in reality more statistical in nature. Popular representations of autism speak about the condition as if it were somehow degenerative and deadly, even though the experience of families caring for adults with the condition demonstrate that those with autism continue to live, grow, and develop as they age. It has been argued that the rhetoric of "defeating autism"—as if it were a deadly disease—is pushed in order to energize medicine and science to provide answers for atypicality and dependency with the same degree of success that it has attained with major pathological conditions (Eyal et al. 2010). However, the experience of families with adults with autism whose challenges get marginalized, misrepresented, or unrepresented show how pathological language might do more harm than good. Similarly, the medicalization of other forms of statistical abnormality suggest that we might somehow cure developmental disabilities, and mental and chronic illnesses, as opposed to the reality which is better described as a mix of management, support, and care. Though the search for cause and cure for these conditions is supported by many, it can discourage speaking about those parts of the experience that diverge from the language of pathology: specifically, the reality of continued existence in the future, albeit in the context of significant needs and social dependencies. The three quotes below represent the contours of this experience: the first are the thoughts of a mother of an adult with autism; the second is Susan Roos on a variety of conditions she associated with chronic sorrow; and the third is from a study discussing the ways in which research on Alzheimer's has focused on curing those with the condition as opposed to funding the care that they often require:

> My son was diagnosed in the mid-70s with infantile autism when he was 5 years old. Today at age 40, he lives at home with me and his father. We were told by the experts when he was very young what we could expect for his future and that he would most likely end up working in a sheltered workshop as an adult. They were pretty much right on with most of their predictions. After graduating from high school, he went to work in a sheltered workshop. After 5 years, he wasn't happy and wanted a "real' job. With a lot of help and encouragement, he was able to leave the

workshop and get a real job. He is currently in his 11th year working part time as a courtesy at a local grocery store. We could not be more proud of him. For a long time he has wanted nothing more than to live independently from us. So far, this has been his greatest challenge. With severe shortages of state funds for supported living housing, it is not possible for him. He has been on our state's waiting list for services for more than 15 years, but because he has parents who are still physically able to care for him, he is not eligible to receive services. This is unfair and unfortunate, both for him and us as aging parents. All of the attention and money is spent on educating children, but once they reach adulthood, they are pretty much forgotten as far as support and services ("Jackie's Story," Parent Letter to *Autism Society*).

The media constantly remind us of the great strides that are being made in finding cures for cancer and that researchers are on the brink of knowing how to restore motor abilities in spinal cord injuries, multiple sclerosis, Parkinson's, and muscular dystrophy. Neural implants of the future will apparently overcome the debilitating effects of many conditions [. . .] The cultural belief that money, enthusiasm, and work can find cures, prevent devastating diseases, and restore physical and mental losses is maintained and strengthened by media reports. The myth that we can forestall death, find answers, and "fix" things that are less than the desired standard is entrenched in the culture. This myth is the driving force for great medical advances and social activism. [. . .] As some individuals appear to be reaping the benefits of new discoveries and innovations in treatment, others may perceive themselves as the "unlucky" ones who are left out of the loop. They may experience their marginality in the dominant culture, and they may also feel marginal (or not included at all) in the hierarchy of research and treatment related to disabilities and losses. The belief in eventual remedies may contribute to the fantasy that life can be imminently perfect and that what was originally meant to be may yet occur. Belief in the potential of restoring what has been lost may increase the disparity between the fantasy and current reality [. . .] Several projections indicate that approximately one in four Americans will be over the age sixty by the year 2030 [. . .] This number will inevitably include more persons with severe and profound disabilities than every before, and health care systems will be strained to cope with this dramatic increase [. . .] Quality of life issues are likely to increase significantly. Professionals working with geriatric populations will need specialized training in an entirely new field, that of aging persons with autism, mental retardation, and other lifelong developmental disabilities. The need for expertise in living wills, "right to die" issues, organ transplants, legalities involved in signing over one's property or life savings in return for lifetime care (for self or other), guardianship, conservatorship, and so on, is strongly

> indicated [. . .] Professionals may find themselves significantly stressed by having to assume roles historically and traditionally assumed by family (Roos 2002: 237, 238, 239).
>
> This paper builds on our prior work concerning the emergence of Alzheimer's disease (AD) as a major social and health concern. Our study was conducted in two phases (1985-1987 and 2009-2011). We examined the historical evolution of the concept of AD and the emergence of the AD social movement in the U.S. [. . .] The characterization of AD as a leading cause of death among the elderly was crucial to sustaining the movement, but also operated as a "double edged sword." By construing "senility" as a treatable, even curable biomedical entity, the movement substantively contributed to the notion of an impending "crisis" of the aging population to be avoided at all costs, compounding the effect of conservative federal policies that emphasized the treatment or cure of AD, and less so the long-term care service needs of sufferers and caregivers that had given rise to the movement [. . .] the continuing hegemony of the medical model establishes a race against the demographic clock, pitting advances in biomedical research against the needs of an aging population (Chaufan et al. 2012: 788).

Jackie explains that, though doctors originally thought her son would end up working in a sheltered workshop, he, with support of his family and community, has been able to secure a job in a local grocery store. Now that he has achieved this goal, he desires to move out of his parent's home, but the funding situation in his state has made it easy for him and his family to achieve this outcome. Jackie notes that the focus on the education of children with autism leaves the needs of adults with the condition relatively underappreciated. It is notable that the education of children with autism falls into the category "treatment," given the way that programs like ABA and other childhood interventions have been described using the language of medicine. Chaufan et al. (2012) might argue that autism, like Alzeheimer's disease, constitutes a case of the "double edged sword" of modern socio-medical collective movements. Both conditions are described as a serious threat, to be avoided at all cost, and this encouraged the raising of large amounts of money to “cure” the threat while at the same time ignoring the true needs of many with either of the two conditions and those who care for them. Roos would likely argue that the attention we have paid to treating (e.g. educating) children with autism and curing those with Alzheimer’s, while at the same time brushing over the everyday needs of those with these conditions and their caretakers, constitute a case of the American belief that “money, enthusiasm, and work can find cures” and “restore physical and mental losses,” “the myth” that we can “ ‘fix’ things that are less than the desired standard” (Roos 2002: 238). This trend of progressivism is rooted in American culture, and while it is linked to some of our greatest achievements it is also responsible for some of our most important failings. Among them is failing to recognize that humane management, social supports, and compassionate care are important processes that must be respected in scenarios were magic bullets and miraculous cures are unavailable.

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