

AUTISM AND THE PERPETUAL PUZZLE: A RHETORICAL ANALYSIS OF  
THREE EXPLANATIONS FOR AUTISM

A Dissertation

by

DENISE MARIE JODLOWSKI

Submitted to the Office of Graduate Studies of  
Texas A&M University  
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2009

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## ABSTRACT

Autism and the Perpetual Puzzle: A Rhetorical Analysis of Three Explanations for  
Autism. (May 2009)

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Autism awareness has increased in recent years in part because it is marked by confusion and controversy. The confusion and controversy stem from the fact that there are many beliefs about autism but little agreement. In this dissertation I examined the rhetoric produced by three primary groups—professional autism experts, caregivers to children with autism and mainstream media. In particular, I studied how each group explains autism. Explanations are vehicles for persuasion; they advance particular viewpoints about an illness.

I conducted a rhetorical analysis of the three discourses produced by these groups, highlighting the most cohesive themes to emerge from the discourse. To study professional autism experts' explanations, I analyzed articles in autism's flagship research journal and research articles from other journals and key books for additional insight. A computer metaphor guided expert explanations of autism. To define autism through one of most advanced and culturally accepted technological devices lent significant credibility to the explanations. Next, I studied the caregiver explanations,

first conducting interviews with 19 parents to children with autism and then I analyzed the transcripts. Caregivers described autism as a social pathology; their children with autism were different and distant, or alien-like. The pathology affected people with autism, their caregivers and their families, many other neuro-typical people, and it also determined the course of treatment for the person with autism. Finally, mainstream media often explained autism in terms of its conflicts, framing its explanations of autism with a war metaphor. The vaccine debate received a significant attention, re-characterizing the role of medical institutions and health practitioners. Caregivers became the heroes, using their personal experiences as weapons against healthcare practitioners and their science. Caregivers also dealt with the invasion of autism, struggling for ways to return their children closer to the boundary that exists between the child with autism and the neuro-typical child.

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## CHAPTER I

### INTRODUCTION

One representation for autism has always stood out to me. Autism Speaks, an autism advocacy group, chose a jigsaw puzzle piece as the organization's symbol. Driving around town or walking through a parking lot, I often saw the familiar symbol on bumper stickers and license plate frames. Autism Speaks has explained how it interprets the puzzle piece, but they seem to have created it to stand as a conversation point for the autism community—visit one of the many discussion boards devoted to its interpretation to witness its polysemy. The puzzle piece is paradoxical. In one sense, autism is, literally, a puzzling disorder. Another common description of autism, where each of the first letters combines to spell out the word autism, comes to mind here: “Always Unique, Totally Interesting, Sometimes Mysterious.” To draw on such explanations is to admit that little is known about autism. In another sense, there is some certitude present in the metaphor. The puzzle suggests that the pieces, or answers, are out there awaiting discovery. On their website, Autism Speaks aligns itself with the latter interpretation. The organization wrote:

Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take

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This dissertation follows the style of *Health Communication*.



action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

([www.autismspeaks.org](http://www.autismspeaks.org))

Throughout this dissertation, the puzzle metaphor and its various interpretations will appear.

Chapters II and III examine how professional autism experts construct autism. From the viewpoint of an autism expert, autism is a puzzle awaiting solutions. Researchers—psychiatrists, psychologists, neurologists and many others—study autism with a solution-seeking worldview. Scientific principles open up various pathways to answers. Thus far their answers for autism are broad-based. Social, communicative, and behavioral manifestations, all observable, constitute autism. Several theories rooted in cognitive studies have encouraged a deeper exploration of autism. There remains little in the way of agreement except for the biomedical approach itself. The groundwork is in place for experts to attempt to solve autism, but the puzzle pieces have accumulated slowly. In these chapters, it may seem as though the autism research community has a narrow view of autism. Writing from the perspective of an autism research and mother of a child with autism, Olga Bogdashina (2006) wrote, “We often focus on certain pieces of the ‘autism jigsaw’ and miss an opportunity to see the whole picture” (p. 9).

As the analysis progresses beyond the expert point of view, readers will learn that multiple explanations for autism co-exist. Autism caregivers (i.e., parents, grandparents, siblings of children with autism) understand the complexities of autism and its attendant puzzle metaphor from the moment they perceive pathology in a child.

The search for a diagnosis, which can take years to resolve, is the first of many complex circumstances. Once the child receives a diagnosis of autism, the puzzle gets more complicated. So many questions are offered, and few answers are available: What kind of treatment do we use? How do we find people to help us? Caregivers bear the burden of seeking answers themselves, though they often receive help from outside sources. As each year passes, more questions, or more gaps, begin to appear, and the answers seem more difficult to obtain. What can we expect as this person becomes an adult? How do we help this person achieve independence? Caregivers live with the ubiquity of the puzzle each day.

Several biomedical reports spurred mainstream media (MSM) to construct autism as a mysterious, puzzling disorder. For example, in 2007, the Centers for Disease Control and Prevention announced that one in 150 children is now diagnosed with autism each year. This statistic confirmed what many speculated in MSM accounts since the late 1990s—autism had become an epidemic. Such reports led to further unanswerable questions: What causes autism? What has caused this increase? How do we prevent and/or treat autism? Parents sought answers urgently, accusing biomedical experts of becoming enemies to progress because the expert point of view seemed to contrast with everyday observations about autism. Parents fought autism in their children, struggling to regain some sense of normalcy in their children and their lives. This war-like approach to autism led to many battles within MSM, some won and lost, but many battles with no resolution in sight. The puzzle metaphor in MSM accounts

refers less to possible solutions and more to the underlying mystery of the frightening pathology that has increasingly invaded children.

In short, autism contains a lot of meaning. I spent months feeling frustrated and uncertain about condensing multiple interpretations of autism into a few chapters. I relieved some of this fear by drawing on my own interpretation of the puzzle metaphor. As a researcher, I aimed to fill in some of the knowledge gaps about autism. Autism experts, caregivers to children with autism, and MSM do the same. Going against the common interpretation of the puzzle piece as a thing waiting to be solved, I found comfort instead in viewing it as an infinite series of mysteries. In fact, Thomas Kuhn (1962) wrote that diseases are not puzzles “because they may not have any solution” (p. 37). I would revise Kuhn’s assertion to describe autism as a perpetual puzzle. Just when a piece seems to fit, new gaps crop up, and this goes on infinitely. Despite its insolvability, as I have also found, the puzzle piece beckons that we persist. Despite its insolvability, it compels us to continue to understand and explain autism. Without this persistence, there would be no discourse, no analysis and no dissertation.

## PROJECT SUMMARY

For a relatively new disorder, receiving the distinction as a mental disorder from the American Psychiatric Association in the 1980 *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)*, autism awareness has increased rapidly. In part, this is due to the emotional and urgent nature of the disorder. Take, for instance, a segment on NBC’s *Today Show* (Bell, 2006) about a possible autism epidemic. Suzanne Wright, co-

founder of the advocacy group Autism Speaks and grandmother to a child with autism, spoke to millions of Americans that morning about autism, a disorder that “doctors are calling a national public health crisis.” Within the segment, Wright revealed that more children than ever received autism diagnoses. Wright strongly urged researchers to devote adequate attention and funding to finding a cause and cure for the disorder; she estimated that, at the time of the broadcast, only 1/10<sup>th</sup> of one percent of the National Institutes of Health’s \$30 billion budget went towards autism research.

Most who are intimately familiar with autism will applaud Wright and Autism Speaks for pushing its agenda to the forefront in American health issues and, even more important, national health policy. Yet however beneficial her appearance was for autism, Wright was likely chastised by some for her appearance on the *Today Show*. Though researchers do agree that in recent years more people receive a diagnosis of autism, little is known about how that number came to be. Wright compared autism to a disease that has spread uncontrollably. Others believe that her use of the term “epidemic” is inaccurate and creates an unnecessary panic. Though not written in direct response to Wright’s appearance, some experts have publicly advanced a viewpoint that would critique her choice of words:

Epidemics solicit causes; false epidemics solicit false causes. Google autism and epidemic to witness the range of suspected causes of the mythical autism epidemic. Epidemics also connote danger. What message do we need to send autistic children and adults when we call their increasing number an epidemic? A pandemic? A scourge? (Gernsbacher, Dawson, & Goldsmith, 2005, p. 58)

The epidemic debate is but a small piece of the uncertainty surrounding autism. The “right answers” to questions about autism sometimes seem impossible to ascertain. For the purposes of this project, the arguments themselves as well as the consensus that does exist provide for fruitful analysis.

The present chapter serves as an extensive summary of the dissertation and also as an argument for using rhetoric to study autism discourse and, more generally, other health discourses. Autism can and has been studied from numerous disciplinary approaches. But the study of rhetoric gets at how people attempt to explain autism amid its ambiguity. Rhetoric, the “ability, in each case, to see the available means of persuasion” (Aristotle, trans. 1991, sec. 1355a) or, more recently, the “use of language as a symbolic means of inducing cooperation in beings that by nature respond to symbols,” (Burke, 1969, p. 43) offers scholars the tools to best understand how people like Suzanne Wright employ language to advance her perspective about autism. What do other caregivers say? What about autism experts? The study of this rhetoric affords understanding of the symbolic construction of the complex disorder of autism and how it has been communicated. My employment of rhetoric will best demonstrate the term autism as a symbolic umbrella, with scientific data, theories of treatment and causation, incidents of daily experience, and feelings of stress and frustration all intertwined underneath.

Many now know about autism thanks to its presence, through countless forms, in American culture. Cultural consumers might find that films like *Rain Man*, covers of weekly magazines (e.g., *Newsweek* and *Time*), national television broadcasts (e.g., *The*

*View* and *Oprah*), national radio coverage (e.g., NPR's *Zorba Pastor on Your Health* and *This American Life*), entertainment-education programming (e.g., the soap opera, *All My Children* and the drama, *The Shield*), and best-selling books (e.g., *The Curious Incident of the Dog in the Nighttime*), offer diverging perceptions as to what autism is. My project further underscores the idea that there are multiple meanings for illness, generally, and autism, specifically. Analysts must look beyond the most authoritative accounts of illness to find equally important, but often undervalued, accounts.

I take the perspective of an argumentation scholar interested in studying conflict and consensus as it exists in three “places”—the public sphere, the personal sphere, and the technical sphere. Translated to this study, I examine the rhetoric produced by three primary groups: professional autism experts (technical sphere), caregivers (private sphere) and MSM (public sphere). Specifically, I focus on how each group explains autism. That is, the three groups have their own explanatory models. As explained further in a later section of this chapter, the explanatory model is a concept best described by Arthur Kleinman (1980, 1988a). He has examined the questions, key terms, symbols and/or metaphors that may characterize the way an individual explains her illness.

My first set of research questions, then, are quite expansive in terms of what they seek:

RQ1: What rhetorical strategies are used to communicate the autism expert explanatory model?

RQ2: What rhetorical strategies are used to communicate the family caregiver explanatory model?

RQ3: What rhetorical strategies are used to communicate the media explanatory model?

Chapters III, IV, and V will attend to these questions, highlighting the most cohesive themes to emerge from the discourse. Though not commonly utilized in health communication, this project's approach closely follows Marsha Vanderford and David Smith's 1996 study of the varied, often conflicting perceptions of silicone breast implants in their book, *The Silicone Breast Implant Story*. Both their text and my project value the medical experiences of many different parties involved in a health issue. We both examine how different spheres of argumentation respond to medical crisis and uncertainty.

The final research question considers the explanatory models and their accompanying rhetorical strategies as they exist collectively. Based on the findings presented throughout the dissertation, the conclusion of the dissertation, Chapter VI, will generate support for a rather obvious generalization about autism and its discourse: it is a puzzling disorder that generates a lot of conflict. My final question is as follows:

RQ4: How do the three explanatory models combine to further construct autism?

I emphasize that the answers to this question are speculative. My hope is to initiate a dialogue about the implications of the three explanations for autism. These remarks will assist in producing the concluding remarks of the dissertation, where I provide a

springboard from which others can offer their own research about autism discourse as it exists today.

Thus far in the introduction I have touched upon several concepts that have yet to be thoroughly defined or explained. The remainder of the chapter will fill in these gaps. It will include a note about axiology; a detailed look at the rhetorical perspective and method, including an introduction to the explanatory model; and a description of the three different types of discourse I will analyze.

#### A NOTE ABOUT AXIOLOGY

Studying a disorder like autism can be both exciting and stressful. The examination of health issues from an academic perspective is rewarding. My findings can potentially assist a wider population of people—people with autism, family caregivers to those people, and the professionals charged to care for them—as I strive to understand autism as it exists beyond the boundaries of biomedicine. Many, like me, pursue health-oriented projects in order to make such a contribution.

At the same time, to enter into autism research as a neutral observer is an impossible task and one that can be vexing. In word choice alone, I fear I may offend or ignore some of the people who intimately understand the disorder. Therefore, in the few instances when I must make choices that may align me with a particular autism “camp,” I do so openly acknowledging that not all will be satisfied. For example, it is difficult to choose from the various terms used to accurately describe autism. In choosing a label to use throughout the dissertation, I considered a number of factors. Officially, the disorder



itself is quite broad and only properly diagnosed when doctors find impairments in social interactions, communication, and certain patterns of behavior (APA, 1994). As later chapters will describe in more detail, recent interpretations of autism have reconfigured it as a part of a group of disorders, called Pervasive Developmental Disorders, with categories including Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (APA, 1994, p. 65). In creating the five categories, psychiatrists hoped to reflect the newly introduced label of autism as a "spectrum of disorders," (see Wing, 1981; Wing 1991). Accordingly, very often experts use the all-encompassing term Autism Spectrum Disorders. Beyond the terminology used in the technical sphere, I also grappled with language use as I conducted interviews with autism caregivers. I spoke with many parents who used the term autism despite an actual diagnosis of PDD-NOS or Asperger syndrome. Ultimately I chose to refer to the spectrum of disorders simply as "autism" because it seemed to be the most commonly accepted term, despite the fact that it is not, technically, all-encompassing. During caregiver interviews, in instances where our terminology differed, I clarified that my use of the term autism referred to other disorders on the spectrum. If necessary, I use terms such as "high-functioning" and "low-functioning" to indicate a general location on the autism spectrum.

## THE RHETORICAL PERSPECTIVE

In my project, rhetoric provides both the guiding worldview and the method in which I conduct my analysis. I begin with a summary of the rhetorical perspective I take up.

Since the writings of Aristotle, rhetoricians have described an important relationship between rhetoric and uncertainty. Aristotle (Kennedy trans., 1991) wrote that people deliberate about things that they have ideas about, but where no certainty or agreement exists. Miller (1990) rightly noted that rhetoric “is made possible and useful by uncertainty” (p. 162). No one can debate an issue if absolute certainty about it already exists. Medicine in particular is an area in which uncertainty abounds, though on the surface it often does not appear that way. Reflecting on the presence of uncertainty she observed at Cornell’s medical school, sociologist Renee Fox (1957) wrote: “There are innumerable questions to which no physician, however well trained, can as yet provide answers” (p. 208). In Fox’s chapter on medical uncertainty, she focused especially on the ubiquity of narratives of uncertainty from medical students. One novice wrote of his initial experiences in the classroom, but his observation painted a far larger picture about uncertainty in medicine:

“Each field will be opened up somewhat sketchily. ... You will begin to paint a picture on a vast canvas but only the center of the picture will be worked in any detail. The periphery will gradually blur into the hazy background. And the more you work out the peripheral pattern, the more you will realize the vastness of that which stretches to an unknown distance beyond.” (qtd. in Fox, 1957, p. 209)

As Fox also noted, psychiatric disorders are particularly vague because there is limited medical knowledge. Autism is difficult to diagnose and is often confused with other psychiatric disorders including schizophrenia, mental retardation and attention deficit

disorder. Little is known about what causes autism and treatments vary widely from person to person. While the naming of autism as a “spectrum of disorders” provides it with some degree of certainty, it really illuminates nothing more than the extremely varied ways in which individuals (or, more precisely, entire families) subjectively experience autism.

To resolve medical uncertainty, medical students, clinicians, physicians, patients, family members and others turn to rhetoric or, more specifically, explanations. Biomedical practitioners might learn these explanations through their textbooks, their teachers or through direct observation. Patients and families may develop explanations through their own personal experience with illness. Rather than serve as absolute certainties, explanations reveal a cultural point of view. The following section expounds on the explanation as persuasive.

### The Rhetoric of Explanations and the Explanatory Model

This dissertation focuses on the rhetorical product that emerges because of the uncertainty about autism. Kenneth Burke (1989) posited that humans rely on symbols to make sense of the world. Along those lines, humans rely on specific symbolic constructions—explanations—to make sense of what they do not know. Sociologist Charles Tilly (2006), who found explanations synonymous with reasons, described humans as “reason-giving animals. ... Only humans start offering and demanding reasons while young, then continue through life looking for reasons why” (p. 8). Explanations are ubiquitous, but this project focuses on their use in a medical context.

Medical rhetorician Segal (2005) argued that “persuasion is a central element in many medical situations” (p. 1). Explanations in particular are vehicles for persuasion; they advance particular viewpoints about an illness. Medical anthropologist and psychiatrist Arthur Kleinman (1988a) observed that patients “are more skillful in the rhetorical deployment of these potentially powerful words to influence the behavior of others in the desire to receive support, to keep others at a distance, to obtain time alone, to convey anger, to conceal shame, and so forth” (p. 11). Kleinman (1980, 1988a) called a person’s notions about a particular illness and its treatment the explanatory model. Patients, family, physicians and many others create these models out of necessity—illness compels people to try to explain it. The notion of an explanatory model is both a method for gathering and a method for assessing explanations. I provide some history of how the explanatory model came to be before further defining it.

Kleinman developed the explanatory model as a way to embrace explanations beyond the dominant biomedical ones. Biomedicine is the marriage of medical practice to scientific principles. Social psychologist Elliot Mishler (1984) provided four key ideas, or “silent assumptions” that comprise the biomedical model: 1) disease is narrowly defined as a “deviation from a biological norm” (p. 4); 2) research does not advance past preliminary stages until a specific etiology, or cause, has been discovered; 3) “each disease has specific and distinguishing features that are universal to the human species” (p. 9); and 4) medical practitioners must follow the doctrine of neutrality set forth by scientific research.

The model is a beneficial one. The establishment of a systematic process for conducting medical practices and explaining medical phenomena has done wonders for the Western world, where some of the most devastating diseases of previous centuries have been eliminated and pose no future threat. Critics of the model, however, have steadily grown in number over the past three decades. Scholars like Kleinman decry it as too dominant. The model's wide acceptance as the authority on illness has subdued the patient's voice. Biomedicine, or evidence-based medicine, supposedly provides factual accounts of illness while a patient's illness experience is seen as uninformed and even irrational (Mishler, 1984). But critics of the model offer the simple reminder that the biomedical model is one perspective, one explanation. For example, psychiatrist George Engel (1977) wrote:

A model is nothing more than a belief system utilized to explain natural phenomena, to make sense out of what is puzzling or disturbing. The more socially disruptive or individually upsetting the [medical] phenomenon, the more pressing the need of humans to devise explanatory systems. (p. 130)

Engel's description of biomedicine as a belief system is an attempt to place it on equal footing with other explanations and to declare all of these explanations as persuasive. His approach is similar that of many scholars of rhetoric who believe, more generally, that scientific knowledge is better classified as an argument than as the truth (Gross, 1990; Scott, 1967). Products of biomedicine, including everything from the symptoms of a disease to the research reports that clinicians produce, explain in particular ways. These explanations may appear to provide absolute certainty because biomedicine is so

authoritative. In reality, the cultural currency of biomedicine places it at a much higher value than other kinds of explanations.

Kleinman (1980, 1998a) agreed with critics of the biomedical model, writing that its dominance troubled him. He saw patients routinely left voiceless and unhealed because biomedicine did not offer room for their illness experiences. Kleinman's anthropological approach to illness led him to study other cultures and their illnesses. Many of the alternative medical systems he wrote about came from China and Taiwan, and he used them to demonstrate the existence of drastically different, but also acceptable, ways to explain illness and healing besides Western biomedicine. Kleinman also used his anthropological background to encourage others to gather illness explanations in a more comprehensive manner. Practitioners and researchers, he believed, ought to ask questions covering a range of topics, including: "1) etiology; 2) time and mode of onset of symptoms; 3) pathophysiology; 4) course of sickness (including both degree of severity and type of sick role—acute, chronic, impaired, etc.); and 5) treatment" (Kleinman, 1980, p. 105). Kleinman (1988a, b) later articulated these five topics in the form of questions he especially encouraged practitioners to ask of their patients. These questions include, but are not limited to: "What is the cause of the disorder? What does the illness do to [the] body? What is the source of improvements and exacerbations? What do [you] most fear about this illness? What do [you] expect of the treatment?" (Kleinman, 1988a, p. 43-44)

Scholars from a variety of backgrounds, including medicine, anthropology, and communication, have embraced Kleinman's explanatory model. Most often, those who

borrow it do so in order to better understand the patient’s perspective on a wide array of illnesses.<sup>1</sup> His notion of an explanatory model is compassionate and inclusive. His work on the subject even goes so far as to delineate between illness and disease, something I take care to incorporate in this project as well. Biomedicine studies disease, focusing on its diagnosis and treatment. Kleinman and colleagues expressed disdain for this viewpoint because it often ignores what they view to be vital components of illness. This biomedical view of reality “assumes that biologic concerns are more basic, ‘real,’ clinically significant, and interesting than psychological and sociocultural issues. Disease, not illness, is the chief concern; curing, not healing, is the chief objective” (p. 255). Kleinman, Eisenberg, and Good (1978) explain that “patients suffer illnesses” (p. 251). They support a biopsychosocial approach to illness, where biological, social, and psychological explanations about illness are equally valued. Thus patients’ explanatory models will incorporate their perception, experience, and coping mechanisms, all of which are culturally shaped by the “social positions [they] occupy and systems of meaning [they] employ” (p. 252). Kleinman is also keen to point out the emotional nature of illness—an illness explanatory model “enables us to grasp, behind the simple

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<sup>1</sup> For chronic venous disease, see Nunnelee, J.D., & Spaner, S.D. (2000). Explanatory model of chronic venous disease in the rural midwest—A factor analysis. *Journal of Vascular Nursing, March*, 6-10; for postpartum depression see Ugarriza, D.N. (2002). Postpartum depressed women’s explanation of depression. *Journal of Nursing Scholarship, 3<sup>rd</sup> quarter*, 227-233; for a Hmong epilepsy EM contrasted with a biomedical version, see Fadiman, A. (1997). *The spirit catches you and you fall down*. New York: The Noonday Press; for EMs about adverse health effects attributed to silicone breast implants, see Vanderford, M.L. and Smith, D.H. (1996). *The silicone breast implant story: Communication and uncertainty*. Mahwah, NJ: Lawrence Erlbaum; for a chronic illness EM measurement tool, see Haidet, P., O’Malley, K., Aniol, J., Gladney, A., Sharf, B.F., Street, R.J., Tran, A., & Greisinger, A. (2002). A tool to measure patients’ explanatory models of illness. *Journal of General Internal Medicine, 17*, S196; and Haidet, P., & Street, R.J. (2006). From the field: Project CONNECT. *Medical Encounter, 20*, 32-33; for an examination of contrasting patient and physician explanatory models, see Sharf, B.F. (1990). Physician-patient communication as interpersonal rhetoric: A narrative approach. *Health Communication, 2*, 217-231.

sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness” (Kleinman, 1988a, p. 28-29). An illness explanatory model, then, gives scholars like Kleinman a unique insight into a illness, one that can only be found by venturing outside the boundaries of biomedical thought.

In this project I do not discount the biomedical model or the disease explanatory model. Chapters II and III will examine the biomedical explanatory model for autism. In these chapters I acknowledge the autism research community as an authoritative group that worked diligently to create an authoritative research trajectory for autism. Chapters IV and V, however, will move beyond the biomedical model to examine the various ways in which caregiver and MSM explanations diverge from the traditional biomedical account. My choice of texts reflects my belief that there is more to autism—and illness in general—than the professional expert’s explanatory model. While I embrace Kleinman’s conception of the explanatory model, I also expand upon it. In studying family caregiver and MSM explanations of autism, I depart from the doctor-patient dyad so commonly studied by Kleinman and other health communication researchers. Kleinman’s work typically stresses the importance of the patient and her explanations within the doctor-patient relationship. I cover new ground in suggesting that there are many illness accounts from many sources.

As previously mentioned, Kleinman’s explanatory model assists researchers in gathering and assessing explanations. I begin a comprehensive summary of my project by first describing how I gathered the explanations. Two of the three sets of



explanations already exist—I examined published accounts of autism from the professional literature and MSM. There was no way I could alter or influence the content of published texts. I also interviewed caregivers and used their interview transcripts as text. To gather together a caregiver explanatory model, I had to devise a strategy. I needed a set of questions that would capture as many aspects of autism as possible. Some of the questions I used are listed below; an exact interview protocol is described in Appendix A.

- What is autism?
- What is the cause of autism?
- What course will the autism take?
- What do I most fear about autism?
- What are the sources of improvements/exacerbations?
- What effects will autism have on my and my child's life?
- What treatments do we use?
- What can we expect from treatment? (Kleinman, 1988a, p. 43-44)

I have also added a few questions that Kleinman does not articulate in his own work.

My research about autism thus far has led me to believe that the following are important to consider:

- Who is responsible?
- What are the chances for a cure?

The answers to these questions are the explanations. My analyses reveal the dominant rhetorical strategies used to advance particular explanations. I now move to discuss how I assessed these explanations.

### Rhetoric as a Method

Rhetoric also serves as a method for analysis. Kleinman (1988b) encouraged as much in clinicians when they examined a patients' explanatory model. He wrote that they should look for "various accounts of the illness with respect to their major plotlines, metaphors, and the rhetorical devices employed to tell the story of the illness" (p. 155). However rhetorically savvy Kleinman was, he is not an expert in rhetorical criticism. I thus turn to Celeste Condit, a rhetorical scholar who has made a rhetorical method explicit. Her method is along the lines of Kleinman's recommendation. In Condit's *The Meanings of the Gene*, she set forth an overarching method for analyzing a century's worth of press accounts about genetics research. She referred to her analysis as a search for rhetorical formations, a common but not often explicit practice for rhetoricians. To describe rhetorical formations in another way, they are the persuasive devices that frame a set of texts, unifying the texts in their overall argument. It is difficult to provide specifics about these persuasive devices because they vary so widely depending on the purpose and context of the discourse. The persuasive devices I identified in this dissertation are commonly known; countless scholars have previously identified them as persuasive.

For readers already steeped in medical humanities literature, it will come as no surprise that metaphors were prominent persuasive devices in each of the three analyses

I conducted. Plenty of research has already examined metaphor's pervasive presence in illness explanations (e.g., Daugman, 2001; Kleinman, 1980; Montgomery, 2001; Osherson & AmaraSingham, 1981; Payer, 1988; Segal, 1997, 2005; Rollins, 2002; Sontag, 1978, 1989). Kenneth Burke (1969) described metaphors as devices used "for seeing something in terms of something else" (p. 503). It seems that people best express the mysterious, intangible inner-workings of the body by drawing comparisons with the tangible phenomena of the world. For many scholars of rhetoric, metaphor "generates the discovery of ideas" (Osborn, 1967, p. 130). More than an ornament for language, over time the metaphor has grown in significance as to assist rhetors in the invention of arguments. Consider, for example, common comparisons between the brain and a machine. The transference of mechanical descriptions onto the human brain illuminates function and purpose for the organ. Furthermore, it allows investigators to structure their research about the brain in particular ways, drawing on mechanical language to further advance their arguments. Readers will find in Chapter III that the autism research community would have little to go on if it were not for the illuminating function of the mechanical metaphor. As Segal (2005) wrote: "Metaphor is a means, then, by which thought is structured and a means by which debate is, to some extent, determined" (p. 119).

Aside from the metaphor, I also identified other rhetorical strategies that acted as supporting devices to the primary persuasive device. Narratives, for example, reinforced the overarching theme in Chapter IV and the overarching metaphor in Chapter V. Like the metaphor, narratives have also received plenty of attention from other medical

humanities scholars (see especially, Charon, 2006; Frank, 1997; Kleinman, 1988a).

Narratives illuminate personal experience. They “enable us to grasp, behind the simple sounds of bodily pain and psychiatric symptoms, the complex inner language of hurt, desperation, and moral pain (and also triumph) of living an illness” (Kleinman, 1988a, p. 29).

In order to best describe each set of texts for readers, I began each analysis by explaining the overall rhetorical situation, including contextual background and the presence of urgency or an exigence. I then focused primarily on describing the enactment of the primary rhetorical formation. But I also considered other rhetorical elements, including the development of ethos or character, how rhetors used evidence to support their arguments, and the location of prominent values. In other words, rhetorical terminology pervades each chapter.

Condit (1999) advised rhetorical scholars to take an agnostic approach to their rhetorical analyses. This once again underscores the idea that explanations are arguments rather than absolute certainties. As physician and author David Morris (1998) argued, illnesses are like texts; they are amenable to multiple interpretations. Devotees to biomedicine, who typically believe in a singular truth, might find the notion of agnosticism troubling. The biomedical model, based on scientific principles, trains researchers to present objective information that contributes to finding the truth. But even this type of truth molds into new shapes over time, shifting direction when a new worldview takes hold in the community (see Kuhn, 1962). Medical knowledge has changed dramatically, for example, since the introduction of pharmaceuticals and

genetics research, to name only two of many influential paradigms. The significance of certain rhetorical formations changes to adapt to the new paradigm. Textual agnosticism, according to Condit, also requires a rhetorical scholar to understand the social context that has shaped a set of texts over time. Chapter II focuses on social context, demonstrating how a paradigm shift in psychiatry greatly influenced the biomedical autism research agenda. An understanding of this historic change is crucial for a rhetorical interpretation of the discourses I analyze.

Rhetorical formations, like the machine-as-brain metaphor, work to produce consensus, but Condit (1999) reminded rhetorical scholars that they can also produce conflict. Drawing again on the puzzle piece as an example, Autism Speaks uses the metaphor to communicate its perspective about autism. The group stands for public and political awareness, biomedical research, and, ultimately, a “solution.” The metaphor communicates this message and persuades people to rally around the organization’s causes. But the rhetorical force of the puzzle piece also provokes. Opponents take issue with the Autism Speaks explanation. Many people with autism believe, for instance, that autism is simply an alternative way of being. They argue that autism is not a mystery that requires a solution or a puzzle with missing pieces. Chapter V in particular will touch upon the conflict brought about by the enactment of a particular metaphor. In the conclusion, I also consider how the metaphors located throughout the dissertation ultimately conflict with one another.

In all, the discovery of rhetorical formations is revealing but overwhelming. It was impossible to include all of the rhetorical formations that I found. I had no plans to

search for “a single unifying principle,” (Condit, 1999, p. 253) a concept that is antithetical to this project. Rather, my openness to all rhetorical formations ultimately point to a set of “important discursive units that recur” (Condit, 1999, p. 253) within each explanatory model. I now move to explain the type of texts I analyze. In this section I also include a justification for text selection.

## INTRODUCTION TO THE DISCOURSE

The three discourse sets I examine include published autism literature, interviews with family caregivers to children with autism and recent MSM coverage of autism.

Combined, they represent an array of explanatory models that construct autism in different and significant ways.<sup>2</sup> Additionally, the discourse choices I have made intentionally expand upon Kleinman’s typical use of explanatory models, which in the past consisted of a practitioner model compared with a patient model. I now introduce each of the three discourses in turn.

### Professional Autism Experts

Chapters II and III examine how professional autism experts construct autism. Chapter II serves as more of a literature review, summarizing some of the most significant autism and psychiatric research from the early to mid 20<sup>th</sup> century. This historical research is widely reported within the autism community (e.g., Nadesan, 2005). Chapter II’s

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<sup>2</sup> For the purposes of simplicity, I describe the sets of discourse as distinct. In reality, it is difficult to make a clear distinction between the three sets of discourse sometimes. Take, for instance, psychologist and autism expert Bernard Rimland, who also had a son with autism.

literature review lays the groundwork for Chapter III. It offers readers the chance to understand the historical research as it is situated in the cultural milieu of its time period. The significant moments in history point to the reasons in which biomedical principles remain so strong in the professional autism research community today. By contrast, in Chapter III I analyze a set of texts and examine the enactment of a particular metaphor.

Primarily in Chapter III, I examine the flagship autism journal, the *Journal of Autism and Developmental Disorders* (hereafter, *JADD*) from its first issue in 1971 to the latest in 2008. *JADD*'s early editorials, research articles and even book reviews give key insight into the ebb and flow of research ideas as a community of scholars came together. It also offers a sense of how this research community changed over time, as well as a sense of which research ideas are, for the time being, here to stay. Using *JADD* as a springboard, I relied on research articles from other journals and key books for additional insight. The most useful books came from some of the current leaders in autism research.

Despite a comprehensive examination of the *Journal of Autism and Developmental Disorders*, I do not attempt to compile a comprehensive expert explanatory model. I readily acknowledge that a complete expert explanatory model is far too daunting a task for this project, particularly because I also focus on two other perspectives. Nonetheless, I believe that the texts I analyzed accurately represent current trends in autism research. In addition, the rhetorical strategies adopted by these experts, who are among the most influential in the field, will likely dictate how others present their own research findings. Rhetoric of science scholars have thoroughly documented

the power of certain rhetorical formations that uphold the medical (and larger scientific) community's guiding worldview (e.g., Bazerman, 1988; Gross, 1990; Segal, 1993).

### Caregivers to Children with Autism

In Chapter IV I examine the caregiver explanatory model. In using the term caregiver, I refer primarily to the parents of one or more persons with autism. In fact, in conducting my interviews, I only spoke with parents. I adopt the term caregiver to recognize that, in general, siblings, grandparents, and other family caretakers could also fall into this category. Though people with autism have themselves contributed to the meaning of autism (Temple Grandin, most notably), I chose to focus on the caregivers because they have intimate contact with the disorder from pre-diagnosis onward.

The texts I use for this analysis differ from the texts used in the other two analysis chapters. Rather than rely on publicly-available caregiver narratives—there are many to choose from—I chose to compile a caregiver explanatory model with the assistance of caregivers in my local community. My intention was to give voice to the everyday experience of autism and gather a range of different viewpoints rather than rely on public narratives that have undergone selection and revision by publishing companies and mainstream media outlets. My plan for interviewing caregivers, including the recruitment strategy and the interview protocol, was approved by the Texas A&M University Institutional Review Board. To recruit interviewees, I approached a local autism support group for help. I also reached out to a few key autism professionals in the community who interact with caregivers every day.



In total, I conducted 19 audiotaped interviews. To compile a caregiver explanatory model, I relied on key questions developed by Arthur Kleinman (1988a). Sample questions included: What words would you use to describe autism? How does autism manifest itself in your child? What treatments have you found effective?. Appendix A contains a full interview protocol. After finishing the interviews, I transcribed and analyzed them. In total, I analyzed 704 double-spaced pages of text. My approach to this analysis did not differ in any way from my analyses of texts derived from expert literature and MSM accounts.

### Mainstream Media

An expert explanatory model draws on biomedicine and uses it to strategically develop a fruitful and credible research paradigm. Caregivers offer a glimpse into the everyday experience of living with autism. Alongside these two perspectives, I also felt it important to consider a very public explanatory model. In Chapter V I examine a MSM explanatory model. The MSM explanatory model combines the biomedical and caregiver viewpoints, but reorients them in order to generate controversy and conflict. Celeste Condit (1999) studied MSM accounts of genetics and argued that their study provided for an interesting negotiation between the lived world and the scientific world. She further explained the difference between an MSM account and other types:

Most scholars have tended to focus on the discourse of intellectual leaders in part because it is more coherent and thus easier to write about and describe. In contrast, ideology, as it appears in public media is necessarily truncated and

incompletely elaborated. Moreover, popular media rarely attempt to present a singular, unified theory of the form that typically occurs in either professional journals or academic books. Instead, public media present discourses with a mix of challenges and responses. They present attractive fragments of theories and blend them with attractive features of other discourses. (p. 11)

Simon Baron-Cohen's theory of the autistic male brain and Clara Claiborne Park's memoir about her life with a daughter with autism are both available for public consumption. However, the fragmented MSM account is by far the most accessible for the general public. Analysis of MSM explanations can draw out a variety of ideological arguments not found in the other texts. Furthermore, MSM accounts address significant topics that receive little attention from professional experts and the caregivers I interviewed. These topics include the autism epidemic and the link between autism and vaccines.

The analysis in Chapter V is the product of my reading recent newspaper, magazine, and internet articles; watching television specials; listening to radio reports; and reading radio and television transcripts from the year 2000 onward. The amount of MSM coverage about autism over the last several years has made it impossible for me to examine everything. It is also impossible to cover that much ground in one single chapter. Instead, I turned to several pieces that best represented a MSM explanatory model for autism. I chose to incorporate some narratives, like those about Jenny McCarthy and Jason McElwain, because their stories remained newsworthy for months.

I include other accounts because they described situations commonly reported in media, but did so in a detailed manner.

Chapter VI does not include any analyses of texts, but is instead a reexamination of the previous four chapters. I consider both the major rhetorical lessons and the many smaller lessons readers can take away from this project. I first summarize some of the major findings from each chapter. Following this summary, I provide some areas that require future research. I then answer RQ4, a question that addresses the overall autism explanatory model. In answering this question, I examine the primary differences among the three smaller explanatory models. I conclude by considering two places of unfortunate disconnection in the overall explanatory model. Citing two specific topics originating in the caregiver explanatory model, I argue that they ought to appear in the expert and MSM explanatory models as well.

## CONCLUSION

Autism is more than simply a word, a revised definition in the *DSM-IV* or one person's experience. The purpose of my project is not to pin down exactly what autism is but instead to advocate for an understanding of it (or any other health issue) through its many explanations. The first three research questions I pose guide me to study the rhetorical formations produced by three groups who have a great deal to say about autism. Their rhetorical strategies will illuminate the role persuasion plays among each of the groups. Readers will learn more about the strategic use of values, the construction of heroes and villains, the employment of metaphors, and many other rhetorical

strategies large and small. The final research question serves as a guide for understanding the greater influence of the rhetorical formations. That is, out of some of the consensus there will also be conflict. How do certain rhetorical formations perpetuate that conflict? By the end of the dissertation I hope that readers will gain a better understanding about the power of persuasion in constructing explanations for autism. The disorder itself, meanwhile, will continue to be a perpetual puzzle.

## CHAPTER II

### AUTISM AS A BIOMEDICAL DISORDER

In order to better understand autism, it is important for readers to know about the history of its construction as a biomedical disorder. Autism as it is known today emerged only after decades of conflict between competing research communities. Autism research began in German psychiatric research circles. These researchers believed that the schizophrenic condition brought about autistic symptoms in people. The psychoanalytic research community embraced this early iteration of autism, conducting much of the research and writing on it in the early part of the 20<sup>th</sup> century. As the current narrative goes, a few key characters—especially Leo Kanner and the American Psychiatric Association (APA)—rescued autism research from the grasp of the psychoanalytic community and relocated it to the capable hands of biomedicine. This chapter further explores this narrative, including the conflict and its current resolution.

The historical account I provide in this chapter differs from other historical accounts of autism in one important way. I emphasize that, to understand the significance of autism literature, one must understand the cultural milieu in which it is inscribed. This chapter examines several commingling problems occurring in the mid-20<sup>th</sup> century, including those faced by the autism research community as well as the larger psychiatry community. These problems collectively initiated a disciplinary crisis. But, as Kuhn (1962) argued, disciplinary crises often bring about a need for new and

improved scientific theories. The community embraces these new theories, shifting disciplinary thinking in fundamental ways. These upheavals are difficult but necessary for the survival of a discipline: “[R]etooling is an extravagance to be reserved for the occasion it demands. The significance of crises is the indication they provide that an occasion for retooling has arrived” (Kuhn, 1962, p. 76). And so out of psychiatry’s disciplinary identity crisis emerged a new framework for understanding mental disorders like autism. This is the framework through which professional autism experts currently explain autism.

The revolution that took place in psychiatry brought about acceptance of a new and authoritative worldview, the biomedical model. In adopting Kuhn’s perspective in my examination the rise of the biomedical model, I affirm an idea I first articulated in Chapter I. Scientific research, rather than articulating absolute truths, expresses localized truths that are constructed by the community. This chapter thus takes a social constructivist position to argue that biomedicine is a constructed view of reality that was developed in order to understand health and disease in particular ways. Many before me have documented how psychiatrists retooled their discipline in order to orient the research agenda towards biomedicine. The power of a small group of individuals played an important part in psychiatry’s revolution.

An incipient biomedical revolution required psychiatrists to develop a reliable and valid system for diagnosis because, as Mishler (1981) wrote, “Establishing a correct diagnosis is one of the chief aims of medical practice” (p. 144). Thus, a prominent character in this chapter’s narrative is the *Diagnostic and Statistical Manual of Mental*

*Disorders-III (DSM-III)*, the diagnostic and classificatory manual constructed by a group of people at the APA throughout the 1970s and released in 1980. Known as the “charter document” (McCarthy, 1991; McCarthy & Gerring, 1994) or “psychiatric Bible” (Berkenkotter, 2001), the text outlines meaningful biomedical knowledge about autism and the almost 300 other mental disorders the manual catalogues. This chapter draws on research that has already contended that the *DSM-III* is more than just a “neutral transporter of information” (McCarthy & Gerring, 1994, p. 151) founded on solid empirical evidence and APA consensus. Instead, “it actually floats on currents of debate and dispute; in this case, debate about how best to understand the mental health field, its ways of knowing, practicing, and teaching” (p. 151). All who have critically studied the *DSM-III* interpreted its publication as a directive for psychiatrists and psychologists to adopt a biomedical worldview when studying mental disorders like autism.

A history of autism, including its situation in the cultural milieu of the time period, is necessary for a number of reasons. First, a review of the significant autism research offers readers a primer for better understanding the analyses in Chapters III, IV and V. Second, in examining the social and institutional forces that have directly affected autism, I provide additional evidence for my belief that one must study autism—and illness in general—as a product of the various discursive forces that construct it. The science of autism is indeed significant, but ultimately one of the many constructions to consider. In a sense, this chapter constructs the jigsaw puzzle’s exterior frame while subsequent chapters address how three groups of discourse attempt to connect some of the pieces together. The rest of Chapter III proceeds as follows: 1) An

introduction to early autism research, including an extended example to illustrate one of the major problems with autism research in the mid-20<sup>th</sup> century; 2) The biomedical model as the solution to psychiatry's disciplinary crisis; and 3) A current review of autism research.

## EARLY AUTISM RESEARCH

### Autism as a Schizophrenic Condition

Autism, many have argued, has existed in various forms for centuries. Scholars surmise that clinicians have encountered children with autism, or those who appeared to have social and communication deficits, for at least two centuries. Prominent psychiatrist and physician Lorna Wing (2000, 2005) wrote that most clinicians labeled these children as insane. The first documented use of the term "autism" occurred in 1911 by Swiss psychiatrist Eugen Bleuler, one of the leading psychiatrists of the time. Initially, autism (derived from the Greek *autos*, or self) referred to a major symptom experienced by schizophrenic individuals. This symptom was so common that many believed it was a core phenomenon of schizophrenia. The term autism derived from Bleuler's desire to describe the behavior in similar terms as Freud's notion of autoeroticism, which in part pointed to a person's neglect of reality and tendency toward introversion (Gundel & Rudolf, 1993; Stanghellini, 2001). Autism, Bleuler believed, appeared when psychic functions split; people used extreme introversion as a defense mechanism in order to avoid conflict between one's desire and one's reality (Stanghellini, 2001). Bleuler described the personality dysfunction as follows:



The most severely disturbed schizophrenics, those who cultivate no further social contacts, live in a world of their own; they have cocooned themselves with their desires, which they see as fulfilled, or with the suffering caused by their persecution, and restrict their contact with the outside world to the greatest possible extent. This process of detachment from the outside world, together with the relative or absolute preponderance of introversion is what we refer to as autism. (qtd. in Gundel & Rudolf, 1993, p. 295)

Symptoms of Bleuler's autism also included emotional indifference, idiosyncratic beliefs and values, inappropriate behavior and, in his later work, irrational thinking (Parnas & Bovet, 1991; Stanghellini, 2001).

Bleuler's introduction of the term autism to the German psychiatric community inspired decades of research about the phenomenological components of autism as it related to schizophrenia. Despite his efforts, Bleuler's work is largely neglected in the modern day conception of autism. Perhaps due to translation issues or perhaps due to the vague language adopted by many phenomenological psychiatrists, present-day experts do not seem to agree on some of Bleuler's major arguments. For instance, disagreement occurred over whether Bleuler believed that autism was a major, but secondary, symptom of schizophrenia (Parnas & Bovet, 1991) or whether Bleuler believed autism to be a psychological disorder in itself (Gundel & Rudolf, 1993). More relevant to the theme of the present chapter is the problem with operationalizing Bleuler's terminology. Bleuler saw those with autism as isolated, emotionally indifferent, idiosyncratic in beliefs and values, inappropriate in their behavior and irrational thinkers.

Bleuer's contemporaries did not do much to help him out. Psychiatrist and philosopher Eugène Minkowski described autism as "poverty," a "loss of the vital contact with reality," and more a defect than a defense mechanism (qtd. in Parnas & Bovet, 1991, p. 12). Psychiatrist Wolfgang Blankenburg wrote that people with autistic symptoms lacked a "natural attitude," or common sense (Parnas & Bovet, 1991). Many psychiatrists believed this kind of language to be too vague, leading to difficulties in diagnosis. Medicine, the overachieving discipline to psychiatry's free-associating and directionless discipline, did not look kindly on diagnostic difficulties. Parnas and Bovet (1991) wrote: "When autism is conceptualized according to the classical objectivistic descriptive model of medicine, it progressively disintegrates, because it defies any simple and operational formulation in this model" (p. 18).

### Kanner's Autism

In the most common iteration of the autism research narrative, it was not until 1943 that a new voice pierced through autism's vague and sometimes contradictory descriptions and its and non-biomedical research trajectory. From this new voice, a new direction for autism and autism research emerged. Austrian-born and educated in Berlin, Leo Kanner, who emigrated from Germany to the United States in 1924, "discovered" modern-day autism. Though he received his MD in Germany, Kanner had no training or exposure to child psychiatry there. Kanner encountered child psychiatry upon an appointment to Johns Hopkins University, where he eventually accepted a position in their newly opened child psychiatry unit. At that time, Kanner had already studied cardiology and

dentistry and quickly absorbed the new discipline through the writings available at the time and through his patients (Sanua, 1990; Eisenberg, 1994). Eleven years after immigrating to the United States, he published *Child Psychiatry*, one of the first important texts on the subject.

Kanner's 1943 article published in the *Nervous Child* did not completely espouse the principles of biomedical research, but he did draw on three important ones that influenced the future of autism research production. The article presented case studies of 11 children, most of whom he had carefully observed since the late 1930s and early 1940s while working at Johns Hopkins. The publication of Kanner's article gave others in the field a new language for describing autism, which for him was not merely a symptom of schizophrenia but its own distinct disorder that deviated significantly from biological norms. He used the term "infantile autism," which others referred to as "Kanner's autism" from that point forward. To support his major claim of autism as a distinct disorder that deviated from typical norms, Kanner drew on a second biomedical principle in listing the features of autism he saw as universal in all of his cases. These symptoms included the desire to be alone, the possession of excellent rote memory and delayed echolalia (briefly described as a pattern of speech in which a person with autism repeats back what another person has said). Finally, Kanner claimed that his conception of infantile autism and its symptoms came about through his neutral observations as a clinician. Though he examined only 11 cases, far too few to make any broad generalizations, Kanner's research style of reporting on neutral observations from a population under study became more commonplace as biomedicine began to take root in

the psychiatric research community. The research stood out in contrast to psychoanalytic research that instead preferred to examine the intrapsychic workings of individuals. Psychoanalysts viewed the distanced study of populations of people as coldly clinical, denying each person's individual experience.

Kanner's first publication about autism brought him recognition and praise as well as criticism. In the article, Kanner hypothesized about the origins of autism, suggesting biological roots of the condition. He wrote: "these children have come into the world with the innate inability to form the usual, biologically provided affective contact with people" (Kanner, 1943/1985, p. 50). But as Eisenberg (2001) and Sanua (1990) both noted, Kanner did not adopt one single etiological approach to autism; he also suggested the social environment as a potential cause. In his early years of research, Kanner was known for supporting the hypothesis of the emotional "refrigeration" of the parents as the cause of autism. The following is a lengthy citation, but one of great importance, because it introduced the world to the "refrigerator mother" hypothesis:

In the whole group, there are very few really warmhearted fathers and mothers. For the most part, the parents, grandparents, and collaterals are persons strongly preoccupied with abstractions of a scientific, literary, or artistic nature, and limited in genuine interest of people. Even some of the happiest marriages are rather cold and formal affairs. Three of the marriages were dismal failures. The question arises whether or to what extent this factor has contributed to the condition of the children. The children's aloneness from the beginning of life

makes it difficult to attribute the whole picture exclusively to the type of the early parent relations with our patients. (Kanner, 1943/1985, p. 50)

His writing on the subject matter appealed to another major faction, psychoanalysts. Their work on the subject garnered significant public attention with the help of people like Bruno Bettelheim (Severson, Aune, & Jodlowski, 2008). In hindsight, most now see the refrigerator mother hypothesis as both defunct and damaging to parents with children with autism. Reflecting on Kanner's early support of the hypothesis, Eisenberg (2001) defended his colleague. He wrote that Kanner's hypothesis rose to popularity because, at the time of writing, psychoanalysts dominated the field of psychiatry. The refrigerator mother hypothesis seemed to fit with the "fashion" of the time. In fact, Eisenberg noted that the commonalities that Kanner saw in the parents can also be read now through another vogue perspective, genetics. Rather than parental neglect or ambivalence, Kanner may have described possible autistic traits inherited from these parents. Thirty years after he published his first article about autism, Kanner (1971) reflected on his initial findings and revised some of his original ideas. He particularly lamented the fact that history had ignored his alternative hypothesis that autism was biological. Additionally, he re-centered the parents as part of the solution, rather than the problem: "Parents are beginning to be dealt with from the point of view of mutuality, rather than as people standing at one end of the parent-child bipolarity; they have of late been included in the therapeutic efforts, not as etiological culprits" (p. 234). Overall, Kanner's research initiated important dialogue for a new and more cohesive autism research agenda. Kanner may have distanced himself from his refrigerator mother

hypothesis, but its existence led to much conflict within the psychiatric research community.

### A Fragmented Discipline

Through the decades, researchers have accepted Kanner's research as accurate and coherent. Yet at the time of his writing, autism research was anything but. In particular, the research lacked a unified body of work with unifying principles. Hans Asperger's research in Vienna during the 1940s and 1950s was a case in point. His dissertation reported his observations of four boys who exhibited autistic symptoms. The symptoms he described comprised a disorder he called "autistic psychopathy," which researchers have since renamed Asperger syndrome because, as Wing (1981) wrote, the American connotation of psychopathy (i.e., criminal behavior) differed greatly from Asperger's intention to describe an abnormal personality type. Asperger observed that in the cases he examined, most of them involving boys, they were socially capable, but eccentric or odd, which often made them appear gauche to typically functioning people (Hippler & Klicpera, 2003). The patients he observed excelled in the fields of arts and sciences, a trait Asperger referred to as extreme male personality (Wing, 2005). Many years later, his work finally influenced the research of other autism experts. Asperger conducted his dissertation research in 1944 during the Nazi occupation of Austria. The combination of the historic context in which he researched and wrote, and the fact that he wrote in German, prevented his work from reaching English-speaking researchers until the early 1980s (Wing, 2005). Though his dissertation was in time found and translated, much of

the work he conducted in the 1940s and '50s was lost or destroyed (Frith, 1991; Wing, 1981).

The Kanner/Asperger research divide illustrates one of the early problems with building a unified body of research—distance, a lack of technology to alleviate the distance, and war disrupted one's ability to construct a worldwide network of research. Yet despite this distance, the two conducted complimentary research. Like Kanner, Asperger believed autistic psychopathy was best categorized as a distinct personality disorder and not a part of schizophrenia. In fact, Frith (1991) wrote that “on all the major features of autism Kanner and Asperger are in agreement” (p. 10)—this, despite the fact that they did not have access to each other's research. In particular, both research populations shared social communication deficits; demonstrated patterned behaviors, including repeated hand flapping and displaying intense focus on certain objects or subjects; possessed an inability to cope with change and often presented special talents. Asperger, however, strongly believed from the time of his first published accounts that autistic psychopathy had a genetic basis (Frith, 1991; Hippler & Klicpera, 2003)

As will be discussed in a later section of this chapter, the introduction of Asperger syndrome influenced the English-speaking, biomedical autism research community. From Wing's 1981 article that introduced the community to Asperger, a fruitful yet sometimes conflict-laden dialogue emerged. Primarily, it instigated changes to diagnostic manuals and influenced the creation of a new term, Autism Spectrum Disorders. However, to this day, significant controversy exists over the relation between

autism and Asperger syndrome. Do they exist on a continuum or are they separate disorders with distinct etiologies?

Distance was not the only issue contributing to the problem of a fragmented research agenda. The presence of competing research paradigms—biomedical psychiatry, psychoanalysis and psychology—seemed to prevent any of the groups from making significant progress with autism research. In particular, many did not want biomedical psychiatry viewed side-by-side with psychoanalysis because their approach to research problems differed. Psychoanalytic theorists studied intrapsychic workings and individual life stories. Their observations and findings did not necessarily translate to valid and reliable information that other scholars could replicate. Biomedical psychiatrists devoted themselves to scientific principles; they made generalizations about autism from their observations of a small group of patients (McCarthy, 1991). Perhaps the best way to demonstrate the presence of these competing voices is to focus in on two scholars whose research, one could argue, sprung from Kanner's initial research on autism. But their clashing worldviews produced conflict, and their conflict is representative of the greater conflict present from the 1950s through the 1970s.

Bruno Bettelheim, a self-proclaimed psychoanalyst, found much success with his research in the 1950s and beyond. Though he initially had little experience with child psychiatry or psychology, he took over the fledgling Orthogenic School at the University of Chicago where he used psychoanalytic theory and milieu therapy to treat children with autism, schizophrenic and other psychological disturbances. The publication of articles such as "Joey: A Mechanical Boy" in the *Scientific American* (1959); magazine



articles published in the pages of *Redbook*, *Parents* and the *Saturday Evening Post* and books such as *The Empty Fortress: Infantile Autism and the Birth of Self*, published in 1967, gave Bettelheim a wide audience for his theories. As has been reported elsewhere, he seemed to have little interest in developing his reputation among psychoanalysts, though his research fell loosely into that paradigm. Instead, he wanted his research to attract the attention of psychiatrists, psychologists and the general public (Severson, Aune, & Jodlowski, 2008).

But Bettelheim's research was really not very scientific. Bettelheim (1967) described the open-ended nature of psychoanalytic theory in the following way:

At the heart of our work is not any particular knowledge or any procedure as such, but an inner attitude to life and to those caught up in its struggle, even as we are. It is an attitude toward others and why they do what they do, which is first of all an attitude toward oneself and why we do what we do; an attitude that was not even available to us before Freud. (p. 11)

Bettelheim also wrote extensively about a guiding idea that he formed at an early age while imprisoned in a Nazi concentration camp. In extreme situations, he believed, humans' psyches could become so badly damaged that they had no choice but to turn inward. Autism was not a neurological- or genetic-based disorder, but one consciously adopted by people who could not cope with their extreme situation. Echoing Kanner's early theory about autism, Bettelheim believed that parents, especially mothers, created this extreme situation for their children when they had little interest in creating a loving environment. The concentration camp/cold mother narrative formed the basis of

Bettelheim's career and—directly defying the biomedical assumption that a researcher always remains objective—it informed and interpreted all of his investigations of children with autism. In perhaps only appearance alone, Bettelheim also mimicked the reporting style utilized by scientists; he reviewed literature and positioned it as a precursor to his analyses, he presented detailed case studies, he drew conclusions and so on. Scientists in the discipline quickly saw through Bettelheim's not-so-subtle research errors, but the general public did not and his work grew the popularity of the “refrigerator mother” hypothesis (Severson, Aune, & Jodlowski, 2008).

But Bettelheim's clearly aligned himself with the psychoanalytic camp, as evidenced by his case studies and review of autism literature. His book, *The Empty Fortress*, presented the case studies of three children with severe autistic afflictions. Bettelheim foregrounded and underscored in each case study the fact that parents created the extreme situation, causing their children to become autistic. There were no hypotheses to test, no research questions, but instead Bettelheim cherry-picked the observations that were most appropriate for his ideas. For example, before going into detail about autism in each of the cases, he began with the mostly depressing histories of the parents. Readers learned that Laurie's mother was perpetually unhappy, once suffering a severe emotional breakdown; her unhappiness, readers gathered, caused multiple failed marriages. Bettelheim also described her as flighty and inconsistent, caring most about Laurie's win at a baby beauty pageant. Marcia's mother was severely depressed from an early age as a result of her father's untimely death. She was indifferent about marrying her second husband, Laurie's father, and eventually,

according to Bettelheim, became resentful for having Marcia. Marcia's father received therapy for severe emotional difficulties, and apparently admitted to Bettelheim that he did not much care for his children ["He who hated being teased, loved to tease small children: 'I like to get babies mad.'" (p. 158)]. Bettelheim began Joey's early history in the following way:

The conditions of life that made Joey decide to be a mechanical contrivance instead of a person began before he was born. At birth, his mother "thought of him as a thing rather than a person." But even before that he made little impression. "I never knew I was pregnant," she said, meaning that consciously the pregnancy did not alter her life. (p. 239)

Bettelheim continued from there, further showing how, through parental neglect, Joey became a person detached from reality and only interested in mechanical objects.

Following his elaborate discussions of each child's early environment, Bettelheim supplied Freudian and other psychoanalytic theory to support his explanations for autism (Severson, Aune, & Jodlowski, 2008). He surmised, for example, that Joey's obsession with mechanical objects—especially objects at the airport—represented Joey's obsession with the departure of his father. Bettelheim interpreted Laurie's inability to defecate properly as a conscious defiance on her part to use all of her body; he argued that Laurie did not fully experience the anal stage in infancy because her nursemaid never treated like an infant. Among other issues, Marcia twiddled, meaning she frequently performed "a rapid shaking of one or two of her fingers" (Bettelheim, 1967, p. 164). Because all actions performed by each child under

Bettelheim's care had an underlying interpretation, twiddling was more than a tic or a way to express nervous energy. He believed that her behavior resulted from her loss of her mother and reality, and Laurie's fingers acted as a substitute for her mother's breast. The case studies contain mostly Bettelheim's (and his staff's) observations of the three cases and his interpretations of these observations. For a more technical, biomedical audience, his case studies did not hold up; that his environmental etiology hypothesis fed conveniently into psychoanalytic theory could not have pleased the biomedical audience with which he desperately wanted to align himself (Severson, Aune, & Jodlowski, 2008).

Bettelheim may owe his career in part to Kanner's refrigerator mother hypothesis. But Kanner's writings indicated his openness in finding many potential causes for autism, and his overall body of work followed in the biomedical tradition of neutrality. Furthermore, Bettelheim did not always agree with what Kanner wrote. In Kanner's observations, for example, echolalia often manifested itself in the way that a person with autism made a request. When a teacher or parent asked the question "Do you want ...?", the child would echo with "you want..." rather than properly say "I want." This became known as I/you pronoun reversal, and most biomedical clinicians saw it simply as a mistake in repetition and a lack of understanding of the difference between the pronouns of "I" and "you." But Bettelheim saw much deeper into this problem, suggesting that when a child with autism refuses to say "I want" it relates to that person's inability or refusal to have a sense of self. He provided evidence from his case studies to support his interpretation, often using examples from a child's ability to

use the word “I”, which typically happened after a significant amount of teaching and therapy. Rather than the child simply learning the difference between “I” and “you,” Bettelheim suggested that such a progression represented the eventual discovery of selfhood.

In *The Empty Fortress*, Bettelheim also took to task another prominent researcher of the time, Bernard Rimland. Much like Bettelheim’s critiques of Kanner, Rimland did not, in Bettelheim’s opinion, take his observations of autism to a deeper, more introspective level. Yet if Bettelheim desired acceptance from the biomedical research community, Rimland succeeded where Bettelheim failed. I turn now to a brief background of Rimland’s work with autism in order to show more thoroughly the clash of two research paradigms.

Rimland, father of a son with autism and founder of the Autism Society of America, was both a research psychologist and a vocal advocate for an autism research agenda that excluded refrigerator mothers. As a research psychologist, Rimland received training in a discipline that had already adopted biomedical principles as their hallmark; he thus described his research as an attempt to “articulate what seems ineffable” (p. 85). Rimland in part used his 1964 book *Infantile Autism* as a forum for discrediting the psychogenic cause for autism and the refrigerator mother advocates. He saw the psychogenic or emotional theories of causation as dangerous and damaging to the parents, and he criticized people like Bettelheim for his lack of biomedical rigor. He also worried that the acceptance of the refrigerator mother hypothesis would minimize the need for others to discover a biological cause(s) for autism. To Rimland, the

refrigerator mother hypothesis convicted many parents with little more than guesswork as evidence. There existed too many cases of attentive parents who had children with autism and negligent parents with typically developing children. Rimland encouraged those who studied autism to properly test their ideas, though he also believed that some of the arguments advanced by psychoanalysts could not be proved or disproved under testing [Rimland's example: "I believed that the child who shows autistic behavior has been traumatized in the early months of life since he symbolizes to the mother so definitely the hated sibling" (Ribble, qtd. in Rimland, 1964/1985, p. 85)].

Instead, Rimland supplanted the emotional theories of causation with arguments for a neurobiological etiology. In other words, Rimland believed that innate brain deficits caused autism. The evidence he supplied came from speculative studies—the absence of technology at the time made it difficult for researchers to properly “see” the brain. He provided nine points for his case for biological causation, and many of these points went on to become cornerstones of autism research into etiology. Two points in particular influenced genetics research: 1) autism, by gender, presented in a ratio of three or four boys for every girl, suggesting perhaps maladaptive genes in males; and 2) of 14 twin sets reported as autistic, 11 were monozygotic (i.e., identical twins). Though perhaps lacking sufficient evidence at the time of his writing, his points were strong enough—they provided enough hope—to convince others that neurobiological research should become an integral part of autism research. From Rimland's perspective, his way was the only humane way to proceed. Supplying early scientific research as his ethos and the pathos of an experienced father, his admonitions to the supporters of a

psychogenesis cause were strong: “To add a heavy burden of shame and guilt to the distress of people whose hopes, social life, finances, well-being, and feelings of worth have been all but destroyed seems heartless and inconsiderate in the extreme. Yet it is done...” (Rimland, 1964/1985, p. 102).

Rimland did not need to fear that psychoanalysts would take over autism research and discourage biomedical research. His appeals to biomedical principles further solidified their importance for autism research (McCandless, 2007). To this day, the precise etiology of autism is far from determined, but Rimland’s work successfully combated the competing theories about autism and greatly influenced the direction of the autism research agenda.

Having just tackled a discussion about the state of early autism research, the next section retreats briefly from autism research in order to provide a broader discussion of the changes in psychiatry that took place in the 1970s. The decision to turn psychiatry into a biomedical enterprise and the establishment of a biomedical charter document greatly affected the autism research agenda. Though autism was born with Bleuler, Kanner and Asperger, its existence and research agenda was ultimately legitimized through psychiatry’s paradigm shift.

## BIOMEDICAL PSYCHIATRY AND THE LEGITIMACY OF AUTISM

The previous section begins to hint at the clash over how psychiatrists and other health professionals believed they ought to conduct autism research. The deep conflicts that emerged from this period of autism research troubled experts who struggled to have their

viewpoint heard and validated. But even more troubling was the fact that the conflicts were widespread in psychiatry. Such divisions, many felt, created greater uncertainty about mental disorders, and this conflict and uncertainty plagued psychiatry and prevented it from becoming a legitimate discipline, one that could receive acceptance within the greater medical discipline. In 1975, psychiatrist Arnold Ludwig, in an essay in the *Journal of American Medical Association*, called the presence of multiple psychiatric worldviews “model muddlement,” and declared: “Psychiatry has become a hodgepodge of unscientific opinions, assorted philosophies, and ‘schools of thought,’ mixed metaphors, role diffusion, propaganda, and politicking for ‘mental health’ and other esoteric goals” (p. 603). And according to Engel (1977), “In contrast [to psychiatry], the rest of medicine appears neat and tidy” (p. 129). As medicine progressed and the biomedical model assumed its dominance in other disciplines, some psychiatrists wished to become unified themselves and aligned with the medical community. Referring to the Greek god of healing, Ludwig wrote, “To the extent that psychiatric physicians largely employ nonmedical models ... they not only forsake their special professional expertise but also abuse their socially sanctioned ‘Aesculapian authority’” (p. 603).

A common language—a language rooted in biomedicine—could set the research community on the proper path toward unification and legitimacy. The community felt an urgency to develop a unified psychiatric profession and a desire to align the discipline with the tenets of the biomedical model. Their desires were rhetorically savvy.



Unification could instruct the larger researcher community how to either fall in or out of line. As Bazerman (1988) wrote:

Only when a community decides there is one right way, can it gain the confidence and narrowness of detailed prescriptions. In rhetoric, “one right way” implies not only a stability of text but a stability of rhetorical situation, roles, relations, and actions, so that there is a little room or motive for improvisatory argument. Within a stabilized rhetorical universe, people will want to say similar things to each other under similar conditions for similar purposes. In this context, prescribed forms allow easy and efficient communications without unduly constraining needed flexibility. (p. 271)

The present discussion then moves to focus on a group of psychiatrists whose efforts moved psychiatry toward a biomedical model primarily through the establishment of a system for accurate diagnosis, “one of the chief aims of medical practice” (Misher, 1981, p. 144). As a result, they created a new reality for psychiatry that attempted to minimize uncertainty. Their diagnostic document became a unifying force for the psychiatric community and, following Bazerman’s ideas, stabilized the rhetorical universe and gave the discipline “one right way.”

### The *DSM-III*

The release of the *Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III)* in 1980 created the dramatic paradigm shift that biomedical psychiatrists hoped to create. In about 900 pages, the authors managed to catalogue approximately 300 mental

disorders. The APA released two earlier volumes—the *DSM-II* was a 150-page, spiral bound text. But psychiatrists overhauled the *DSM-III* in order to provide a comprehensive classification system of all known mental disorders. Robert Spitzer, psychiatrist at the New York State Psychiatric Institute at Columbia Presbyterian Medical Center, was appointed by the APA to take the lead in drafting the third volume. Spitzer himself was science-minded, having drawn on his own experiences with therapy as a teenager to develop a positivist approach to psychiatry. As a 2005 *New Yorker* article documented, Spitzer felt that “the best way to master the wilderness of emotion was through systematic study and analysis” (Spiegel, 2005, p. 56). Spitzer went to work in forming 25 committees, comprised entirely of people who viewed themselves as scientists. People at Columbia referred to the appointees as “DOPs”, or data-oriented people (Spiegel, 2005). The committees met frequently with Spitzer and, as recalled by several former members, the meetings were often chaotic. It seemed that only those with the loudest voices could get through to Spitzer, who spent the meetings furiously trying to keep up with his own notes rather than moderating.

Yet out of the chaos emerged a product that satisfied the DOPs. Ultimately, a few simple biomedical principles guided how the committees developed each mental disorder entry. All disorders were thought of as natural rather than interpersonal or societal; all entries described how the disorders differed from normal behavior. Furthermore, *DSM* authors only had interest in cataloguing behaviors visible to the human eye (Rutter & Shaffer, 1980, p. 383). Researchers did not see patients as “individuals but as members of populations grouped according to observable symptoms”

(McCarthy & Gerring, 1994, p. 150). McCarthy (1991) also observed that the authors of the *DSM* focused on “identification and then explanation”— after naming a mental disorder, they gathered observations in the search for patterns and correlations (p. 361). The APA also concerned itself with relieving psychiatry’s common problem with establishing diagnostic reliability; the criteria set forth for each mental disorder were designed to enable clinicians to make consistent diagnoses. Though perhaps not strictly biomedical, the APA also believed that the disorder should be “worthy” of clinical attention. The syndrome and corresponding behaviors, etiology and mode of treatment were described as distinct from other syndromes. The disorders had to either occur in a substantial amount of the population or, in cases of rare syndromes, be severe enough to be considered a public health threat (Rutter & Shaffer, 1980).

The introduction of the *DSM-III* occurred amidst much turmoil. Psychoanalysts and psychologists knew of the APA’s plans to reorganize. Though many psychiatrists participated in the writing of the *DSM-III*, few knew how the larger community would receive it. To the surprise of Spitzer and his colleagues, its introduction at the 1979 APA assembly received a standing ovation (Spiegel, 2005). But its success is best measured intertextually; the publication incited an explosion of biomedical psychiatry research. The psychiatric community published approximately 2,000 research articles between 1980 and 1987 concerning the manual’s categories and criteria (McCarthy, 1991, p. 375). A good chunk of those research articles addressed the categories and criteria set forth for autism.

Despite the positive response, many in the community were angry. In the

making of the manual, the authors had continually sparred with psychoanalysts about their favored diagnoses. To the dismay of the psychoanalysts, negotiations did little good; the *DSM-III* effectively eradicated their language and, by some accounts, diminished their profession. For example, depressive neurosis was one of the most common diagnoses in the 1970s. But it appeared only parenthetically in a handful of the manual's entries (Spiegel, 2005). Additionally, at the time of the *DSM*'s creation, psychologists dominated psychiatrists in number (McCarthy & Gerring, 1994). Psychologists at first did not receive the *DSM-III* well, and they initially boycotted the manual. Also in response to the charter document—by all accounts a bold assertion of power—psychologists hoped to counter with their own manual. This attempt failed. But from the start, the biomedical psychiatrists knew they had to tread lightly with psychologists and they developed a strategy to dominate the psychologists without alienating them. Some APA affiliates argued publicly that mental disorders ought to be considered a subset of medical disorders (McCarthy & Gerring, 1994). But psychologists protested so loudly that the *DSM* authors went to great lengths to avoid the subject matter and use only language in the manual that they felt would not offend psychologists. *DSM* authors used the term “clinician,” for example, as a universal name even though they clearly wrote the manual for psychiatrists and physicians. Psychologists, many of whom also worked within the biomedical model, eventually ceded their protests and joined in their support of the manual.<sup>3</sup>

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<sup>3</sup> See McCarthy & Gerring (1994) for a more extensive discussion about the battle between psychiatry and psychology in the 1970s and '80s.

### Autism and the *DSM*

The biomedical model offered some important benefits to the psychiatric community. Once known only by niche research communities, mental disorders such as autism gained newfound legitimacy and significance thanks to Spitzer and the APA. Previous *DSMs* classified autism much in the way that Bleuler had, as a core symptom of schizophrenia.<sup>4</sup> In adding autism to the *DSM-III*, the APA consulted many biomedical autism experts when writing its entry. The APA broadened the term infantile autism to become a part of a class of disorders called Pervasive Development Disorders (PDD). Six mandatory criteria for diagnosing infantile autism were set forth as follows:

1. Onset before 30 months of age;
2. Pervasive lack of responsiveness to other people;
3. Gross deficits in communication skill;
4. Peculiar speech patterns, if speech is present;
5. Bizarre responses to aspects of the environment; and
6. Absence of delusions, hallucinations, loosening of associations, and incoherence.

(APA, 1980, p. 89)

The symptoms mirrored many of Kanner's early descriptions of autism, but there were also some changes. The APA considered all disorders, including infantile autism, as multi-axial. That is, psychiatrists acknowledged that multiple disorders or conditions could exist alongside the primary diagnosis of autism. The notion of a multi-axial

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<sup>4</sup> Psychiatric research outside the biomedical realm still exists, especially in Europe, and those professionals continue to refer to autism as a primary symptom of the schizophrenic personality. See, for example Stanghellini, 2001; Volkmar, 1987.

diagnosis plan had particular implications for autism and mental retardation, which were no longer considered mutually exclusive. Mental retardation and autism, or autism and any other number of mental disorders, could both present in combination within a person.

Since the release of the *DSM-III*, the manual has seen widespread use. The acceptance of the *DSM-III* allowed researchers to embrace a common language. This language enabled them to pursue research projects that would combine to create a unified voice for the research community. The creation of this new psychiatric worldview also benefited people outside of the research community. This common language helped to bridge the divide between patients and therapists who could now better unite in their search for diagnosis and treatment (Rutter & Shaffer, 1980). The manual's classification was structured to give "fool-proof little recipes" (Spiegel, 2005, p. 60)—the 1980 PDD entry listed 6 symptoms, or steps, to autism diagnosis—that aided in consistent diagnosis, another of the purported benefits of having a classification system.<sup>5</sup> In turn, better diagnosis enabled researchers to gather good sample populations for research. Outside of hospitals and clinical practices, the court system, social service departments, prisons, schools and welfare offices also found the manual valuable, for better or for worse.<sup>6</sup> For example, the manual has shaped the way insurance companies determine eligibility for mental health treatment (McCarthy & Gerring, 1994).

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<sup>5</sup> Diagnostic consistency remains suspect by critics of the manual; see Kutchins & Kirk 1997.

<sup>6</sup> See Kutchins & Kirk's (1997) first chapter for a discussion on how the manual diminished Anita Hill's sexual harassment case against Supreme Court Justice Clarence Thomas.

Authors of *DSM-III* welcomed commentary and criticism. Almost as quickly as the APA released the *DSM-III*, researchers turned their attention to the changes necessary for the next edition of the manual. Despite some of the groundbreaking research done by Kanner, Eisenberg, Rimland and others, many felt that the PDD entry lacked extensive empirical testing.<sup>7</sup> Fred Volkmar, child psychiatrist and primary investigator for APA autism research projects, voiced several concerns about the *DSM-III*. He argued that the PDD entry in the *DSM-III* did not have enough empirical support and, consequently, clinicians could not make accurate diagnoses (Volkmar, 1987). Inconsistency in diagnosis threatened the quality of necessary educational interventions. Diminished opportunities for intervention meant less opportunity to reverse the many negative afflictions that a child with autism can experience. Volkmar eventually spearheaded the effort to conduct extensive field trials, and these trials would become the basis for the *DSM-IV* entry for autism (e.g., Volkmar, et al., 1994).

The APA readily acknowledged that they had a work-in-progress on their hands. Thus, significant revisions were necessary in order to “keep up,” so to speak, the legitimacy of the charter document and, more broadly, the role of biomedicine in psychiatry. The *DSM-III-R*, released in 1987, responded to some of its criticism. They changed “infantile autism” to “autistic disorder” in order to reflect the notion that autism, though mostly diagnosed in young children, is a lifelong disorder. The revision also contained more detail that captured the developmental changes experienced in the

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<sup>7</sup> Though many autism researchers are quick to point out that autism research was much further along at this point than some of the other disorders listed in the *DSM-III* that appeared to be created out of thin air. (Kutchins & Kirk, 1997; Mesibov & Van Bourgondien, 1992; Spiegel, 2005)

lifespan of a person with autism. The APA added another category within PDD called Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS) for those who, at the time of diagnosis, did not fulfill all of the criteria for autistic disorder. In a clear attempt to improve consistency in diagnosis, the authors added more diagnostic criteria for all the disorders that fell under the PDD umbrella and they provided more descriptions for those criteria.

Though not quite to the scale of the *DSM-III*, extensive work went into the construction of the *DSM-IV*. It took six years to complete. Approximately 1,000 psychiatrists and mental health professionals participated in the revision process, costing the APA and other affiliated agencies millions of dollars (McCarthy & Gerring, 1994). Once again, with the release of the *DSM-IV*, its authors hoped to “achieve acceptance of psychiatry as a mature, research-based specialty within medicine” (p. 149). During its construction, the APA also had to contend with the *International Statistical Classification of Diseases and Related Health Problems-10 (ICD-10)*. Published by the World Health Organization in 1992, its content signaled to the APA that the forthcoming fourth version of the *DSM* had some catching up to do. The *ICD-10* catalogued far more than just mental disorders (it primarily contained a comprehensive list of diseases and morbidity statistics), but its mental disorders section grew in comprehension. The *ICD-9*, released in 1975, had an entry similar to the *DSM-III*, and it was influenced by key autism researchers like Kanner and Michael Rutter (Dulcan & Wiener, 2004). Rather than PDD, the *ICD-9* referred to autism as a subtype of “psychoses with origin specific to childhood” (qtd. in Dulcan & Wiener, 2004, p. 262). But the *ICD-10* changed its



direction and included PDD as well as several more classes of disorders within PDD, including Rett Syndrome, Childhood Disintegrative Disorder, and Asperger Syndrome. It also included more historically oriented criteria, referring to descriptions at age of onset (Volkmar et al., 1994). A large field trial, conducted at 21 different sites around the U.S. and the world and supported by 5 grants, used the *ICD-10* as well as the *DSM-III* and *DSM-III-R* to better study the reliability and validity of each of the texts in terms of diagnostic criteria. Ultimately, Volkmar, *et al.* (1994) recommended that the *DSM-IV* mirror the PDD entry in the *ICD-10* for consistency purposes and because they found it to be a much better diagnostic tool. Based upon these recommendations, the PDD entry in the *DSM-IV* closely resembled the *ICD-10*. The *DSM-IV* listed a triad of impairments that someone with a PDD will possess. This included impairment in social interaction, which can include one or all of the following sub-criteria: problems with eye contact and other body language, lack of emotional reciprocity, failure to develop relationships with peers and absence of spontaneity in sharing enjoyment with others. Communication impairment can include language delays, the inability to initiate or maintain a conversation, repetitive use of language and absence of spontaneous play or make-believe with others. Finally, the impairment of stereotyped behaviors includes repetitive motor mannerisms like rocking or hand flapping, the maintenance of rigid routines, an intense fixation on certain objects and intense fixation on certain subjects (APA, 1994, p. 70-71). The 1994 manual followed the *ICD-10* in broadening the classes of disorders within Pervasive Developmental Disorders to include Autistic Disorder, Rett's Disorder,

Childhood Disintegrative Disorder, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (APA, 1994, p. 65).

The 1994 manual also better reflected the notion of autism as a spectrum of disorders, a controversial concept introduced by Wing (1981).<sup>8</sup> That is, autism, Asperger syndrome, Rett's syndrome, PDD-NOS, and all other developmental disorders are all related, but vary in their severity.<sup>9</sup> A person's specific diagnosis depended upon which and how many sub-criteria within each of the three major impairments he possessed. For example, a person diagnosed with autism must meet eight of the *DSM-IV*'s sub-criteria. Asperger syndrome, on the other hand, requires an individual to meet five or six different sub-criteria, thus making it a milder PDD. The rationale for considering disorders like autism and Asperger syndrome on a continuum of severity, according to Wing (1981), was simply a matter of acknowledging the similarities between autism and other disorders. Wing cautioned, however, that researchers know very little about each disorder. It is still quite possible that, despite their similarities, each disorder may have very different etiologies.

Ever concerned with reinforcing their legitimacy and retooling their official language, the APA has scheduled a *DSM-V* release for 2012. It is difficult to determine what exactly, if anything, will change in the PDD entry. Some scholars such as Wing (2000, 2005), for example, have publicly advocated for more changes. There is particular displeasure about the current conception of Asperger syndrome. It often

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<sup>8</sup> In fact, authors writing in the flagship journal for autism, *Journal of Autism and Developmental Disorders*, commonly use the term Autism Spectrum Disorders, or ASD, rather than PDD.

<sup>9</sup> Against the *DSM*, Wing (1981, 2000, 2005) has argued that social interaction, verbal and nonverbal communication and imagination are the three impairments central to PDD and its diagnosis.

presents very mildly in people, and that makes the syndrome difficult for clinicians to diagnose with consistency if the person receives a diagnosis at all. Additionally, Wing (2000, 2005) argued that the *DSM-IV* entry did little to reflect what Asperger initially described in his own research. Either the description of the disorder should change to match Asperger's accounts, she argued, or the APA should remove Asperger's name from the disorder. In all, however, the research leading up to the release of the fourth volume of the *DSM* pleased autism researchers, and some have evaluated the PDD entry as one of the most empirically validated disorders in the manual (Volkmar, 1994).

Despite the attempts at revision, both biomedical and other criticism of the *DSM* lingers. First and foremost, the *DSM* does not totally adhere to biomedical principles; questions about reliability and validity remain, particularly regarding entries that provide relatively vague checklists for behavior. Diagnosis comes about through patient and family reports, and it requires a knowledgeable clinician to effectively interpret these reports. This stands in contrast to traditional medicine, where lab tests, x-rays, and other tools offer greater consistency in diagnosis. Ultimately, the success of the manual depends on individual interpretation, and this threatens reliability (McCarthy & Gerring, 1994). Second, from the construction of the *DSM-III* onward, APA authors defied the once-common view of mental disorders as "not clearly bounded but on a continuum with normal behavior" (McCarthy & Gerring, 1994, p. 159). To adhere to biomedical principles, mental disorders became far more distinct. Yet some of the *DSM's* entries, some might argue, do not differ significantly from normal behavior. Kutchins and Kirk's *Making Us Crazy* took a particularly critical stance against the *DSM*, arguing that

the inclusion of everyday behaviors, whether normal or otherwise, found their way into the manual and, as a consequence, have skewed what society views as acceptable behavior. The authors cited an instance in the 1970s, when the APA sought to pathologize homosexuality and Post-Menstrual Syndrome (PMS). Many at the APA exerted significant influence in order to ensure the inclusion of homosexuality and PMS in the manual, but public outcry caused the APA to back down. Neither disorder made it to publication, but it nonetheless caused critics to worry about the slippery slope between dysfunctional and typical behavior. But other sets of everyday-seeming behaviors have constituted legitimate disorders, such as Excessive Motorized Speed Disorder (EMSD). EMSD, as described by the *DSM*, is disorder characterized by an overwhelming desire to speed, and this desire can cause distress to the individual. By the APA's account, Kutchins and Kirk wrote, "Every sports car enthusiast, speed boat operator, and motorcyclist would be mentally ill" (p. 252). Even some forms of autism, some believe, could potentially exist on a continuum with neuro-typical people. Noted autism researcher Simon Baron-Cohen (2002) recently wondered whether "Asperger syndrome (AS) should necessarily be viewed as a disability or, from a different perspective, as a difference" (p. 186). Finally, some continue to feel troubled by the ultimate goal of the classification system—to label people. If, as the authors of the *DSM* suggest, these labels represent one viewpoint about the inner-workings of the mind, why then are labels so often treated as fact? The rhetorical force of the *DSM* and the widespread adoption of its language has created a terministic screen; the language

produced by the *DSM* overshadows other possible ways of explaining autism and other mental disorders.

## CONCLUSION

Since the explosion of autism and other kinds of psychiatric research following its biomedical revolution, researchers have continued to fill in the uncertainty gaps, or jigsaw puzzle, with more pieces. The purpose of this chapter, in part, was to introduce readers to some of the knowledge the research community has produced about autism. Chapter III will continue in this vein. In this chapter I also intended to introduce to autism research and psychiatry as socially constructed entities. The APA appointed data-oriented people to create a manual that presented psychiatry with a unified language. This point of view became the correct way to explain mental disorders, though as others have pointed out, this locally held “truth” is often imperfect. Writing amidst the discussions leading up to the release of the 1980 volume, Joseph Zubin (1977/1978) pointed to the flaws of a socially constructed, but authoritative document. First, the so-called observable behaviors documented in the manual came about as the result of many years of debates among committees. Second, the *DSM* was also susceptible to external influence. In some instances, such as in the homosexuality and PMS entries, this influence was probably for the better. Zubin also argued: “Scientific values were bent to suit the needs of psychiatry, third-party payments, certification, and economic exigencies of one sort or another” (p. 5). But no one can deny that the APA’s strategic construction of a charter document has perpetuated a biomedical psychiatry far

beyond expectations. The appearance of the manual alone gives the impression of authority; in the library, the 900-page reference book sits alongside other authoritative documents like dictionaries and encyclopedias.

The construction of a biomedical worldview contributed to the perception of an overall reduction in uncertainty about mental disorders. As Michael First, one of the *DSM-IV* contributors, admitted, the *DSM* “provides a nice, neat way of feeling you have control over mental disorders,” but it is merely “an illusion” (qtd. in Kutchins & Kirk, 1997, p. 260). In reality, the descriptions offered in the *DSM* fill in a small number of pieces in the much larger mental health puzzle. A 900-page manual communicates certainty in a very powerful way, but what we do not know about mental health could fill thousands of pages. Zubin (1977/1978) observed, “Our map of psychopathology is no better than the map of the world conceived by the ancient cosmologists before geographic exploration became possible” (p. 6). It is here that the rhetorical force of the *DSM* is quite evident; it offers so much certainty when, in reality, little is known.

The next chapter continues to work with the notion of the *DSM* and the biomedical model as the creators of certainty. The historical context addressed in the second chapter will prove useful as the analysis examines the rhetorical strategies that autism experts adopt in explaining autism. What are these rhetorical strategies? How do these rhetorical strategies continue to perpetuate the biomedical explanatory model? A deeper analysis of the professional literature about autism will begin to uncover some answers to these questions.

### CHAPTER III

#### AUTISM, BIOMEDICINE AND THE BIRTH OF A METAPHOR

Chapter II introduced readers to psychiatry and autism research as socially constructed disciplines. Following Leo Kanner's first articulation of infantile autism, theories and further articulations abounded, but they often collided with one another, producing disagreement rather than cohesion. This problem existed on the whole in psychiatry, and the biomedical psychiatrists combated disagreements by making efforts to mainstream their own ideas and exclude all others. Since the 1970s, autism research continues in the tradition of biomedical research.

However, autism research now goes far beyond how the American Psychiatric Association initially chose to define it. It is thus necessary to devote another chapter to autism research and rhetorical construction. This chapter accepts the biomedical paradigm as the dominant worldview and delves deeper within. It is within this broad worldview that a smaller dominant paradigm now exists. Psychiatry took the lead in molding autism research as we know it today, but several other disciplines have since taken over. Clinical psychologists, neuropsychologists and neuroscientists (to name a few) have influenced a new line of thought and argument within the autism research community.

With the assistance of Kuhn's (1962) influential notion of a paradigm shift, in Chapter II I argued that a crisis in psychiatric research brought forth a need for a new

worldview. The *DSM-III* supplied the language that constituted that new worldview of psychiatry and autism research. In this chapter, I further examine the language that constitutes autism research. Specifically, I trace the rise of a new metaphor, the brain-as-computer metaphor, that has guided the autism research trajectory toward further community cohesion. Regarding the place of metaphor in science, Daugman (2001) wrote that “[t]he life cycle of the dominant metaphor in a scientific theory demarcates the life science of the paradigm itself, and the adoption of new metaphors is said to be the signature of transitions between paradigms” (p. 23). The computer metaphor was introduced to autism research in the early 1970s (e.g., Kahn & Arbib, 1973), but took more than a decade to really resonate. The growing presence of the metaphor in autism research lent the study of autism even more of a biomedical and scientific authority. It propelled the research into the 21<sup>st</sup> century, lending it considerable credibility as a cutting edge approach. The guiding metaphor encourages certain lines of argument and directs researchers to understand autism in its terms. As a metaphor within the larger puzzle metaphor, it opens up particular pathways that will inevitably lead to particular answers; the brain becomes the puzzle awaiting solutions.

In the analysis of this metaphor, I draw upon a variety of autism research texts. Primarily, I examine the *Journal of Autism and Developmental Disorders* (hereafter, *JADD*) from its first issue in 1971 to the latest in 2008. *JADD*'s early editorials, research articles and even book reviews give key insight into the ebb and flow of research ideas as a community of scholars came together. It also offers a sense of how this research community changed over time, as well as a sense of which research ideas



are, for the time being, here to stay. Using *JADD* as a springboard, I relied on research articles from other journals and also key books for additional insight. The most useful books came from some of the current leaders in autism research including Uta Frith, Simon Baron-Cohen and Beate Hermelin.

The chapter proceeds first with some more context. I provide additional detail about how an interdisciplinary biomedical research community took over autism research in the 1970s. This context sets up an exigence, or urgency, that was satisfactorily answered by the computer metaphor. I then briefly introduce the interdisciplinary subject known as cognitive studies, responsible for producing the computer metaphor. From there I proceed with an examination of the computer metaphor in autism research.

#### A TASK FORCE WITH A GOAL

In examining the history of autism research, psychiatrists' desire for a paradigm shift in the late 1960s and early 1970s cannot be understated. The APA task force took almost a decade to overhaul their diagnostic procedures and disciplinary language in order to move psychiatry toward biomedicine and away from other humanist approaches.

Biomedical psychiatrists with an expertise in autism felt similarly. The *Journal of Autism and Childhood Schizophrenia* (renamed in 1979 the *Journal of Autism and Developmental Disorders*), first published in 1971, was the biomedical community's initial attempt to establish their own charter document of sorts. Their hope was that their research articles would constitute a community of scholars unified under the principles

of biomedicine. Spearheaded by child psychiatrist and modern-day “founder” of autism Leo Kanner, “a task force of scientists representing many fields of endeavor” (Brown, 1971, p. 2) united with the purpose of better understanding and helping children with autism and other “psychotic” disorders. The task force then launched the journal. The mission of the journal, as outlined in its first editorial, communicated a clear agenda:

As the list of the Board of Editors shows, this journal proscribes no theoretically or otherwise constructed roads to understanding psychotic children, but wishes to promote scientifically ascertained observations and facts from every source which can widen our horizon, whether they confirm, expand, reduce, or negate existing hypotheses. (Brown, 1971, p. 2)

The makeup of the editorial board also helped to support the mission. Kanner held the editor-in-chief position. Child psychiatrists with biomedical interests held Associate Editor positions. The editorial board was a bit more expansive. It included more child psychiatrists, a geneticist, a biochemist, a pharmacologist, a neurologist, an ethologist, pediatricians, psychologists and education specialists. Only one of the child psychiatrists on the board had a psychoanalytic background.

Despite this clear mission, the articles initially published in *JADD* still reflected the fragmented community of decades past. Between 1971 and 1978 a handful of articles rooted in the psychoanalytic tradition appeared. These articles existed alongside articles containing repeated criticism of the psychoanalytic approach. Biomedical researchers especially criticized the psychogenic, or causal, theories of autism, and others accused this research tradition of impeding scientific research progress in the

areas of diagnosis and etiology (Brown, 1973; Darby, 1976; Wing & Wing, 1971). To the credit of Kanner, the psychoanalytic articles he included were narrow in scope. They addressed theories of childhood development with no mention of controversial theories of etiology. Rene Spitz (1971), for example, stayed within the disease theory of biomedicine in writing about social affective disorders as indicators of underlying disease rather than as disorders themselves. Margaret Mahler and Manuel Furer (1972) elaborated upon a separation-individuation theory, explaining that the critical time of separation-individuation for an infant could become disrupted and bring about autism. Yet even the Mahler and Furer piece was questionable because they openly acknowledged the difficulty others would have in replicating their theoretical findings in other research projects—a clear violation of the guiding principles of the journal.

If the journal initially tolerated Spitz, Mahler and Furer, the psychogenic theorists were not. Perhaps the most vocal critic of psychoanalytic theory was Eric Schopler, psychiatrist and founder of the TEACCH (Program for Treatment and Education of Autistic and Related Communication Handicapped Children) program. Schopler also took over as editor of the journal in 1974 when Kanner became too ill to continue. One can assume that, with Schopler's background as a psychiatrist for children with autism and other mental illnesses, he saw first-hand the damage done when other therapists blamed parents. Of the psychogenic theories like Bruno Bettelheim's, Reichler and Schopler (1971) argued that they lacked scientific evidence and created a community of distanced experts who intentionally usurped parental expertise. This expert-parent relationship caused difficulties for parents who only wanted to better

understand their children's conditions (Schopler, 1976a). Schopler (1976b) directly critiqued Bettelheim and his theory while doling out a negative review of Bettelheim's 1974 book *A Home for the Heart*. Bettelheim's research, he wrote, contained significant bias and lacked scientific validation for his arguments. He used the book review to warn other experts that, contrary to Bettelheim's claims, readers would learn nothing about differential diagnosis, details about autism and schizophrenia or running a therapeutic center; but they would receive a lot of misinformation.

Even the small sliver of psychoanalytic research permitted in the early years of the journal was squeezed out by the late 1970s. The final psychoanalytic article to appear in the journal followed up on the progress of a patient who was originally a part of Kanner's first case study about autism (DesLauriers, 1978). "Clarence" sought the professional help of the author because he wanted to find a girlfriend. DesLauriers suggested that Clarence's desire for love and his eventual success in finding it meant that his autism (and all others' autism) was, at its core, a disorder of affective contact. Clarence learned how to find a partner and, thus, was cured of all of his problems. Unlike the other psychoanalytic articles in the journal, the journal published two responses written by other members of the editorial board to follow the original article. The critics discredited the study for lack of proof (Eisenberg, 1978) and sloppy research that drew broad conclusions from a single case study (Anthony, 1978). Anthony even wondered whether Clarence had autism at all. This final appearance of psychoanalysis in *JADD* stands as a final reminder of why the task force formed to create a journal in the first place. Psychoanalytic ideas—so dominant in the 1950s and 1960s—took away

from biomedical research and generated hypotheses and theories that were thick on description but too quick to draw conclusions.

In the 1970s, most published articles in *JADD* pursued research firmly grounded in science. But even the gradual elimination of psychoanalysis from the pages of the journal did not foster total unification of the community. Researchers from many disciplines answered the initial call of the task force, bringing forward varying explanations for the diagnosis, cause and treatment of autism. Some of these disciplines were very new (e.g., genetics), while others were close to falling out of favor (e.g., behaviorism). It would take some time before the research could gel together around a few guiding theoretical tenets. The elimination of psychoanalysis, combined with the need for a cohesive research tradition, created an opportunity for one major research paradigm to step forward. Cognitive studies, an interdisciplinary combination of linguistics, psychology, computer science and neurology, answered the call. It became an ideal perspective from which to understand autism because it grounded the research tradition firmly in science and it moved the research trajectory forward in innovative ways.

#### COGNITIVE STUDIES AND THE COMPUTER METAPHOR

Cognitive studies came together with the assistance of several different disciplines.

First, from psychology, it drew on the ideas of Jean Piaget (1923, 1924). Piaget believed that a child's cognitive capacity developed in accordance with a pre-existing plan in the brain. This plan guided the brain to develop in stages. Where experience was

previously believed to be the primary factor in a child's development, Piaget believed that experience and the *a priori* cognitive structure shared equal responsibilities in the development process. Piaget advanced his theory on developmental psychology in the 1920s, but it was not until the 1960s when linguistics reaffirmed its significance particularly when linguist Noam Chomsky (1968) adopted it for his model of transformational grammar. Chomsky suggested, contrary to popular belief at the time, that humans were born with the brain capacity to develop language skills. While most others believed language came about because of experience, Chomsky echoed Piaget in arguing that experience nurtured the innate brain structures.

Most importantly, cognitive studies borrowed principles from computer science. Adopting the computer as its master metaphor, cognitive studies restructured how people understood the brain. For some, the metaphor offered insight into the programming of our brain, or "the sequence of symbol manipulations that underlie thought" (Howard, 1983, p. 11). For others, it pointed to possible physical structures—modules or networks that acted similarly to a computer's central processing unit in controlling thought and outward behavior (Nadesan, 2005). Neuroscience in particular took up the metaphor as its guide, defining the brain as a central command system that controls thought and action through a series of complex networks.

Metaphors, as Burke (1969) has argued, are devices "for seeing something *in terms* of something else" (p. 503, emphasis his). The adoption of this mechanical metaphor stemmed from a longstanding tradition in medicine of viewing the body as a machine (see Daugman, 2001; Osherson & AmaraSingham, 1981; Payer, 1988). In

Payer's (1988) account of Western medicine, she entitles her chapter about American medicine "The Virus in the Machine." From the very beginning of their medical careers, students are indoctrinated with the body-as-machine metaphor. Anderson (1989) wrote:

Medical students' first job is to dissect, to study the human machine as an incredibly complex set of interlocking systems, each of which must be meticulously and repeatedly disassembled so that when the time comes to practice medicine, they will know exactly how the mechanism fits together. (p. 9)

The brain is a particularly complex organ in the body, and it is only fitting that scientists assigned it a more specified mechanical metaphor.

The transference of mechanical descriptions onto the human brain illuminates function and purpose for the organ. As early as fifth century BC, "the School of Hippocrates advocated an early hydraulic model of mind based on the four humors, whose preponderance or imbalance could be related to mental dispositions" (Daugman, 2001, p. 26). Descartes compared his brain to an automaton—an early version of the robot—in its remarkable ability to consistently receive sensory information, memorize, generalize ideas, express emotion, and move the body (Vartanian, 1953). Regarding the current computer metaphor, consider a key computer science term, "cybernetics," which derives from the Greek word *kybernētēs*, translating to "helmsman controlling the ship" (Daugman, 2001, p. 26). The computer metaphor, along with earlier metaphors for the brain, had in common a desire to assign bodily agency to the brain.

Viewed through a medical lens, however, greater control belongs with the experts, or technicians, of the brain. The computer metaphor implies that, if computers

can be examined, manipulated, or fixed, the same can be done to the brain. Nadesan (2005) wrote: “[t]he cognitive paradigm’s metaphor of the mind as computer appealed to parents who sought to program their children with just the right skills and aptitudes required in an increasingly competitive and technical workplace” (p. 108). The brain-as-computer comparison, and parents’ and practitioners’ ability to control it, seems a favorable alternative to the psychoanalytic theory of decades past. Parents are relieved of two burdens: 1) that they in some way caused autism in their children, and 2) that the damaged, or metaphorically virus-ridden, brain cannot be fixed.

The ethos of the computer also helps to explain the metaphor’s appeal. The device is synonymous with cutting-edge and complex technology. We rely on computers in our daily lives, but few of us are capable of understanding how they function (as I learned first-hand when the hard drive of my computer crashed during the production of this chapter). To align a discipline like psychology or psychiatry that struggled to gain acceptance as a legitimate science with the ethos of the computer was strategic indeed. Nadesan (2005) wrote:

By appropriating the computer as the metaphor for the mind, the discipline of psychology persuaded the academic world and the public of its legitimacy and relevance for late-twentieth-century life. [...] The blend of neurology with the cognitive framework afforded the latter legitimacy while providing the former a coherent representational framework for modeling the brain-mind relationship. (p. 109)



The influence of cognitive studies drives the rest of this chapter forward because it drives the current autism research agenda. Burke wrote that a powerful metaphorical concept like that of the computer will serve “as the cue for an unending line of data and generalizations” (1945, p. 95). Indeed, under the umbrella of cognitive studies, the research problems are endless. In the 20 or so years since the cognitive studies paradigm began to dominate the discourse, it has only continued to increase in value. It serves a very important explanatory function for researchers. Specifically, three theories best represent how autism research has developed over the last 20 years and how it has laid the groundwork for future research.

#### AUTISM AND THE COMPUTER METAPHOR

Much like the task force that guided autism towards biomedicine, it would take a community of scholars in positions of power to steer autism research in the direction of the cognitive studies paradigm. In 1982, *JADD* published a special issue devoted to neurobiological research for autism. In the introduction to the issue, two researchers at Yale Child Study Center wrote what amounted to a mission statement about the future of autism research. In part, they yearned for more rhetorical unity as a means for increasing research in areas of psychology and neurobiology:

More than any other resource, there is a critical shortage of clinical investigators who are scientifically committed to research on autism and similar disorders. To be effective, these investigators must work in centers of research that are sustained over many years during which various biological, behavioral, and

educational disciplines can share perspectives, methods, findings, and questions. Biomedical researchers on autism must be active in the broader field of developmental biological research, poised in a position to capitalize on advances in theory and methodology and to contribute knowledge about the developing brain and behavior. (Cohen & Shaywitz, 1982, p. 107)

An answer to this call was already in the making at universities in and around London. London is home to many well-known autism researchers including Sir Michael Rutter and Lorna Wing. The first long-term autism experiments were carried out at Medical Research Council's (MRC) Cognitive Development Unit at the University College London in 1969 by Beate Hermelin and Neil O'Connor (1970). The MRC Cognitive Development Unit would produce much more autism research in years to come. In the 1980s, Uta Frith worked with Simon Baron-Cohen, then a PhD student, and Alan Leslie, doing his postdoctoral work, to produce some theories that would change the way researchers explained autism. Their devotion to biomedical research and their collective acceptance of the cognitive studies paradigm would give the autism research community a much-needed sense of rhetorical unity. This sense of unity propelled the cognitive studies paradigm into a position of great explanatory power. This power still thrives today.

It is important to note that, during the rise of the cognitive studies paradigm in autism research from researchers at the MRC Cognitive Development Unit, *JADD* was not the go-to vehicle for publishing this research. Rather, *JADD* seemed to lag a few years behind. For example, the most notable Theory of Mind articles appeared in

*Psychological Review* (Leslie, 1987) and *Cognition* (Baron-Cohen, Leslie, & Frith, 1985). Though impossible to intuit exact motives for why this occurred, I speculate that the adoption of cognitive studies afforded autism researchers greater credibility to publish in a range of journals. The expanse of these publications might, in turn, lend greater credibility to the scholars as experts in cognitive studies rather than as autism experts.

I turn now to outline three major theories of autism and the presence of the computer metaphor in these theories. The *DSM* documented key observable behaviors people with autism present; the computer metaphor extends these explanations, further explaining why these behaviors occurred and hypothesizing about how the dysfunctions might happen. In short, the *DSM* offered an answer to the question, what is autism?, and the computer metaphor begins to answer questions about how autism happens and why it happens.

### Theory of Mind

The *DSM-IV* autism entry described impairments in eye-to-eye gaze, abnormalities in social interaction and an inability to participate in symbolic or imaginative play. The first of the major cognitive studies-driven theories, Theory of Mind (ToM), uses the computer metaphor to push for more answers. ToM suggests that humans are *hard-wired* with the ability to read others' minds. Suppose a child plays with a toy and then he drops it on the ground. When his mother looks at the child and his toy, the boy will instinctively know that this look means that she wants him to pick it up. People with

autism often do not have a ToM, meaning that their hard wiring does not function in a way that enables them to read another person's mind (or eyes). Frith (2003) called this an inability to "mentalize". Frith, Leslie and Baron-Cohen discovered ToM by studying whether children with autism could interpret others' mental states. Drawing on mechanical language, Frith (2003) wrote:

This enterprise was built on the radical assumption that the mind of the infant is equipped from birth with mechanisms that accumulate knowledge about important features of the world. We assumed that even the newborn child has built-in expectations about objects and about people and responds to them differently. ... Our idea was that theory of mind was critically based on such a mechanism and that, if this mechanism was not working, development would go wrong and autism would result. (p. 80)

Leslie (1987) brought greater understanding to ToM through his study of pretend play. He also drew on the computer metaphor, focusing on the mechanical term "decoupler," which Leslie believed to be an important mechanism that fails in the child with autism. This decoupler routes thought between two circuits, the imaginary and the real. For example, other children can understand that using a banana as a phone (representation) is not the same as using an actual phone (reality) because they have a decoupling device that appropriately routes their thoughts and actions. Children with autism lack the decoupling device—all thoughts and actions are routed into the realm of reality. The absence of pretend play, Leslie argued, is indicative of a larger problem of mind reading. Again, a person with autism only understands his reality, and not others'. In 1995,

Baron-Cohen presented what would become the most developed explanation of ToM in his book, *Mindblindness*. At the cognitive level, Baron-Cohen argued that “the mindreading system has . . . four separate mechanisms or subcomponents” (p. 84), concurring with earlier speculations that ToM was “domain specific” (Leslie & Thaiss, 1992). When working properly, the modules set in motion a chain of events in which a person can follow a person’s eye gaze, pretend play and mind read. Baron-Cohen wrote that, in autism, these mechanisms, or modules, “. . . come apart or ‘fractionate’ from one another” (p. 58). Through evolution, Baron-Cohen posited, brains developed the capability to mind read. He wrote: “If you are living in a social group of 200 [as opposed to two], making sense of the social behavior is staggeringly complex. One needs a powerful device—or set of devices—to make sense of actions, rapidly, in order to survive” (p. 14). ToM is the most developed and studied of the three major theories about autism, and it has expanded to explain other known deficits, covering the areas of joint attention, eye gaze and empathy.

#### Weak Central Coherence

The *DSM-IV* autism entry also reported on limited patterns of behavior and intense fixation with parts or objects. Weak Central Coherence theory (WCC) takes a new tack on these outward behaviors, focusing instead on how a person with autism receives—or inputs—information. WCC suggests that people with autism input data in smaller, more piecemeal way than typically developed (i.e., neuro-typical) people. Like ToM, WCC originated in the MRC Cognitive Development Unit with Frith and several of other

colleagues. Of Frith's theory, Francesca Happé (1999) explained: "Central coherence (CC) is the term she coined for the tendency to process incoming information in its context—that is, pulling information together for higher-level meaning—often at the expense of memory for details" (p. 217). Perhaps the simplest example is how people put together a jigsaw puzzle. Neuro-typical people need a picture of the end-result as a reference point; the individual pieces seem meaningless on their own without a bigger picture. Frith, on the other hand, found that children with autism could easily put together a puzzle without a picture (Frith & Hermelin, 1969). They seemed focused on either individual pieces or small clusters of puzzle pieces. So while typical children have a "central cohesive force" (Frith, 2003, p. 161) built into their cognitive system, a person with autism has a cognitive system characterized by detachment. But rather than seen as a disability, followers of WCC prefer to frame autism as a disorder with different abilities. Their internal cognitive systems endow them with the ability to process information in great detail. One of the most fascinating lines of research coming out of WCC is the savant abilities that some people with autism have. For example, Mottron, Peretz and Ménard (2000) studied auditory processing in people with autism and found that they can remember absolute pitch very well and can also detect single wrong notes within a larger song. Especially in these kinds of studies, the computer comparison is evident. The perfection that is required to detect small errors or recall and project perfect pitch seems something that only machines like computers, rather than humans, can achieve.

## Executive Function

The *DSM-IV* does not catalogue all of the behaviors that characterize autism, and the final theory, autism as an executive disorder, accounts for many of these undocumented characteristics. The theory does explain what the *DSM* implies, that autism is a dysfunction of control. It is the only theory to not have roots at the Cognitive Development Unit at the College of London, but instead came together nearby at the University of Cambridge. Executive Function theory (hereafter, EF) assumes that the brain controls all actions. Like the old metaphor of the brain as ship's helmsman (Daugman, 2001), EF implies that there is a central control mechanism located in the brain. Keeping in line with the computer metaphor, the mechanism is the central processing unit (hereafter, CPU), or the device that executes computer programs. With autism, there is a dysfunction of the control mechanism. This affects planning, inhibitions and "...holding information online in working memory" (Happé, 1999, p. 217). The brain's executive function controls many different cognitive operations. Certain clinical tests have shown executive dysfunction in children with autism quite well. Ozonoff (1997) wrote about a sorting task in which children were assigned to sort blocks according to a specific pattern. Midway through the experiment, the children were told that the sorting pattern had changed. Neuro-typical children could easily adapt and sort according to the new pattern while children with autism could not. EF also explains the presence of repetitive behaviors such as hand-flapping or rocking (Turner, 1997). Drawing on the mechanical metaphor, Frith (2003) wrote:

A living machine such as human brain never stands still. It constantly responds to stimuli. Even when it does not respond, it runs, just as an engine continues to run in neutral gear. Brain impairment often means that the organism cannot respond flexibly and quickly. Still, the mental engine runs. Often the activity is quite unidirectional and appears as endlessly repeated loops of behavior. (p. 174)

Frith went on to explain that, while all humans experience nervous tics or repetitive behavior to some degree, people with autism lack the instinct of knowing when to stop. Furthermore, their inability to understand socially inappropriate behavior—also an executive dysfunction—prevents them from stopping strange repetitive behaviors in the presence of others. Devotees to the theory of autism as an executive disorder have suggested that EF precedes ToM. A lack of planning and behavior monitoring may lead to the disengagement from others' personal mental states (Russell & Jarrold, 1998). That is, a dysfunction in the central control mechanism of the brain may lead to split in the cognitive modules that control mindreading. ToM is a program that depends upon the effective operations at the level of the CPU.

#### Bottom-Up Research: The Limits of the Computer Metaphor

Experts consider the three explanatory theories I just described to be “top-down” explanations (Loveland, 2001). Such theories use observable autism behaviors and attempt to explain those behaviors through specific mental functions or dysfunctions. The computer metaphor affords top-down experts an endless avenue for generating hypotheses about brain structures. Terms like decoupler, information processing and



CPU are just a few of the many that explain autism and the brain and mind. Bottom-up researchers, unfortunately, do not have the same luxury. They begin their studies with physical brain imaging (Loveland, 2001). The computer metaphor offers insight and credibility to hypothetical cognitive structures, but does not assist as much in the physical interpretation of the brain. This area of research addresses questions about causation, a topic with many hypotheses but few definitive answers. Previously, researchers could only examine a physical brain through brain tissue of the deceased. EEGs, MRIs, fMRIs and PETs make it possible to examine the brain of a person with autism as he performs a task or processes stimuli. Researchers can now see the active brain, but they have difficulty interpreting what they see. Twelve years ago, Geraldine Dawson, one of the most respected neuroscientists devoted to autism research, wrote that “...it is clear that persons with autism have neuropsychological impairments in a wide range of domains, a fact that suggests that autism probably involves dysfunction of multiple regions rather than only one region of the brain” (1996, p. 179-180). Since the time of her writing, little has changed with what experts know. Current reviews of the literature (e.g., Frith, 2003; Nadesan, 2005) openly acknowledge the preliminary nature of bottom-up research. Once more explanations are found, the puzzle pieces will begin to come together. Future research can and probably will change the way experts understand autism, including how it gets classified and categorized. For example, consider a new and hypothetical classification system offered by an autism researcher to describe the various “types” of autism:

- Perceptual autism (linked to damaged limbic system)

- Perceptual Asperger syndrome (linked to frontal lobe problems)
- Reactive autism (limbic system)
- Reactive Asperger syndrome (frontal lobe)
- Induced autism (limbic system)
- Induced Asperger syndrome (frontal lobe)
- Secondary autism (caused by accident or illness) (Bogdashina, 2006, p. 234)

Bogdashina's explanation underscores the centrality of the brain as the cause of autism and moves away from the current behavioral diagnostic scheme.

The three top-down theories of autism and the bottom-up approach focus on the responsibility of the brain for causing autism. Proficiency in the three theories will foster proficiency in reading *JADD* or other biomedical autism texts because the theories are so prevalent now in the professional literature. The computer metaphor lends these theories the credibility necessary to move autism research past outdated research agendas like psychoanalysis as well as the basic information set forth in the *DSM*. Experts' adoption and regular appropriation of the ubiquitous and high-tech device enhances their explanations of autism. Regarding intervention and treatment, however, the cognitive studies paradigm has not yet overtaken the dialogic space occupied by the behaviorist paradigm. In the following section I briefly outline the behaviorist and cognitive perspectives as they relate to treatment.

## Theories of Treatment

Though the cognitive studies paradigm dominates autism explanations, competing theories still exist, especially in the realm of treatment. Treatment and intervention is a very complicated aspect of autism research. In a scan of books on Amazon.com or in a basic Google search of autism interventions, one can find dozens of options and approaches. Rules about diet, treatments to relieve allergies, facilitated communication devices and auditory integration are a few of the more popular approaches to autism existing in a sea of expert advice. But, as Catherine Lord (2000) pointed out, scientific testing does not keep up with the latest trends that are available for public consumption. This lack of testing is due in part to the time it takes to test an intervention. There is also a preoccupation problem—many biomedical researchers who study intervention are fixated on their own approaches and refuse to bend to the trends.

The behaviorist perspective, the site of much preoccupation, is the leading paradigm for the design of interventions because, as O. Ivar Lovaas, premier autism behaviorist, posited, the notion of autism as a pathology is—for treatment purposes—useless. Lovaas explained: “The identification of structural damage to the cortex of autistic children will not help to treat autistic children any more than the identification of damage to optic fibers helps a blind person to see” (1979, p. 379). In other words, even if experts could locate a neurocognitive problem or problems within the brain, “neurology does not possess a theory of behavior” (Lovaas, 1979, p. 317). Applied Behavior Analysis (hereafter, ABA) offers the most comprehensive approach to treating autism. It breaks the problematic behaviors down into its smallest parts: echolalia, self-

destructive behavior, difficulty in answering questions, for example. It also relies on a system of positive reinforcement for task accomplishment. As Laura Schriebman (2005), a student of Lovaas, wrote, behaviorism is accepted because it is the only treatment option with thorough scientific validation. It is the primary treatment option because it remains the most reliable option.

But, after examining the principles behind behaviorism further, even behaviorists draw implicitly on the computer metaphor. Recall an earlier quotation from Nadesan (2005) in which she explained that parents accepted the brain-as-computer comparison because it suggested that children could be programmed to behave in certain ways. In ABA treatment, the eradication of negative behaviors relies on the repetition of other positive behaviors. This repetition, one might argue, re-programs the brain. Indeed, since cognitive studies began to gather steam in professional discourse, the behavior and the brain became ever more intertwined. The marriage of these two major research topics has even swayed Lovaas himself into thinking differently. As the technology has advanced, he admitted to links between cognitive studies and behaviorism. Writing in 1989, Lovaas and Smith reported on some preliminary studies that show possible linkage between successful behavioral intervention and the reversal of some underlying neurological problems.

The perennially popular ABA also has many limitations, and these limitations parallel what one might expect to find in a bug-ridden operating system. While language and behavior improves overall, individuals with autism exhibit some behaviors that seem strange to others: they still depend on external cues about how to behave, they are often

unable to initiate spontaneous behavior, they give rote responses to questions without understanding the meaning or significance and they fail to initiate requests or commands. Like computer programming, it is impossible to expect perfection with any autism intervention.

The cognitive studies paradigm has, for the most part, assumed that the brain is *like* a computer. It is not uncommon, however, to read descriptions in which experts blur the line between what Schiappa (2003) called theory and observation, which in this case refers to people abandoning the brain-as-computer metaphor in favor of the computer-*is*-brain explanation. Daugman (2001) reported that many theorists believe that literal comparisons ought to be made between the computer and the brain. Because of some of the characteristics exhibited by people with autism, in combination with society's fascination with artificial intelligence (Nadesan, 2005), the metaphor slips away and the brain *becomes* a computer. The conception of the autistic brain as a form of artificial intelligence is not a new one. I turn now to one of the more extreme enactments of the computer metaphors, the study of the autistic savant.

#### The Computer Metaphor Articulated Literally

Thus far I have presented various ways in which the computer metaphor guides autism research. This discussion would be lacking without a discussion of autistic savants—within this literature, the metaphor slips away and the brain becomes a computer. The view is that people with autism—and savants, especially—differ because they have

computers for brains. These interpretations exist in part because, culturally, the computer-like stereotype is also reinforced.

The 1988 film *Rain Man* is perhaps the most popular fictional representation of autism. The savant in the film, Raymond Babbitt, instantly counts a large number of toothpicks as they fall to the ground and he counts cards while gambling in Las Vegas. When he answers difficult math problems for a physician—who must check Babbitt’s answers using a calculator—we know that Babbitt must possess his own calculator in his brain. Bruno Bettelheim once observed the following about one of his patients with autism, whom he labeled “Joey the Mechanical Boy” (1959):

Once, in a fury, he cried “My knees must be absolutely stiff so I can’t bend them.” And he took a piece of cardboard and tried to wrap it around him so that the knee joint could no longer bend. When we asked him why, he said, “So my body won’t hurt.” To become rigid, unfeeling, machine-like, was the only protection he knew (1967, p. 268).

Bettelheim argued that children with autism adopt machine characteristics to compensate for their inability to become totally human, an impairment directly caused by their parents’ failure to give the children proper affection. Feeling unloved and psychologically damaged, Bettelheim suggested, a child’s psyche drives someone like Joey to “fix” himself by becoming a machine.

Though autism experts have roundly discredited many of Bettelheim’s ideas, the mechanical descriptions have persisted to the point that many individuals with autism embrace this characterization. Temple Grandin (1996), one of the most notable figures

in the autism community, described herself as having a computer-based recording device much different than the neuro-typical memory. In part, she corroborated Bettelheim's observations when she wrote that this device helped to make up for characteristics she lacked. For example, people with autism often have difficulty interacting with others in social situations. When Grandin found herself in a situation where she did not know how to act, she drew on her "CD-ROM memory of videotapes" (1996, p. 138) to recall how she ought to behave. She wrote: "Recently I attended a lecture where a social scientist said that humans do not think like computers. That night at a dinner party I told this scientist and her friends that my thought patterns resembled computing and that I am able to explain my thought process step by step" (1996, p. 138).

In the professional literature, researchers have attempted to understand why some people with autism appear to have computers for brains. The savant character is a well-known stereotype, but it is greatly exaggerated. In reality, only a small percentage of people with autism are savants. Very often their exceptional ability is quite narrow and it exists in tandem with mental retardation (Hermelin, 2001). Savants, researchers found, can possess one of several kinds of exceptional skills: calendar calculation, musical abilities such as hearing a piano concerto once and then playing it back with few errors, mathematical talent, knowledge of many languages and drawing. The calendar calculator is the most common type of savant ability (Hermelin, 2001). Its name alone places a computational device inside the head of the person. Hermelin has studied savants for three decades now. She described the savant calculators in the following way:

Calendar calculators are able to identify, usually within seconds, on which particular day of the week a specific date fell or will fall. They are intensely interested in dates and often the first question they will ask someone is not “what is your name?”, but rather “when is your birthday?” This, for them, is the most important information they need about other people. (2001, p. 75)

Accounts from scholars like Hermelin do not do much to distinguish between the brain-as-organ and brain-as-computer. Baron-Cohen (2003) gave an account of a five-year-old boy who believed that his brain was a computer. He wrote:

At the age of five, he asked his school teacher how computers work. She explained to him that computers store information in binary code so that every bit of information is either present or not. He immediately said, “But that’s how my brain works!” and gave himself the nickname “Binary Boy” (p. 138).

The calculating and computing abilities have repercussions in other parts of a savant’s life. Most neuro-typical people would find it quite strange to encounter a person who skipped friendly conversation for questions about birthdays and other significant dates. Baron-Cohen (2003) could be describing the basic characteristics of a computer when explaining that people with autism prefer closed systems, things that are “knowable, predictable, and controllable” (p. 135). Furthermore, like a computer, spontaneous social situations—the situations all humans encounter daily—pose a challenge because savants cannot predict and plan ahead of the situation. Behavior in these settings often leads outsiders to believe that people with autism are strange. A savant’s obsessive interests, like calendars, can dominate a conversation.



Baron-Cohen has offered several explanations for why people with autism—including savants—behave more like a computer than a human. Recall that ToM posits that people with autism cannot interpret others' mental states. Some people with high functioning autism, like Grandin, realize that they must try, and so they draw on past experiences to guide them through interactions. Many others do not realize that they ought to try to engage in socially appropriate behavior and so they focus on what they know (their obsessive interests) or avoid interactions altogether. Frith (2003) wrote an extended account of a conversation she had with a person with autism who seemed to be competent in all areas except social interaction. I include here a small part of that account:

UF: Now you live in that lovely flat, upstairs?

R: Yes.

UF: Is that really good?

R: It is.

UF: Do you do some cooking there?

R: Yes, I do.

UF: What kinds of things do you cook?

R: Anything.

UF: Really. What is your favorite food?

R: Fish fingers.

UF: Oh, yes...And you cook them yourself?

R: Nearly.

UF: That's very nice.

*(Again, my attempts to make Ruth volunteer information were unsuccessful. All I could do was ask leading questions which she answered with perfect honesty. At no point did she try to create an impression, one way or the other, for instance by boasting or denigrating her cooking or reading skills.)* (p. 116-117, italics hers)

Baron-Cohen (2003) also offered a second theory, extreme male brain theory.

He argued that female brains are best characterized by their ability to empathize. Male brains are more computer-like—they systematize rather than empathize. Most males and females fall somewhere in the middle, having the ability to do some empathizing and some systematizing. Baron-Cohen found through testing that people with autism have extreme male brains, brains that behave more like computers. People with autism test worse than most males on tests like the Faux Pas test, “Reading the Mind in the Eye” test and the Friendship and Relationship questionnaire. They score well, on the other hand, on intuitive physics tests and, in general, prefer math to other basic subjects.

The application of the computer metaphor has expanded the autism research agenda in many different directions. Professional literature continues to look to cognitive studies in order to better understand the mind, the brain and how autism affects them. This dominant paradigm is clearly very fruitful and shows great promise for research advancement. Quite paradoxically, then, there are some constraints in the continual reinforcement of this conceptual metaphor. The next section addresses these constraints.

### Computer as Metonymy

Burke wrote that the metaphor is an equivalent term to “perspective” (1954). Indeed, the previous section has demonstrated that the cognitive studies research agenda carries a particular viewpoint about what autism is, what might cause it, and even how to treat it. By the definition of metaphor, the computer is a tangible object that stands for something intangible (the brain). But also by definition, the cognitive studies paradigm reduces the complexity of the human brain to a culturally familiar object. I conceive of this reduction in a couple of ways. In part, professional literature subverts the person with autism in favor of the autistic brain. The brain is itself subverted for the more precise explanation, the malfunctioning computer or the “virus in the machine” (Payer, 1988). Subversion occurs because autism researchers have adopted the rigors of scientific research, honing in on its principles further under the influence of cognitive studies. Consequently, the humans are lost from the pages of *JADD* and other professional literature. Elsewhere, Waltz (2005) observed that autism research is “...heavily laden acronyms, numbers, citations and specialist language...” (p. 428). The person with autism becomes the *object* of study, reduced to examinations of behavior and the brain. Waltz (2005) continued: “these children have become disembodied brains: ‘cases’ without names or faces. They are labeled as members of a group (‘AD children’ or ‘AS children’) rather than individuated” (p. 428). The depersonalization of the computer metaphor carries over into the character of the person with autism. The calendar calculators and other savants are defined through their mechanical parts. All

other human elements seem to fall away; “they are dehumanized in their rendering as cyborgs” (Nadesan, 2005, p. 131).

Furthermore, while on the one hand the computer metaphor generates countless lines of argument for autism researchers, it also places a limit on the types of research and the types of argument considered acceptable within the research community. That is, the cognitive studies paradigm creates an *a priori* frame for autism research.

Biomedical critics disliked psychoanalytic research in the 1970s in part because psychoanalysts worked within a singular guiding frame. Cognitive studies researchers enter into an examination with a preexisting set of assumptions; this time, they have science and credibility on their side. Critics of cognitive studies have inevitably stepped forward to offer alternative perspectives. Loveland (2001), for example, argued that researchers in psychiatry and psychology should also consider an ecological approach to autism research. She wrote:

autism is not a static condition existing within a person, but a developmental process that can only be understood as taking place through the interaction of person and environment. Thus, autism is located not “within the head” of the person with autism, but in a disordered relationship between person and environment. (p. 22-23)

This view is compatible, rather than competitive, with cognitive studies. Researchers, Loveland argued, should not ignore cognitive studies research. Instead, her perspective encourages scholars to consider how brain impairments lead to disordered environment-person relationships. Loveland’s approach attempts to avoid the reductionist trap of

cognitive studies by acknowledging the totality of the environment in which a person with autism functions.

Though the cognitive studies paradigm clearly places limitations on what can be studied, it has led to a great deal of advancement in the areas of psychiatry, psychology and neuroscience. Reduction is, after all, common within behavioral science (Burke, 1945). Scientific progress has relied not only on good ideas and good metaphors but the rhetorical unity binding them. Furthermore, most autism researchers and caregivers would argue that the current viewpoint fosters a far friendlier and more humane environment than the psychoanalytic viewpoint of decades past. For the time being, cognitive studies approach has firmly planted its roots into autism research. Rather than throw the research community into upheaval, scholars like Loveland are wise to suggest compatible viewpoints or, as is often the case, revisions to the research paradigm and trends. These viewpoints can, to a certain degree, co-exist because they do not threaten to overthrow the paradigm or encourage the subversion of scientific principles. In 1997, a new autism journal (*Autism*) arrived, purporting to offer a more practical approach to autism research. Studies about ToM, WCC and EF and its related theoretical constructs dominate the journal but speak directly to educators and health practitioners about issues pertaining to diagnosis and treatment. The editors also called for essays and articles that spoke to the experiential side of autism (Jordan and Holwin, 1997). For example, a recent article, entitled “Make me Normal,” reported on interviews that the author conducted with grade school children with autism. The authors found that many of these

children viewed autism as a burden and longed to fit in with their classmates. *Autism* has explicitly stated a need for complementary approaches to autism research.

*JADD* has also made some efforts throughout the years to incorporate alternative perspectives to autism. In the 1970s and early '80s, *JADD* created a forum called "Parents Speak" where parents contributed personal essays about their experiences and/or beliefs about autism. Articles with subject matter similar to "Make me Normal" also appear with some regularity in *JADD*. In the past few years, for example, the journal has published a handful of social scientific studies, including examinations of parental and sibling stress (Benson, 2006; Macks & Reeve, 2007), the effect of autism on marriages (Renty & Roeyers, 2007), and the utility of social support (Siklos & Kerns, 2006).

## CONCLUSION

Relying on *JADD* as the pulse of autism research, I began this chapter by examining in further detail the ways in which biomedical autism researchers sought to achieve power, status and unity within their research community. Through editorials, book reviews and research articles, *JADD* contributors first set out to purge most of the psychoanalysis from the scholarly dialogue. This purge was followed by the acceptance of a new paradigm, cognitive studies. With cognitive studies came the rise of an influential metaphor, the computer as brain. This metaphor continued in the tradition of comparing the body to a machine, this time around drawing on the ethos of the most advanced and culturally accepted technological device for the benefit of autism research. The presence

of the metaphor continues on indefinitely, though if history has anything to say about it, it will one day fall out of favor. Daugman (2001) wrote: “One of the edifying if uncomfortable lessons to be learned from the history of brain metaphors presents itself whenever we feel astonished by how inappropriate the categories and metaphors of past eras seem to be: when we marvel at the possibility than anyone could ever have thought *that*” (p. 25).

Like the metaphor, the definitions and even categories for autism are grounded in a particular moment; in the end, they are quite permeable. Experts no doubt value the research that went into the creation of the *DSM-III* and *DSM-IV* autism entry. As experts delve further into theories derived from cognitive studies, they will inevitably move away from outdated explanations. What experts know about autism today will probably pale in comparison to what they will find in the next few decades. That the study of autism is so focused on the study of the brain only further bolsters its symbolic importance in humans. Current technology still does not adequately interpret the brain for us. Should experts discover areas in the brain that set the developmental disorder in motion, they will bring about new definitions and perhaps even new categories. Definition and classification, in other words, are only meaningful when a community of experts believes it to be so.

The intention of this dissertation is to seize upon explanations and metaphors as they exist in this moment. To complement and contrast the expert’s computer metaphor, the next two chapters examine other metaphors that exist outside of the expert realm. Read individually, this chapter points to a narrow point of view about autism. Observed

in conjunction with the media and caregiver perspectives, autism becomes the complex, confusing and mysterious disorder that so many have described previously.



## CHAPTER IV

### ANTHROPOLOGISTS ON MARS: AUTISM AS A SOCIAL PATHOLOGY

The professional study of autism, as Chapters II and III have shown, is a predominantly biomedical endeavor. A paradigm shift in the 1970s within psychiatry led experts to view autism and all other psychiatric disorders as diseases. Experts defined and diagnosed autism through a list of observable behaviors. A basic definition of autism appears in psychiatry's official charter document (see McCarthy, 1991; McCarthy & Gerring, 1994), the *Diagnostic and Statistical Manual of Mental Disorders*. Within the past two decades, cognitive studies, a popular research paradigm that combines psychology, computer science and linguistics, brought its master metaphor to bear on autism research. This research now locates autism pathology in the brain. Experts draw upon the brain-as-computer metaphor to further explicate the pathology. Their work drives most of the current professional literature about autism.

Despite the persuasive biomedical explanations for autism, there is still much more to the disorder that does not regularly appear in the professional literature. The practice of biomedicine often receives critique because it reduces the human being to smaller body parts (the brain) and, as a consequence, dehumanizes the patient. The present chapter and Chapter V move beyond the biomedical explanatory model for autism and delve into more experiential territory. By experiential, I refer to the broader understanding of autism that can only come from living with it, both as a person with

autism and as a caregiver to a person with autism. In this chapter, I examine the caregiver explanatory model for autism.

George Engel, a professor of psychiatry and medicine, received the credit for first suggesting an alternative approach to the biomedical model (see Engel, 1977). In his original article on the subject, he intended to educate other health practitioners about the psychological and social factors that, in addition to biology, determine illness, wellness and the large gray area in between. Engel's writing on the subject matter has influenced many medical humanities scholars who welcomed scholarship concerning the human side of disease and illness. Most importantly, the approach reinstated the significance of the social life as it is affected by illness: "From the perspective of the individual, the social world and the body-self each influence the other" (Lewis-Fernandez & Kleinman, 1994, p. 68). Furthermore, as Mishler (1981) has argued, illness can negatively affect a person's experience in the social world. Beyond the biological, illnesses like autism disturb social relationships (Mishler, 1981). I found this to be true of the caregiver interviews I conducted for this chapter; they preferred to explain autism as a social pathology rather than as a pathology of the brain. The biopsychosocial approach to autism will become quite clear as this chapter progresses. I will touch upon the biomedical-based symptoms of autism, but the narrative will quickly move beyond the biomedical to explore how these symptoms set in motion a range of social problems for families with autism.

In addition to the biopsychosocial approach, a caregiver explanatory model will also reveal a new interpretation of the puzzle metaphor that frames this project. I

include a variety of caregiver narratives so that readers can better understand autism as caregivers see it: as a series of challenges that caregivers must face. Some of these challenges have answers, though they may take months or years to solve: What is my child's diagnosis? How do I treat autism? Other challenges remain: How can I educate neuro-typicals about autism? What does the future hold for my child? The following chapter explores the various ways in which caregivers go about solving these challenges. Before proceeding with the analysis, I present some additional information about caregivers and the interview process I undertook to assemble the caregiver perspective.

#### A CAREGIVER EXPLANATORY MODEL

In adopting the term caregiver, I refer primarily to the parents of one or more persons with autism. I recognize that siblings, grandparents and other family caretakers may also fall into this category. However, in conducting my interviews, I only spoke with parents. I thus use the terms "caregiver" and "parent" interchangeably throughout this chapter. I chose to focus my analysis on caregivers, rather than people with autism themselves, because caregivers experience autism from pre-diagnosis onward, long before the person with autism can understand it himself. In the beginning, caregivers become experts in their children's development as they begin to recognize some abnormal behaviors and missed developmental milestones. Once the child is diagnosed, caregivers bear the responsibility for seeking out, learning and implementing various treatments. They also share in the responsibilities for determining the course of education for their child. And, finally, once school has finished, caregivers bear the

burden of determining what will happen next. Through these experiences and many others, caregivers develop a detailed explanatory model for autism.

The texts I used for this analysis differ from the texts used in the other two analysis chapters. Rather than rely on publicly-available caregiver narratives—there are many to choose from—I chose to compile a caregiver explanatory model with the assistance of caregivers in my local community. My intention was to give voice to the everyday experience of autism and gather a range of different viewpoints rather than rely on public narratives that have undergone selection and revision by publishing companies and mainstream media outlets. My plan for interviewing caregivers, including the recruitment strategy and the interview protocol, was approved by the Texas A&M University Institutional Review Board. To recruit interviewees, I approached a local autism support group for help. I also reached out to a few key autism professionals in the community who interact with caregivers every day.

In total, I conducted 19 audiotaped interviews. Seventeen of the 19 parents interviewed were female. According to the non-profit group First Signs, autism “cut[s] across all lines of race, class, and ethnicity” ([www.firstsigns.org](http://www.firstsigns.org)). In a review of various epidemiological studies, psychiatrist Eric Fombonne (2005) found an equal distribution of autism among different race and ethnic backgrounds. Precise epidemiological numbers about race and ethnicity are difficult to obtain because autism lacks an exact diagnostic measure. Seventeen of the 19 parents I interviewed were Caucasian; of the other two, one was Hispanic and the other Asian. Compared with the general epidemiological picture, my interviews lacked an equal distribution of people with

different race and ethnic backgrounds. In part this is due to the demographic makeup of the community, where Caucasians are by far the majority. There is a prominent Hispanic population in the community, however, and several Hispanic mothers wished to participate in the study. Unfortunately, they were not proficient in English and I did not have the resources available to conduct and translate interviews from Spanish to English. The age of the caregivers' children with autism ranged from four years to 23 years old, with two over the age of 21. My sample lacked people over the age of 21 in part because of my method of recruitment. In relying on the local schools to pass the word along to caregivers about my study, I excluded those no longer receiving school services. The length of the interviews ranged from 40 to 111 minutes with a mean of 67 minutes. Interviews mostly took place in various public places around town such as coffee shops and the library. In two instances the participants preferred to conduct the interview in their homes and two others preferred to do the interview at their workplaces.

To compile a comprehensive caregiver explanatory model, I relied on key questions developed by Arthur Kleinman (1988a). Sample questions included: What words would you use to describe autism? How does autism manifest itself in your child? What treatments have you found effective?. Appendix A contains a full interview protocol. After finishing the interviews, I transcribed and analyzed them. In total, I analyzed 704 double-spaced pages of text. My approach to analysis did not differ in any way from my analyses of texts derived from expert literature and mainstream media accounts. Following Kleinman's (1988b) recommendation for analyzing explanatory

models, I examined “various accounts of the illness with respect to their major plotlines, metaphors, and the rhetorical devices employed to tell the story of the illness” (p. 155).

I begin the analysis portion of the chapter by introducing two brief narratives about two different families I met. I present the stories of two families—Sarah, Peter, Chris, and Alex and Carmen and Jonathan—in an effort to introduce readers to the dominant tropes that drove the caregiver explanations for autism. I also include these stories to capture the uniqueness of each autism experience. The stories illuminate just how different autism appears from family to family. Indeed, they reemphasize the point made so many times about autism: no two people with autism are alike. No matter how varying autism was in each family, one common thread appeared in all of the explanations I analyzed. Caregivers used specific terminology and told certain narratives in order to convey the radical difference and distance between a person with autism and a neuro-typical person. These tropes used to convey difference and distance constructed people with autism as alien-like or foreign. This overarching explanation stems from the notion of autism as a social pathology. That is, the difference and distance between a person with autism and neuro-typical person is so drastic that it affects their own social life, the lives of caregivers and their families and many other neuro-typical people.

Sarah, Peter, Chris and Alex<sup>10</sup>

I had the opportunity to interview Sarah and Peter separately about their two sons with autism. Their older son, Chris, is the higher functioning of the two brothers. Their younger son, Alex, is also a teenager but is, developmentally, only 17 months old. Alex does not understand much language—he does not speak but can understand “maybe 10 to 15 words.” Chris’s autism is quite different. He eventually developed regular language, though the family has found it difficult to communicate with him. Chris is very sensitive to sound and often cannot listen to or speak to his family and other people because it is, sensory-wise, too overwhelming. Sarah reported that she knew Chris was different even as a baby. He refused to nurse because he did not like to be held, and his refusal to eat “almost killed him.” Sarah explained that Chris, before diagnosis, was a “weird baby”:

He always had that kind of vacant stare. He would kind of come in and out. We have pictures of him like looking real cute and smiley and all that, but we have other pictures that are just downright scary. You know it’s like “I hate you.” You know what I mean? There’s no affect at all and that’s weird for babies because they’re either cute, smiling or unhappy.

Despite his weird and distant behavior, the family did not know their first son had autism. After all, it was the early ‘90s and public awareness was minimal. When they did receive a diagnosis, Sarah recalled that she felt scared, confused and heartbroken. She explained:

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<sup>10</sup> All names have been changed to protect the identities of the caregivers and their families.

We didn't know who he was anymore. ... It was terrifying because it was like, where have we been? Why haven't we seen this? How did we not know? And we had taken him to all his well-child checks, we had done all of the good mommy things. And we kept saying, "There's something weird about this kid." He was just—he just wasn't right and that whole first week [after the diagnosis] was just a blur. ... I was so freaked out. It was just, who is this little alien? You know? And it was all of a sudden I realized how far away he was from me.

Eighteen months after Chris's diagnosis, his brother Alex received an autism diagnosis as well.

At the time of the interview, Sarah and Peter emphasized that autism, for both of their sons, was primarily a disorder that affected communication. Peter said, "It's not like talking to a regular person." Chris often relied on echolalia—or habitual repetition of words—at seemingly inappropriate times (like in the grocery store) or when interacting with others. In particular, Chris repeated words and expressions that he picked up from classmates or through television and movie dialogue. Peter explained: "We first really noticed this about five years ago when he started getting really interested in Warner Brother cartoons. And it was like he was almost borrowing the actions or expressions from those to do social interaction." In one particular instance, the family had guests over to the house and, as it grew later in the evening, Peter recalled: "Chris comes out in his pajamas and says, 'Party's over. Scram!' Which was clearly a cartoon thing." This pattern of speech is no doubt strange, and at times it has made him seem deviant. Peter also recalled a time when Chris received a suspension from school



because he echoed some derogatory language that his classmates must have also used. Chris's echolalia has also impacted the delivery of his speech. Peter said: "I've noticed that he has four registers of speech. He has sort of what I would think of as normal Midwestern, talking like me; Texas white southern; black and cartoon."

Meanwhile, because Alex cannot speak at all, the family has particular difficulties communicating with him. Sarah equated their interactions with Alex to be, at times, like communicating with a foreigner:

There will be days where I will call Peter in and say, "Can you give me a translation from the autistic? I don't know what he wants, you know, I just can't figure this one out." And then there are days when he can't figure out what Alex wants and I figure it out. And sometimes it comes down to just changing the CD from Springsteen to the Dixie Chicks and then he's happy. But he has no way to say, "Hey, Mom, I'd really rather be listening to the Dixie Chicks right now."

So, it's always guessing. Communication is not the nice, clear model that we're taught.

Despite the language barrier, Sarah and Peter have watched Alex develop in other ways. He can make eye contact, which is something many people with autism find very uncomfortable. He responds to his name and his sensory difficulties with touch and sound have diminished significantly. Alex, however, is very much unlike a neuro-typical person. Sarah said:

I had to wait until he was eight for my first hug [from Alex]. Never stopped me from hugging him. I don't think he understood, but the first time that he walked

over to me of his own volition and put both hands on me, I mean, I fell apart. I mean, to wait eight years for a hug from your child. Most people can't even imagine that. You know, [babies with autism] don't do that thing where they stand up in the crib and reach for you, because they don't care. They'd just as soon be left in the crib.

Sarah and Peter worry about what to do with Chris and Alex once they are no longer in school. As other caregivers will explain later in this chapter, the distance between the neuro-typical and autism worlds are so great that adults with autism find it very difficult to function independently in the neuro-typical world.

#### Carmen and Jonathan

Carmen first noticed that something was wrong with her son, Jonathan, when he was a little over a year old. Language delays and odd behavior were the first indicators of a problem: "I noticed that he wasn't using words anymore, he was babbling. And he was spending a lot of time looking at things that twirled and he seemed a little, I don't know, distant? And so I started trying to find help." After receiving a diagnosis of autism, Carmen said that her son's behavior got progressively worse:

I noticed that he was no longer playing with his dad. And he started not playing with his sister. And I felt one day that I was losing him as well. And I didn't want to lose him. So I found out that he loves spaghetti. More than anything, he loves spaghetti. So the way I could keep him with me is to put my fingers up and say to him "spaghetti fingers." ... And I could keep him for just awhile you

know? He would make some eye contact and he would stay with me. So I would use that several times during the day.

Yet the fact that the family was “losing him” frightened Carmen. She described the appearance of autism in her son to be “like somebody going through a black hole.”

Through Carmen’s interview, I ascertained that Jonathan was a person with high-functioning autism. He communicated well with his family, he did well in school and community college, and he had a satisfying part-time job at the time of our interview. Carmen said Jonathan’s autism manifested itself mostly in his difficulty in understanding the complexity of human emotions and motives. Carmen shared one notable example. She described Jonathan as a very moral person, always intent on doing the right thing. This observation corroborates with others’ accounts of autism. People with autism often see things in black and white, right and wrong. This tendency is very different than in the neuro-typical world, where morality exists on far shakier ground; rarely can events be viewed in black and white terms. Another caregiver I interviewed, Nina, described it best:

I mean if it’s right, it’s right; if it’s wrong, it’s wrong. There are no gray areas for [my son]. So he gets very upset if you do something that falls into the black region that you shouldn’t be doing. And now I’m just afraid that if it doesn’t diffuse when he’s older then he will have a very hard time with people. Because I found as I got older that when you’re dealing with people, most of the areas are gray, right?

Carmen's son Jonathan experienced this clash of worlds after the terrorist attacks on September 11, 2001. Jonathan was in school on that day and watched many of the initial gruesome scenes of the attack on television. He could not, according to Carmen, comprehend the human motives at the source of the terrorist attack, and assumed that all people were equally murderous. Carmen said:

The images were stuck [in his brain] and he didn't have any way to express it. But he had started doing things he'd never done before. He hit a couple of his best friends. And he felt so bad about it afterwards. And he was he was angry all the time and he felt bad about that so finally he attempted to hang himself.

Carmen, herself a special education teacher, encouraged her son to communicate his intense emotions through his drawings. It took him a long time to do this, however, because he was scared. She said, "And the fear stemmed from the idea that man was irreparably cruel, bad, evil. And that something had brought it out and it was going to be permanent." To remedy the situation, Carmen took Jonathan out of school and drove around the state visiting relatives and observing the scenery. Carmen said:

And along the way I kept saying, "Look out at the countryside. What do you see?" And then he described what he saw but then I'd tell him, "And it's peaceful. And there are good people going about their jobs. And they are taking care of their land and the people around them." ... Just to show him that there was safety, and that people are learning from these experiences.

By the end of the trip, Carmen felt that Jonathan had progressed: "It really helped relieve some of the fear that he was living with inside. So that he's learning the balance between

yes, people are good, but they do stupid things sometimes. So it's helping him." Carmen also encouraged Jonathan to try acting, and through that activity her son started to show more progress in understanding neuro-typical thought:

What he said about it was that he's found a place to be free because everybody's scripted. Everybody knows their part. And he gets to repeat that part over and over and over again until he understands his motivation and other people's motivation. And what he finally discovered in one of the plays was who he was supposed to be in relation to everybody else. But in order to get there he had to understand where everybody else was, which is Theory of Mind.

Jonathan's acting began to close the gap between him and his neuro-typical peers.

These two narratives accounts construct autism in very specific ways. At an early age, language deficits and odd behavior prompted Sarah, Peter and Carmen to perceive their children to be "alien" or lost, like "somebody going through a black hole." Chris and Alex have obvious problems with communicating—Alex can barely communicate at all and Chris often does through echolalia. Jonathan is a better communicator, but still lives a very different life than other neuro-typical people. What these stories have in common is that they begin to create two worlds, one where people with autism live and one where neuro-typical people live. Caregivers might perceive their children as alien-like because their behaviors violate neuro-typical expectations. Meanwhile, people like Jonathan might also perceive themselves as aliens living in another world. Neuro-typical behavior, such as the September 11<sup>th</sup> terrorist attacks, are too difficult to understand in the black-and-white world of autism.

In the next section, I further examine a framework that will guide the rest of the analysis. This framework involves tropes that portray autism in terms of its difference and distance from neuro-typical people.

#### “AN ANTHROPOLOGIST ON MARS”

The tropes that frame caregiver explanations coincide with published autobiographies and professional literature about autism. One particular standout is the notion of the “anthropologist on Mars,” which comes from an observation made by Temple Grandin, a high-functioning person with autism, as she spoke with neurologist Oliver Sacks about the works of William Shakespeare. Grandin, who holds a Ph.D. in animal science and is currently Associate Professor at Colorado State University, expressed frustration in understanding Shakespeare’s plays, as they often contained complex human emotions and circumstances. Sacks (1995) wrote that Grandin’s incomprehension of neuro-typical behavior stretched back to her childhood: “Something was going on between the other kids, something swift, subtle, constantly changing—an exchange of meanings, a negotiation, a swiftness of understanding so remarkable that sometimes she wondered if they were all telepathic” (p. 272). Of her difficulty with Shakespeare and social interactions in general, Grandin said to Sacks: “Much of the time I feel like an anthropologist on Mars” (Sacks, 1995, p. 259). The notion of an anthropologist on Mars conveys difference; Grandin’s statement posits that she is a different type of person than the neuro-typical people that surround her. The location in which Grandin places herself, on Mars, magnifies the difference even further. In constructing the distance

between herself and others, or between Mars and Earth, Grandin means to suggest that there is a sizeable difference between herself and neuro-typical people.

The anthropologist on Mars trope is noteworthy because it resonates with other personal accounts and expert findings on the subject matter. In an essay about living with high-functioning autism, one man wrote that he concurred with Grandin's alien metaphor:

Being autistic does not mean being inhuman. But it does mean being alien. It means that what is normal for other people is not normal for me, and what is normal for me is not normal for other people. In some ways I am terribly ill-equipped to survive in this world, like an extraterrestrial stranded without an orientation manual. (Sinclair, 1992, p. 302)

Gary Mesibov (1992), psychiatrist and director of TEACCH, wrote that counselors who adopted the assumption that people with autism are like "visitors from a foreign culture" (p. 145) have seen positive results in their work. Other autism researchers have produced accounts similar to Grandin's remarks, finding that people with autism sense the sizeable difference between themselves and others. Unfortunately, these studies only include high-functioning people with autism like Grandin. One respondent said that "he tried for years to 'fit in and be like everyone else,' but he finally realized that 'fitting in and being myself was a paradox. It is impossible for someone with autism'" (Hurlbutt & Chalmers, 2002, p. 106). Simon Baron-Cohen (2002) has also weighed in on the idea of autism and difference, though he limited his claims to people with Asperger syndrome only. He wrote that the differences reside in the core: people with Asperger syndrome

are object-centered and neuro-typical people are person-centered. Baron-Cohen's hypothesis remains in dispute, but the gist of his argument lends support to the argument presented in this chapter. Caregivers believe that people with autism are different, almost alien-like or foreign, in comparison with neuro-typical people.

In the present analysis, it is important to consider tropes about difference and distance in light of autism as a social pathology. Consider a few examples from the stories of Sarah, Peter, Carmen and their sons. Sarah described her son, Chris, as a "weird baby." When they received his diagnosis, she wondered, "Who is this little alien?", adding, "And it was all of a sudden I realized how far away he was from me." The difference and distance between Chris and his parents caused them to have difficulty feeding him and communicating with him. Their other son, Alex, did not speak at all, and a language barrier literally stood between them. Sarah said that she and Peter relied on one another to provide translations for him in order to have his needs met. She also compared Alex to neuro-typical babies in terms of their social behavior, remarking that he did not act like he wanted to be with her. She said, "[babies with autism] don't do that thing where they stand up in the crib and reach for you, because they don't care." Carmen recalled when Jonathan started showing odd behaviors, stating that she felt as though she were losing him, and that is was "like somebody going through a black hole." Later in life, Jonathan continued to struggle with understanding neuro-typical motivation, feeling that those people were very different from him. His lack of understanding continued to the point when, after September 11<sup>th</sup>, he tried to kill himself. Carmen said she worked to solve this problem by taking him on a long drive and



showing him the goodness in most humans and she encouraged him to take up acting. Jonathan's difficulty in understanding neuro-typical motives, however, will likely continue for the rest of this life.

The rest of this chapter will continue to examine the caregiver explanatory model for autism. All of the caregivers I interviewed addressed the themes I highlight within this explanatory model. In specific instances where caregiver explanations differ, I try to point out the different nuances. First, my analysis will draw upon various tropes of difference and distance as they pertain to symptoms of autism.

## SYMPTOMS OF AUTISM

Caregivers did occasionally use a biomedical lens to explain autism. Several briefly described autism as a pathology of the brain. For example: "His wiring is messed up" (Donna), "His brain didn't really quite function right" (Dianne), and "[Autism is] a state of development of your mental capacity in your brain" (Roger). Parents also looked to current biomedical research trends when describing what they believed to be the potential causes of autism. The majority pointed to genetics and the environment as co-instigators of autism. Genes produced the possibility for autism and parents pointed to environmental toxins, ranging from pollution to food to vaccines, as possible "triggers".<sup>11</sup> Caregivers' explanations of autism symptoms were also a fruitful site in which to locate a more comprehensive biopsychosocial approach to autism. Previous

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<sup>11</sup> Chapter V will closely examine the vaccine debate and the contingent of vocal parents who believe that vaccines caused the autism. By comparison, only a very small number of caregivers I interviewed believed strongly that vaccines caused autism in their children.

research has indicated, for example, that autism symptoms are a significant source of stress for the whole family (Gray, 2006). I examined specific terms and narratives that caregivers used to convey difference and distance, constructing autism beyond the biomedical. Through their explanations of autism symptoms, they transformed autism into a social pathology.

With one or two exceptions, the caregivers I interviewed reported delays, regression in or an absence of language altogether around the age of 24 months. This coincides with expert literature about autism (see APA, 1994; Tager-Flusberg, 1999). Moreover, caregivers consistently explained that these language difficulties indicated the first signs of abnormality, even pathology. Language is, after all, one of the most significant signs of childhood development. Language distinguishes humans from other animals. Its absence or abnormality violates the presupposition that humans are social beings. This violation sounded an alarm for many caregivers. Mary recalled:

We first realized there was something wrong when he was 18 months old because he said a word and then he stopped saying all words altogether. ... And then we thought at first he wasn't talking because he had fluid in his ears, and then we got that issue cleared up. ... Once we got the fluid out, it took about three months and he still wasn't talking. We realized there was something more going on.

Summer shared a similar story, saying, "I remember and [his behavior was] very different from other kids, but then the real push for us [to see a doctor] was the lack of communication. It's almost like he's the group [of children with autism] that have

language and then regress and lose it.” Keri offered another variation on the same theme with regards to her daughter:

Her speech had always been really clear and her development was very normal. ... Then her speech started becoming garbled. And [she] just started with the echolalia and repeating things, what other people said. She was—if she repeated a sentence you said, she might get the first word and the last word right and then fill in the middle with gibberish.

This prompted Keri’s family to seek out a diagnosis as well.

Overall, caregivers described language deficits as one of the most memorable physical manifestations of autism. Language problems were the first signs of autism and they were also the first signs of a pathology in the parent-child relationship. Language barriers prevented caregivers and their children from connecting. Parents struggled to figure out how to get their child’s needs met and, without language, communication often failed. Dianne spoke about the stress she felt because of her son’s language problems, saying: “It’s frustrating for me because when he really wants to talk he can only hold your face and kind of say what he wants. It’s frustrating for him and frustrating for me because you know he’s trying to tell you something and he can’t get through what he really wants to tell you.” Echoing the emotions of Dianne, Cristina also could not communicate very well with her daughter. Her narrative conveys the distance and difference felt by many other caregivers:

She just sort of lived in her own world. It was just really hard to manage her because she—you never really knew if she understood what you were saying,

what you were asking. She's so visual that finally I got to realize that. And I'm so verbal, so it's just, you know, it's so hard. Because, you know, you just don't think about the way your face, your body language [looks]. I think what happened was she just became a student of my body language to figure out what I wanted.

Cristina's explanation recalled a barrier between herself and her daughter. Yet her explanation also suggested that the barrier can fall away, and mutual understanding is possible. Like learning a new language, Cristina finally realized that her daughter responded to visual communication. Meanwhile, her daughter became a student of her mom's of body language. Despite the connection that Cristina and her daughter achieved, the overall social pathology, due to language deficits, persisted. Cristina recognized just how different her daughter was in comparison to neuro-typical children: "You go and [visit] your best friend [and she] has a three-year-old daughter and she's saying, 'Mommy, I wanna wear my pink dress today! And my ballet shoes!' And da-da-da-da-da. And your kid won't even say 'yes' to asking if you want juice." Apart from the obvious language difference between the two girls, Cristina's example also constructed a neuro-typical girlhood ethos consisting of pink ballet outfits. She contrasted this neuro-typical construction with her daughter, who still could barely speak let alone possess the agency to develop her inner girl.

During the early years of development, caregivers also frequently noted that their children did not interact or play in the same way as neuro-typical children did. Once again, these observations coincide with professional literature about autism (APA, 1994;

Baron-Cohen, 1995; Leslie, 1987). Caregiver explanations focused intently on the social pathology underlying these symptoms, often remarking that their children had no friends. Lori said: “He doesn’t really have any friends. He’s never really had any friends.” Regarding Chris, her high-functioning son with autism, Sarah observed: “With Chris, the only creature on this planet that he has ever used the word ‘friend’ to refer to is Rex [the family dog]: ‘Rex is my best friend.’” Donna also saw a barrier between her son with autism and other neuro-typical children his age: “One time at my stepmom’s house at a party, [my son] was on one side of the room and all the kids were on the other side of the room.” Cristina’s explanation was similar: “We’d go to the playground. ... And she’s just like—all the other kids play together. She’s over here by herself. She won’t even stick with me. You know? Just wants to go off alone.” Donna’s and Cristina’s examples continue to construct the neuro-typical child as very different from child with autism. Neuro-typical children play together, and children with autism play alone. The distance is palpable, as the children with autism play away from the neuro-typical children.

Based on the observations of some caregivers, the pathology existed between rather than within the two worlds of neuro-typicality and autism. Keri watched for many years as her daughter struggled to have normal social interactions with other kids. At the time of our interview, her daughter had finally found a friend: “One of her best friends also has Asperger’s syndrome. And those kids seem to gravitate toward each other without knowing it for whatever reason.” Virginia’s son Bobby does not speak, creating tremendous obstacles between him, his family, and other children his age. But, as

Virginia explained, Bobby flaps his hands to communicate, and she has seen how other people with autism respond to this: “I went to [a sandwich shop] the other day and there was a flapper behind us. Bobby was like, “Hello-o-o-!” [she demonstrates how he flaps his hands]. You know similar spirit. Similar spirit. Bobby was really excited. He flapped, then [the other boy] flapped. They could have lifted the table—so funny.” Keri’s and Virginia’s explanations suggest that, at least for some caregivers, children with autism do socialize, but only with others like them or, perhaps, from the same world.

Caregivers have also described how the problems with social relationships evolved with age. Moving away from the image of the child playing alone on the other side of the room, caregivers said that their children eventually recognized the importance of socializing with others. The social pathology remained, however. Marilyn and Roger’s daughter used to tell children to “go away” when they approached her and asked her to play. Marilyn described how this behavior has changed:

And now she is actually saying that she really wants friends. And the problem is her understanding that [making] friends isn’t all about you, it has to be about both people, so it kind of takes some learning on her end to learn about the give and take of a friendship. But she has, I mean just in the past probably two years, said that she wishes she had some friends.

Egocentricity persisted despite the fact that Marilyn and Roger’s daughter sought to interact with the neuro-typical world. A common explanation among many caregivers, Marilyn and Roger’s daughter focused too intensely on her own interests and could not

understand that, in the neuro-typical world, different people have different interests. The *DSM* described the problem as an observable symptom of autism. People with autism often display “restricted repetitive and stereotyped patterns of behavior, interests, and activities” (*DSM*, 1994, p. 70-71). As caregivers explained, these restricted patterns of behavior and interests continued to plague social relationships with neuro-typical peers. Virginia, who has both a high- and a low-functioning son with autism, described her high-functioning son, James, as follows:

He’s gotta work extra hard to have conversations to, you know, to get along with kids. In all these years he’s only been invited to one birthday party. He says, “But, I have conversations with people all the time.” But the conversations are about him talking about aerodynamics and building an airplane. And he might talk about it for 30 minutes because he loves to talk about it and the different angles. He’d take out a protractor or whatever he’d need, you know, drawing out angles. And the other little kid is like, “Huh?” You know a little 10-year-old kid. And, they’d just be polite and listen to him as long as they can and some of them will just like run off and then some will say, “Shut up!” And then he’s like, “I don’t know what I did.” But he’s learning.

Even though James speaks English relatively well, Virginia described her son as speaking a different language than his neuro-typical peers. Her narrative evoked the person-with-autism-as- foreigner metaphor. An example provided by Cristina also explicated autism as difference, due in part to her daughter’s obsessions:

Like if she met you, she would start asking you like, “What’s your favorite color?” and, you know, “What’s your favorite drink?” She’s totally—she gets like little mini-obsessions. So she’s like right now into soft drinks. She wants to know what everybody’s favorite soft drink is. And then like when the Sunday paper comes and all the ads are in there, she’s finding the pictures of the Dr. Pepper and, I mean, that’s just one weird thing about her. ... And so she has a hard time with normal social interaction because, you know, people don’t just want to sit there and talk about Cokes for, you know, two hours or whatever.

The explanations I examined above indicate that there is much more to the physical symptoms of autism than what is described in the biomedical literature about autism. Language deficits are the first obvious marker of autism. They create significant strain on the parent-child relationship as they both puzzle through figuring out how to communicate with one another. The language and social barriers also engenders major differences between children with autism and their neuro-typical peers. These differences become even more apparent when caregivers explain how their children fail to interact—or make friends—with others. In part, this is due to the intense fixations that children with autism have. These fixations generate a failure to understand a neuro-typical perspective and scare off misunderstanding neuro-typical people.

The next few sections move away from caregivers’ explicit enactment of the difference-distance tropes. In keeping with the overall framework for the chapter, I now consider how autism treatment fits in. If the pathology lies in social interaction, autism treatment must attend to this problem. Treatment is thus unlike the traditional Western



biomedical intervention. First, I introduce the alternative treatment narrative as told by caregivers. Second, I posit that special educators and caregivers become the primary practitioners in this new treatment narrative. They act as social liaisons, working to introduce people with autism to the neuro-typical way of life. As caregivers also explained, they bear the burden of educating neuro-typical people as well.

#### AN ALTERNATIVE TREATMENT NARRATIVE

Health practitioners today still find a major role in the traditional, biomedical illness narrative. James Trostle (1988) wrote that, since the early 20<sup>th</sup> century, the growth of public health concerns gave rise to the authority of practitioners. They “began to consolidate their control over the business of healing in the United States and to increase their influence over the health-related activities of their patients” (p. 1302). I raise this point because, as caregivers discussed their treatment methods for autism, both successful and unsuccessful, the typical early childhood practitioners—family doctors, pediatricians, even developmental pediatricians—were notably absent. Chapter V touches upon mainstream media coverage of the subversion of biomedical authority and a general distrust of practitioners due to the question about the role of vaccines in causing autism. In the caregiver narrative, parents initially looked to their practitioners for help in the diagnosis of their children. They received little assistance from them, however, and caregivers characterized them as largely incompetent and

unknowledgeable.<sup>12</sup> Furthermore, special education laws in the United States redistributed autism expertise to other professionals, namely special educators working in public school districts.

Very often, caregivers' search for a diagnosis turned into a lengthy journey. It would often take several years to reach an answer to the question, what is wrong with my child? Lois, herself a member of the medical profession, said:

Our first doctor didn't want to diagnose us, so to speak. And I don't know if he didn't want to deal with it? Because if you diagnose it, you have to deal with it. Or if he just thought that I was looking for something that wasn't there. ... I don't know. I don't know if they don't want to believe what the parents say? I really don't know.

After careful consideration and daily observation, Cristina and her husband began to suspect autism in their daughter. They hoped their pediatrician would say the same:

We took her to the pediatrician who was the, I don't know, won pediatrician of the year award the year before. And [my daughter is] sitting in my lap and I'm like, "You know what? There's something wrong. I don't know what's going on but, could it be autism?" "Oh, no! No, no, no! Look at her! She's sitting in your lap! She's letting you touch her. She's obviously...." Because his perception was that kids with autism have sensory overload or, you know, just whatever.

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<sup>12</sup> Three caregivers did share somewhat different stories. They noted that their family doctors did play a major role in the diagnosis and facilitation of treatment for their children, prescribing psychopharmaceutical medications or acting as an advisor to the child's overall treatment plan.

If caregivers were lucky enough to eventually receive a diagnosis of autism from a practitioner, they also expressed discontent at not receiving anything more than that. As Dianne explained, after the diagnosis, she was left with little more than a label: “I could never get a doctor to tell me what it was, and then when [my son] was four years old they sat down and they told us he was autistic. But they tell you he has autism but they didn’t actually explain what that meant either.” When Sarah and Peter received the diagnosis for their first son, they began asking questions: What does this mean? What should we do? What should we read? Sarah recalled that the practitioner responded in the following way: “Oh you don’t need to bother yourself with that now. You just have to get used to the fact that your son is not going to Harvard.”

Years after receiving their diagnoses, caregivers still expressed exasperation at the medical profession in general. Due to these experiences, caregivers reported that they sought out other options. By law, many of them discovered, there was another option. The Individuals with Disabilities Education Act, established as law in 1975, mandated that schools bear the burden for special education, including autism care. The diagnosis and treatment of autism thus fell to the responsibility of the school district and its staff of special education professionals. These professionals stood as the experts, greatly diminishing the significance of the traditional biomedical practitioners. Accordingly, caregivers regularly referred to their children’s special education professionals as the people most instrumental in implementing a treatment plan. In this treatment narrative, however, caregivers assigned themselves a significant role as well.

Because the parents interact with their children every day, they naturally learned the most effective ways to minimize many of the symptoms of autism.

Not all caregivers made the link between treatment and cost, but those who did were quick to mention the cost of implementing treatment in therapeutic settings outside of the school district. Interventions like Applied Behavior Analysis and Auditory Integration cost thousands of dollars. Some but not all health insurance plans will cover these types of treatment. I would argue that the high cost of these treatments further increased the importance of teachers and caregivers in their treatment narratives. Because much of the massive expenses and hassles with insurance, parents relied most on what was free and easily accessible to them.

Another important aspect of this alternative treatment narrative involves the methods of treatment. As described by caregivers, autism treatment is primarily a means of performing a social intervention, whereby special educators and parents draw upon techniques that attempt to instill neuro-typical behaviors into the person with autism. Conversely, special educators and caregivers also developed techniques that proved successful in removing some of the negative behaviors brought upon by autism. Caregivers welcome these changes, explaining that when their children function better in the neuro-typical world, everyone feels happier because of it. Meanwhile traditional medical approaches, including the prescription of psychopharmaceuticals, remain available as a secondary treatment option, although, for many, not an ideal option. Donna, whose son took Prozac at the time of our interview, described the order of treatment in the following way: “First you do all the behavior modification, you do all

that stuff, then you go to a neuropsychologist and get evaluated, and then you go to a doctor, and then you go to the medicine. They don't just put you on it." In looking at the overall autism treatment narrative, parents foregrounded their own significance in treating autism in accompaniment with special educators, backgrounding the more traditional types of health practitioners.

### Special Educators and Caregivers as Cultural Liaisons

Is autism a sickness that harms the child? Is autism nothing more than a generic descriptor attached to a person with a very different personality type? Caregivers brought these questions up repeatedly, many of them continually wrestling with the answers. These answers also changed over time as their children grew up. One common thread stood out. Caregivers all sought change to some degree, from pursuing the miraculous recovery to simply trying to find better ways to connect. They wanted to introduce their children to a neuro-typical way of life and hoped that they would assimilate. In becoming the cultural liaison, caregivers did much of the work themselves to instill some change. They also relied on teachers who, by law, also became cultural liaisons to people with autism.

The Education for All Handicapped Children Act of 1975, later renamed the Individuals with Disabilities Education Act (IDEA), was the first federal law in the United States that gave financial incentives to states whose public schools agreed to provide a free and appropriate education for special needs children. Before this time, as Sacks (1995) has noted, medical institutions such as state hospitals bore the primary

responsibility for caring for people with disabilities such as autism (see also USDOE, 2000). IDEA mandates that states offer education for special needs persons aged three years to 21 years, offer early intervention services to special needs children under the age of three (often referred by caregivers as Early Childhood Intervention, or ECI), educate teachers about caring for special needs children, provide an Individualized Education Plan (IEP) tailored to the student's specific educational needs and ensure joint parent-teacher participation in the development of the IEP. Each state enacts IDEA differently according to their special education budget and, as some caregivers would argue, the overall value the state places on special needs people. The caregivers I spoke with have also observed that these educational services vary from county to county; the more rural, the fewer the services provided. Because I only recruited locally, the caregivers I interviewed schooled their children in either one of two area school districts, both located in the same county. Some had lived previously in other counties or states and thus drew comparisons between the qualities of education they received. Overall, they were pleased with the services provided by both of the local school districts.<sup>13</sup>

In part, the school districts received high marks from caregivers because they also specialized in the diagnosis of autism. IDEA mandates that there be experts available in each school district to recognize and diagnose disabilities like autism. More than anything else, diagnostic services are in place because the state wants to ensure that only those with special needs, as defined by the state, access the services. As a collateral

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<sup>13</sup> Services include diagnostic services, speech therapy, counseling, special education classes and, depending on the case, transitioning to mainstream classes. Each caregiver and child receives a specific treatment plan for the year during the yearly IEP meeting. Specific treatment plans vary widely and can include therapeutic treatments like ABA, depending on the willingness and ability of the school's staff.

effect, however, these educators were more reliable and efficient at diagnosing autism than the local pediatricians and physicians. Special education professionals understood the world of autism. In a study about the importance of special educators, Helps, Newsom-Davis and Callias (1999) wrote, “Teachers work closely with children at a time (early childhood) and under circumstances (new environment and demands, close peer contact) when typical features of autism are most obvious.”

Caregivers spoke of many creative ways in which educators acted as cultural liaisons. All children endure lessons in potty training, vocabulary and conversation skills. These habits and skills do not seem to come naturally for children with autism; they need far more assistance in learning these neuro-typical skills. Caregivers credited special education professionals in instilling them in their children. They also spoke about the benefits of direct observation, which enabled special education professionals to search for problematic social pathologies, or the instances in which troubled social interactions between the student with autism and her peers occurred. Virginia explained:

A student worker pursuing her doctorate goes and observes James in class and then she makes notes. But she doesn't ever talk to him in class because she doesn't want to be singling him out. And then they have times when he comes to her classroom—usually on Thursdays for about 30 minutes—and she points out things that she saw in the classroom and asks him different ways of how he should have handled a social situation.

Caregivers referred to these one-on-one meetings that Virginia described as social skills training. Students learned things that many neuro-typicals instinctively know:

conversation skills, conversation initiation, conflict management and acceptable versus disruptive behavior, to name a few. Cristina spoke of one special educator who made an important discovery about her daughter's conversation deficiencies. The finding came about through a test the educator used, called ABLES:

[The teacher] discovered, by doing this meticulous ABLES thing, that [my daughter] could not ask a question. She used statements with rising intonation. So: "Go to the mall?" That's a statement, you know? Instead of saying, "Mom, when are we going to the mall? Can we go to the mall?" So, you know, all those years of the speech therapist trying to get her to repeat things or, you know, just repeating things doesn't help. Figuring out a structure like, "Okay, these are the five question words: Who, what, when, where, why?" So she figured out a structure on how to teach.

More generally, Peggy described a communication notebook that her son's teacher used to communicate with Peggy. The notebook consisted of observations about Peggy's son, including areas in which he had improved socially and the areas still needing work.

Special education professionals assisted many parents in getting children an autism diagnosis. They also acted as a cultural liaison, introducing and helping them to assimilate into the neuro-typical world. Caregivers also voluntarily took on the role of cultural liaison for their children with autism, laboring tirelessly to assimilate their children into the neuro-typical world and also trying to educate neuro-typical people about the world of autism.



It is probably not a coincidence that, out of the 19 people I interviewed, 17 were mothers. I try not to look too deeply into this fact, as most of the mothers assured me that the fathers also actively took on a treatment role. But the mothers also told me that they handled most of the coordination and implementation of treatment. Previous research has found this to be true with the overall autism caregiver population (e.g., McGrath, 2006). Indeed, also in line with other research on the subject, many mothers acknowledged that they either had to completely give up or scale back in their professional lives in order to become a better facilitator for their child or children (Gray, 2002). Virginia explained why it was she gave up her career to care for her two neuro-typical children and two children with autism: “I really felt good about my job so it was really hard to give that up. But not having the stress of that job made me such a better mom because then I could just focus on the kids. So I needed to do it.” Employed full-time, Lois also described herself as a “total care taker.” She added, “Just this past month or two have I regained a hobby. I mean before that it’s just been whatever it’s taken to make it through the day with the kids, from morning to night.” In giving up careers and hobbies, many of these mothers left most of the neuro-typical world behind. Cristina, for example, referred to the space in which she existed as the “special ed world.” She defined it as an “invisible bubble” that kept her from reentering the neuro-typical world and also prevented her from fully understanding the world of autism. Even more so than special educators, who presumably left their special ed world behind at the end of the work day, caregivers (i.e., mothers) lived in a liminal space, or a “threshold” in between

two different spaces or worlds (see Turner, 1969; van Gennep, 1961). They served as true liaisons, then, in trying to connect these two worlds together.<sup>14</sup>

Many of the caregivers I interviewed carried out their own methods of treatment or tried to continue with the types of interventions the children received through the school. Elizabeth, for example, had studied special education in college. She said:

I was just using my own instincts as a parent and then my special ed training without really realizing it. I was doing a lot of what would have been normally done in early intervention. ... Even before diagnosis, I knew; it just was a normal reaction to training. And then when I got the book—when we got diagnosis and I got the books, I was going, “I’ve already done this. I’ve already done this. Why would I pay someone to do this? Home training? I’m doing more than the in-home trainer.” ... I mean, he literally had his time scheduled; we did full token economy, earning chips and spending chips. I had years of stacks where I kept the records of this token economy.

Parents also found visual cues to be effective tools for teaching their children how to adapt to a neuro-typical-type daily schedule. People with autism prefer strict routines and dislike change. With proper visuals, caregivers found they could better introduce their children to a more varied schedule and prepare them for new places and new routines. Carmen, for example, took her son Jonathan to an autism conference in a nearby city. He did not adjust well to the change and responded by throwing a violent

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<sup>14</sup> Similarly, other literature has referred to parents as co-therapists because they undertake much of the responsibility for treatment (see Pakenham, Samios, & Sofronoff, 2005).

tantrum. Carmen remembered what she learned in the conference that day and started drawing:

And he got it! I drew the little man—that we had left the ranch full of cows and came to the city. I drew the city, and then talking to him at the same time and showing him when the sun came up and when the sun goes down. And what he has to do during the day: he's gonna watch cartoons so I put a TV, and then go eat lunch, and then go swimming, and then cartoons again in the afternoon. And then I would be out of the conference and we would go to dinner out someplace.

With that little schedule card he was OK. He knew what time it was.

Another caregiver I interviewed took her role as liaison to a more professional level. She used her knowledge of visual cues to start her own business helping other parents introduce their children with autism to the neuro-typical schedule. Several years prior, she found an effective tool in her charm bracelet. She used different charms on a bracelet to communicate with her son about his upcoming activities (e.g., first school, then a soccer game, then computer, then eat, then sleep). Gradually, he became accustomed to an ever-changing schedule. His family, in turn, could participate in many more activities with the whole family. From this, the caregiver created her own business. Other caregivers could purchase bracelets with many different kinds of charms in order to help their children with schedules and transitions.

Many parents reported having some degree of experience with Applied Behavior Analysis, or ABA. The previous chapter discussed this social intervention in depth, noting its popularity among parents and researchers because of its proven efficacy

(Schriebman, 2005). Sharon and her family, for example, dedicated themselves to the approach. They spent time in California working with a therapist and also trained several therapists in their home to continue with the program. She told me that she had even considered moving her family to a state on the east coast, where she heard that all special educators implemented ABA in their classrooms. Sharon found ABA an effective tool for cultural assimilation. She recalled their first summer using the program: “In that summer, he started talking, he starting making eye-contact, he started responding to his name; it was huge, huge summer, we were so excited.” For financial reasons, Sharon’s family had to temporarily discontinue the ABA treatment for their son. Sharon said she was very frustrated because she knew that if they had the money, through ABA her son would be well on the road to living a more neuro-typical way of life.

As described in Chapter III, ABA continues to receive criticism because of its inability to instill “natural” neuro-typical behavior in people with autism. Children who use the program still depend on external cues about how to behave, they are often unable to initiate spontaneous behavior, they give rote responses to questions without understanding the meaning or significance and they fail to initiate requests or commands. Several parents I spoke with expressed concern about ABA for similar reasons. Mary reported using ABA to help her son talk and potty train, but had since moved on to other approaches, explaining, “Because we feel like we don’t like the way that they teach social skills in ABA, with the rote scripts and, you know, that kind of thing.” As a special educator as well as a parent, Carmen also saw limitations to ABA.

She described ABA therapists as attempting to “jam” children with autism (“round pegs”) into a “sort-of-less square hole,” an analogy that criticized ABA for focusing more on neuro-typical assimilation than adapting to the needs and learning style of the person with autism.

Caregivers worked intently on social intervention and cultural assimilation, and the examples above serve as evidence for this. Even in carrying out other types of treatment, including restricted diets and herbal remedies, the focus remained on removing the social pathologies of autism and moving the child towards a more neuro-typical way of life. Caregivers had heard anecdotally about the benefits of diets, for example, but few parents saw the results. Sharon reported successfully implementing the gluten-free, casein-free diet with her son. She said that it helped her son sleep better at night which, in turn, helped improve his behavior problems.

Ultimately, parents expressed hope that their work could translate to their children becoming independent adults. The definition of independence varied with each caregiver. Regarding her two sons with autism, Virginia explained:

I appreciate that he’s autistic but I also appreciate what kind of world he’s got to live in. And we have to make sure that he’s got the tools to exist in this world that we live in. You know, on the internet they have this society of autistic people who think that they can exist without interacting with this world and they consider themselves their own community. I can’t think of any other disabled group because even, you know, the deaf and the blind. They all interact with this world. But the boys are gonna have to interact.

Virginia then described what she hoped for her lower-functioning son:

I want him to be able to use his words enough to be able—like you're in a foreign country. He walks in [to a coffee shop] and he can say, "I want coffee please." If that's all he could say, I think that he could get by with it. They would think he was weird, you know, because they might say, "Oh, that's a pretty shirt you have on." And he goes [confused look]. But they hand him the coffee and he says, "Thank you."

Virginia drew on the foreigner trope in describing how he hoped her son could interact as an adult. Most caregivers did not explicitly draw on such tropes, but instead defined independence through common neuro-typical benchmarks such as college, employment and marriage. Peggy worried about one of those benchmarks for her 23 year-old son: "Employability is the biggest issue. Because he is so very very bright, but so very very odd." These neuro-typical benchmarks, as Mary noted, remained distant for many people with autism:

We are hoping that [our son will] go to college at least. We're hoping that he'll ultimately be able to live independently, but we know that the statistics are not on our side right now. Only three percent get married. ... And approximately that percentage live independently. So 97 percent are, you know, they might have normal IQs and be able to hold down a job, but they can't function in daily life.

Summer hoped to simulate neuro-typical activities when her son reached adulthood.

If we find something he could do and then we could train him, that would be excellent. Whether it was in our home and we were the overseers, whether it

another group or whatever. I think that would be, probably, independence in some way, any sort of independence whether independently doing something that he likes or some type of skill. ... You know, if I'm having to pay whoever to employ him. You know, "He's not bringing home a paycheck, he's not working for you, can I pay you a hundred dollars?" Or a thousand dollars, whatever the case.

Before Summer could arrange any kind of work, though, she recognized that they needed to do a lot more work to bring him into the neuro-typical world: "I think [we hope] for communication to increase at a level where he can communicate with us verbally or in writing. I mean in some sense to convey some more complex thoughts and reasoning and also comprehend them."

If caregivers hoped for some type of assimilation, they also feared the opposite: continued isolation. Several caregivers specifically mentioned the fear of institutionalization. These caregivers had children nearing or just past the age of 21, the age at which the school district services cease. In his longitudinal study of caregivers to children with autism, Gray (2002) also found that parents began to worry more about institutionalization as their children became teenagers. Given that all caregivers I interviewed remained adamant about working towards independence, it is safe to assume an implied rejection possible institutionalization. As Peter explained of institutionalization, "Well, I mean, if I chose to, it's the thing that can cause me to lose a great deal of sleep." Institutions seem to counteract the years of social interventions performed by special educators and caregivers. They isolate people with autism and

other disabilities, removing them from social interactions with most of the neuro-typical world. This isolation could precipitate other bad things, including neglect, manipulation or abuse to their children and a lack of freedom. Mary explained to me:

I really would like [my son] to, like I said, live completely independently—not be in a group home. An institution is not an option. It’s just not. ... The scary thing for me is that he won’t have choices. I guess is the best way to boil it down. Because I want him to be able to choose where he lives. I want him to be able to choose, you know, what kind of services he receives. I want him to be able to choose what kind of job he has. And I don’t want him to be boxed in by programs or state services or institutions that won’t allow him to choose, you know, what, the direction that his life takes.

Sarah and Peter also discussed the harsh reality of their children’s futures. At some point, they said, they have to prepare for the fact that their children will both be alone in the world. Peter hoped: “Just knowing that it would be, you know, five minutes after I’m dead that they’re in the best place they could possibly be. Because that’s really all that I’m worried about. It’s that sort of long term placement.”

As described by caregivers, the assimilation of children with autism into the neuro-typical world can seem one-sided. Parents and special educators, themselves mostly neuro-typical,<sup>15</sup> sought extensive social interventions in order to reduce the social pathology and, in turn, enable children with autism to become more like their neuro-typical peers. It is also important to recognize that caregivers experienced the social

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<sup>15</sup> Although there were no official diagnoses, some mothers wondered whether the fathers of their children also had autism.



pathology of autism beyond the behaviors they observed in their children. According to many parents I interviewed, most neuro-typical people, unaware about autism and its symptoms, required some form of social intervention as well.

#### TOWARDS NEURO-TYPICAL ASSIMILATION

The caregiver account also gives insight into a more holistic view of autism as a social pathology. As liaisons, parents felt responsible for introducing autism to the neuro-typical world. Assimilation in this direction, however, proved difficult. Caregivers overwhelmingly agreed that most neuro-typicals knew very little about autism, especially the physical manifestations, such as tantrums or other inappropriate behavior. Autism is diagnosed through a checklist of physical manifestations. Most unsuspecting neuro-typical people, however, do not know about this checklist. Without these well-known visible markers for autism, it may as well be invisible. Peggy, for example, remarked: “Right now you would probably never know [my son has autism] if you just looked at him.” Even neurologist Sacks wrote, regarding his first encounter with people with autism during his visits to a state hospital, “Most of the children looked physically normal” (p. 251).

As a consequence of this lack of knowledge, caregivers lamented that the neuro-typical public, themselves foreigners to the world of autism, *mis*interpreted the physical manifestations. For example, Summer said:

[With autism] you just have you have to put up with so much more. When your kid is throwing a tantrum in the grocery line and everybody is giving you the

look from around the aisles, you're laughing. You're laughing because, normally, it's because you have a bratty kid. But in our case it's because the flickering lights are driving our autistic kid through the wall.

Caregivers no doubt viewed public outbursts or strange behavior as undesirable. But they thought worse of the neuro-typical misinterpretations. Drawing on knowledge from their own world, the general public could only see children with autism as misbehaving and bratty. The public often took their misinterpretations a step further, visibly and audibly condemning the child with autism and the parents. Through their narratives, caregivers sought to prove that their children were not the only ones with bad behavior. It also extended to the neuro-typical world, thereby extending the social pathology of autism.

This pathology, or negative judgment, affected the identity of caregivers. Many of them perceived that, during these misunderstandings, the public held caregivers responsible for the misbehavior. Sharon experienced this problem: "To me, that's our biggest [issue], is how [autism] presents itself. I think just that if you didn't know anything about autism or anything about special needs, I think that just an average person and will look and judge [my son] as an ill-behaved child. He just needs discipline and better parents." Lori elaborated further about the negative judgment the public has imparted on her:

When I walk with my kid in Barnes and Noble and he has a meltdown in the children's section, people just think I'm a bad parent. They don't say, "Oh what disability does your child have?" They look at me like I fed him too much sugar.

In fact I've had somebody ask me that before or something like that because it looks like there's nothing wrong with him. And that is so stressful for him to go out in public and have a meltdown or, you know, have some of his behaviors that are different than the average person. And then have people say things or give you those looks or whatever. ... So then when they act weird or they act out or they melt down or whatever, you know, you're a bad parent, they're a discipline problem. There's never sympathy or concern or effort to help. It's just judgment. That kind of thing. So that's frustrating.

Lori's frustrations once again underscore the real differences between the world of autism and the neuro-typical world. Her problems, as she said, began with her son's odd behaviors. But the pathology lies in the unsympathetic patrons at Barnes and Noble.

To help solve this problem, or to become a better liaison between neuro-typicals and people with autism, caregivers wished for—and have procured—a rhetorical device to assist in introducing autism to the neuro-typical world. Examples include t-shirts, business cards and bumper stickers with the word “Autism.” These visual aids act as an explanation for autism—in particular, what it is and how it manifests itself in public places. Such markers are explicit, though they function much in the same way of other implicit visual aids, from bodily or facial markers (e.g., absence of limbs, Downs Syndrome) to mechanical (wheelchairs).<sup>16</sup> Summer explained:

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<sup>16</sup> Interestingly, this is the reverse of what is often seen in stigmatized communities. Sociologist Erving Goffman (1963) explored the phenomenon of “passing” as a mode of secrecy in hiding one's stigmatized identity as homosexual, disabled, ethnic or un-Christian, for example. Instead, caregivers attempt to overcome a different stigma: the bratty, spoiled child that throws tantrums in public or who defies requests. Caregivers have said that they prefer to have visual markers in order to reduce this stigma. A label suggests, “I'm not a bad parent and my child is not misbehaving. He has autism.”

I love these little cards, I don't know if you've ever seen them but I just ordered some the other day because I just wanted to see what they said. And one of the autism groups up in North Carolina, Connecticut—I don't know where—makes them up, and they say, “I'm sorry if my child bothers you, but he has autism.” And it goes on to explain what autism is. So it's like you can toss it to someone that's giving you the evil eye as you have to rush out of the restaurant or, you know, or drag your kid out of line or something like that. I thought, what a great idea, you know?

In just a few words, this exterior label disrupts the neuro-typical narrative of the spoiled or undisciplined child and reorients the story with a new explanation. Furthermore, these visual markers such as t-shirts or cards function as a supplemental voice for the liaison. They assist caregivers in bringing the two worlds closer together by teaching neuro-typical people how to properly interpret the behavior. Sarah expressed her hope as follows:

It shouldn't be unusual if Chris were to yell an obscenity in the middle of the grocery store, which he has been known to do, that instead of people kind of looking at me like, “My goodness, can't you control your child?”—and, of course, the answer to that is, “No I really can't”—you know, [the reaction] would be just a smile and a wave. And maybe [neuro-typicals will] think, hey, maybe this kid is not sent from hell; maybe he's just got a problem.

That many caregivers hope to educate the public about autism shows a desire for a merger of the two different worlds. Through various types of social interventions,

people with autism learn how to live among neuro-typicals. Now caregivers have begun a movement to educate neuro-typicals how to live among people with autism.

## CONCLUSION

This chapter shifted from a biomedical perspective to a biopsychosocial approach. Accordingly, I argued that caregivers described autism as a social pathology. As a consequence of this pathology, caregivers described their children with autism as different and distant, or alien-like. Caregivers used various tropes and narratives in order to convey the radical difference and distance between a person with autism and a neuro-typical person. The pathology affects people with autism, their caregivers and their families, and many other neuro-typical people.

To round out the analysis of explanatory models, I offer a final autism perspective. The following chapter outlines a mainstream media explanation for autism. The caregivers I interviewed in the present chapter had not voiced their autism explanatory models in major public forums, with the exception of one family that had received some local media coverage. In the next chapter I continue to examine autism, including the caregiver perspective, but from a very different angle. These caregivers and other autism advocates commanded the national stage, appearing on newspapers, radio, internet forums and television shows. Drawing on their experiences with autism, these advocates worked to challenge the status quo and fight autism within their children.

## CHAPTER V

## AUTISM AND WAR: A NEW ARTICULATION OF AN OLD METAPHOR

Mainstream media (MSM) coverage of health issues has become an important resource for many people (Dutta-Bergman, 2004). Those wanting to learn more about autism will find a wide range of information available in MSM, including lay descriptions of the autism theories described in Chapter III. For example, an article in *Newsweek* outlined Theory of Mind in an effort to go beyond the basic *DSM* explanation for autism (Cowley, Foote, & Tesoriero, 2000). Though an article like this may seem informative and objective, it is important to recognize that MSM accounts contain a point of view, whether or not it is intended by the author. The authors of the *Newsweek* article, for example, described Theory of Mind as a definitive explanation for autism when, in reality, it is one of three major theories on the subject matter. Though MSM accounts may not get the details of science and medicine exactly right (Clarke & Robinson, 1999), there are strategic choices made in the creation of a story. These strategic choices comprise an MSM explanatory model.<sup>17</sup>

In fact, the development of a comprehensive MSM explanatory model is a difficult task precisely because of the various ways in which a journalist might approach autism. Autism's ambiguity produces a great deal of fragmentation and conflict. There

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<sup>17</sup> I use the term explanatory model throughout this chapter for the purpose of consistency. Elsewhere in the literature it is more commonly known as media framing (see Iyengar, 1991). I recognize that the two terms are interchangeable.

are many points of view about what autism is, what causes it, and how best to treat it. That journalists and producers cull from many different sources only adds to the fragmentation and conflict. Consequently, locating consistency within these texts is a challenge. The challenge is a common one for scholars examining MSM texts. As Condit wrote (1999):

[P]opular media rarely attempt to present a singular, unified theory of the form that typically occurs in either professional journals or academic books. Instead, public media present discourses with a mix of challenges and responses. They present attractive fragments of theories and blend them with attractive features of other discourses. (p. 11)

But there is something exceptional about MSM coverage of autism. Unlike scientific texts, MSM coverage is attuned to the drama that autism discourse generates. Narratives about the distrust between caregivers and medical institutions, the inability for science to answer questions about autism and the daily struggles of life with autism are only a few of the many themes that MSM can uniquely capture.

The biopsychosocial approach continues as the guiding approach for this chapter. This means that, much like the caregiver explanations in Chapter IV, mainstream media (MSM) accounts of autism meld together biomedical and social viewpoints. As this chapter unfolds, however, readers will notice that, unlike in the previous analysis chapters, conflict between biomedical and social explanations permeates the discourse. This apparent conflict led me to consider the importance of Mishler's (1981, 1984) elaboration of the biopsychosocial point of view as it exists in medical encounters. I

found Mishler's (1984) description of conflict between the "voice of medicine" and the "voice of the lifeworld" as the most appropriate frame for addressing the existing conflict in MSM explanations.

In his analysis of physician-patient interviews, Mishler (1984) noticed that physicians and patients had distinct voices. These two voices did not always unite in conversation amicably. The voice of medicine refers to the physician's or, more generally, the biomedical expert's assertion of control. In the context of the doctor-patient interview, Mishler's preferred unit of analysis, he found that doctors controlled the course of the conversation and redirected it as necessary in order to achieve a biomedical outcome, whether that was making a diagnosis, creating a medical history or devising a treatment plan. The voice of the lifeworld refers to a patient's use of personal and social contexts to explain illness. The voice of medicine, Mishler wrote, tends to consider the voice of the lifeworld "nonmedically relevant" (p. 91). The voice of medicine will interrupt or repair the voice of the lifeworld in an effort to return the conversation towards a biomedical agenda.

Much like Kleinman's notion of an explanatory model, I draw on the broader rhetorical lesson of Mishler's competing voices. In this chapter, the voice of medicine and the voice of the lifeworld conflict on a much larger scale. In the context of certain controversies about autism, the voice of medicine asserts explanations about autism using scientific evidence as its definitive support. The voice of the lifeworld, meanwhile, refuses to accept the authority and control of the voice of medicine. It fights back, drawing on personal experience and narratives as its counter.



With this conflict in mind, I argue that a military metaphor guides the narratives produced in many MSM accounts. Like the computer, war and military have significant cultural meaning in society (Lakoff & Johnson, 1980). Though the military metaphor had existed in medicine for centuries, Golub (1997) posited that, in recent times, it reshaped itself in post-World War II discourse of Western medicine: “In the prevailing wartime mentality, science began to grow and an all-out ‘attack’ on disease was made” (p. 215). Biomedicine, in need of funding, used the metaphor as a means of conveying urgency for their agenda. To date, military terminology has maintained its presence in medical discourse, enhancing both professional and lay explanations about diseases such as cancer, tuberculosis and AIDS (see Kleinman, 1980; Montgomery, 2001; Rollins, 2002; Segal, 1997, 2005; Sontag, 1978, 1989). Segal illustrated: “*Invading* microbes are resisted by the body’s *defence* [sic] mechanisms or by pharmaceutical *magic bullets*; in the *battle* with cancer, we *bombard foreign* cells, and we *fight* for our lives” (Segal, 2005, p. 123, italics hers). The appropriated language conveys aggression, a mentality that biomedicine—especially American biomedicine—has long encouraged (Payer, 1988). However, as I discuss further this chapter, the direction of the aggression (toward whom, from whom) has changed considerably.

Autism itself makes this analysis of metaphor different than much of the work that has previously attended to the use of the military metaphor in medical discourse (Hodgkin, 1985; Segal, 1997, 2005; Sontag, 1978, 1989; Wallis & Nerlich, 2005). Autism is a lifelong disorder, and so there is no overt threat of death. However, there is no cure for autism and no specific treatments that work for every person. So rather than

a war with a beginning and an end, a collection of MSM accounts about autism present life with autism as a life of endless battles. The enemies in these battles vary, and they are not always the traditional enemies that accompany other diseases. In the following pages I draw on military themes to best demonstrate how MSM enact this metaphor to frame or explain autism.

The present analysis is the product of my reading recent newspaper, magazine and internet articles; watching television specials; listening to radio reports and reading radio and television transcripts from the year 2000 onward. The amount of MSM coverage about autism over the last several years has made it impossible for me to examine everything. It is also impossible to cover that much ground in one single chapter. Instead, I turn to several pieces that best represent a MSM explanatory model for autism. I chose to incorporate some narratives, like those about Jenny McCarthy and Jason McElwain, because their stories remained newsworthy for months. I included other accounts because they described situations commonly reported in media, but did so in a detailed manner.

I begin this analysis with some important contextual background. This will provide some initial groundwork from which I can further explore MSM explanations.

#### THE PUZZLING AUTISM EPIDEMIC

Over the past decade, several government agencies have argued that autism is on the rise. These findings have generated many questions about whether autism has become an epidemic in our country. Interestingly, MSM discussions about an epidemic describe

an autism “surge,” (e.g., Judd, 2002; Kantrowitz & Scelfo, 2006) which is a term recently appropriated by the United States government for military purposes (see Lakoff, 2007). The surge, in conjunction with the notion of an epidemic, tapped into a collective anxiety about widespread disease and suffering that dates back centuries to a time when citizens believed that epidemics were divine punishment (Golub, 1997). Autism as an epidemic is particularly frightening because there is little agreement about what causes it and there are no known cures or even preventive measures. Two reports—one from California and the other from the Centers for Disease Control and Prevention (hereafter, CDC)—directly fed MSM anxieties about a surging autism rate.

Beginning in the late 1980s, the state of California began counting the number of people with autism utilizing regional disability centers and comparing this number against utilization by people with other disabilities. Measurement began in January of 1987 and ended in December of 1998. Contrasted with other disabilities like cerebral palsy and mental retardation, the number people with autism utilizing California’s services increased dramatically, from 4.85% of the population to 9.37% (CDDS, 1999). The report further stated:

In just the past year, there were 1,685 persons with autism taken into the system. The number of persons entering the system far exceeds the expected number determined by traditional incidence rates. Estimates suggest that, compared to the other disabilities, net growth in the number of persons with autism is on average about 3 percent greater each year. Because the current trend has

continued for the past several years, it suggests that relatively faster growth in the number of eligible persons with autism will continue. (p. ii)

The authors of the report stressed that they only measured client population and not incidence of autism. However, the numbers they presented raised important questions that would be further explored in coming years. In 2002, the authors reported their findings to the California legislature and noted that they had seen a continued increase in access to services since the publication of the original report (Blakeslee, 2002). The issue became relevant to the national MSM because, as an expert stated in *USA Today*, “California is the canary in the coal mine. What happens to us will happen to everybody else” (Manning, 2005, p. 2D).

Around the time of the California report, the CDC embarked on a study of its own. In 2007, it released a report that had confirmed the suspicions raised by the earlier state report. The CDC report stated that, by the age of eight, one in 150 children will have an autism diagnosis. The statistic instantly became the frame for every subsequent media report about autism. The statistic combined urgency with a sense of doom—many families out there had children with autism and many more will. It seemed to confirm what many had already suspected—that autism had become an epidemic.<sup>18</sup>

A small community of experts produced the California and CDC reports. But the wide dissemination of these reports through MSM established autism as a disorder of great concern. An air of mystery surrounded the disorder, particularly because many of the questions raised were met with few definitive answers. Accordingly, it was at about

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<sup>18</sup> Media accounts do not hesitate to use the term “epidemic”, although many professionals think it unwise. See Fombonne (2000); Gernsbacher, Dawson, & Goldsmith (2005); Shattuck (2006).

this time that the term “puzzling” became a stock word to draw upon when describing autism. For example, CNN’s Wolf Blitzer introduced a 2002 segment about autism by saying, “California is dealing with a puzzling and heart wrenching health issue, the rate of autism in the state’s children has almost tripled in the last 15 years and no one knows why” (Feist, 2002). Similarly, an episode of ABC’s *World News Tonight* began their show in the following way:

We’re going to take a closer look at autism tonight. This puzzling disorder impairs someone’s ability to interact with the outside world. What is especially troubling is that diagnoses of autism are increasing dramatically in children across the country. Look at this chart from California, for instance, which charts the surge over nine years. There are similar results from other states. Doctors are mystified about the reason behind the increase, and the country is struggling to handle it. (Judd, 2002)

Health practitioners with knowledge about autism offered their opinions on the subject matter. Rather than communicate a sense of authority and calm, they seemed to further exacerbate the trope of puzzlement. For example, CNN’s doctor-in-residence, Dr. Sanjay Gupta (2003), invited the physician who serves as the chairman of the Autism Society of America to discuss autism. Throughout the interview, the physician offered a variety of potential causes of autism: exposure to certain plastics, exposure to industrial chemicals and even the new car smell were all a possible neurotoxin for infants. But he could not offer anything more than preliminary research on these matters. On *World News Tonight*, a doctor at the International Research Center

described his practice as chaotic because of autism: “We all feel like we’re a captain of a lifeboat off the Titanic, trying to decide who can we let in when we’re surrounded by people who are more or less drowning with this disease.”

Conflict narratives became a common way for MSM to communicate the confusion and controversy about such an uncertain disorder. Parents and healthcare practitioners advanced opinions about autism, with little agreement among and between them. These conflict narratives brought forward a military frame, structuring the conflict and confusion as a part of an ongoing autism war. One topic of particular interest to MSM served to completely re-characterize the role of medical institutions and health practitioners. The controversy about childhood vaccines received a significant portion of the media coverage about autism, in part because it was one of the few tangible hypotheses offered to answer the question of “why?”.

Details of the vaccine controversy, as presented in MSM, call to mind the problems experienced in times of modern warfare. In wars such as Vietnam and Iraq, the dominant institution, with good intentions, imposes its will on a group of people whose lives, in turn, are only made worse. With the assistance of William Fulbright’s political insight, I begin to articulate a new military metaphor as it is used to explain autism.

#### WHEN SCIENCE IS NOT ENOUGH

To begin, it is important to delineate between two separate accusations about childhood immunizations that often blend together in public debates about autism. Some have

hypothesized that the Measles-Mumps-Rubella (hereafter, MMR) vaccine leaves traces of the measles virus in the child's gut. A small percentage of children cannot properly combat the presence of the virus, which then goes on to cause inflammatory bowel disease, which then can lead to developmental problems in the brain. Others have hypothesized that the presence of thimerosal, a mercury-based preservative found in vaccines, weakens a child's immune system. The threatened immune system can cause problems as severe as brain dysfunction. Both debates go on despite the fact that scientific research, to date, does not support a correlation between either MMR or thimerosal and autism.

The MMR vaccine debate is a good case study to outline because the parties involved in creating the controversy are clearer. The major themes that emerged from this case parallel the themes found in the thimerosal debate. The debate took shape in the mid-1990s in England, where Dr. Andrew Wakefield was studying the measles virus and inflammatory bowel disease at a research hospital. In 1998 Wakefield and several colleagues published a brief report in the prestigious medical journal the *Lancet* where they speculated about a possible link between the measles virus, inflammatory bowel disease and autism. The MMR "jab"—a slang term for vaccine in the UK and an appropriately demonizing one at that—was not mentioned in this report. Rather, as Tammy Boyce (2007) reported in her analysis of the controversy, Wakefield held a press conference at his hospital announcing the findings and going a step further to draw a correlation between the MMR vaccine, inflammatory bowel disorder and autism. In this conference Wakefield also recommended that doctors consider administering the vaccine

in three separate doses rather than all together. Wakefield's co-authors, also present at the press conference, respectfully disagreed with Wakefield's hypothesis and recommendation. Initial media coverage about the conference was balanced and did not generate any panic (Boyce, 2007). Wakefield persisted with his claims, publishing another article about his hypothesis in 2000.

Logic has always remained on the side of the medical institutions in the larger debate about vaccines. Research to this day does not corroborate Wakefield's claims. His colleagues continued to openly disagree with him, publishing their disagreement in the *Lancet* (Murch, 2003). Furthermore, an investigation led to the exposure of Wakefield as a less-than-objective clinician. Prior to the 1998 *Lancet* publication, he had financial ties to multiple interest groups that accused vaccine manufacturers of wrongdoing (Boyce, 2007). It was also found that, before the 1998 publication, Wakefield received patents for a single dose measles jab.

Given these details, it seems quite inexplicable that the current MSM (and thimerosal) vaccine narrative positions the vaccine manufacturers, medical institutions such as the CDC and FDA and pediatricians as the enemies. Many caregivers blame either MMR or thimerosal for causing autism, and many more parents have hesitated in allowing their young children to receive vaccines of any kind. A *New York Times* article wrote: "The issue has become one of the most fractious and divisive in pediatric medicine" (Harris & O'Connor, 2005, p. A1). The CDC had to hire extra security for its employees who worked with thimerosal, and "one vaccine expert at the Centers wrote in



an internal e-mail message that she felt safer working at a malaria field station in Kenya than she did at the agency's offices in Atlanta" (p. A1).

But as Fulbright posited, modern warfare does not concern matters of logic. Rather, caregivers in particular have challenged the medical establishments because the establishments possess an "arrogance of power" (Fulbright, 1967). Arrogance of power is

a psychological need that nations seem to have in order to prove that they are bigger, better, or stronger than other nations. Implicit in this drive is the assumption, even on the part of normally peaceful nations, that force is the ultimate proof of superiority—that when a nation shows that it has the stronger army, it is also proving that it has better people, better institutions, better principles, and, in general, a better civilization. (Fulbright, 1967, p. 5)

Fulbright's insights parallel the smaller battle taking place in the vaccine debate. Members of the Western biomedicine have perpetuated an ethos of "better": better practitioners, better institutions, better principles and a better society. The chief mantra for practitioners—above all, do no harm—is one of good will. But the voice of medicine has attempted to assert control over the debate, and the voice of the lifeworld refuses to relent. Caregivers, as MSM reported, genuinely believed that the ethos of better, with its intransigent vaccine schedule, had caused their children harm. Practitioners and scientists denied the harms, falling back on their principles of better science. The continued imposition of this ethos on to a community of people in the throes of chaos created serious friction.

That Wakefield became the primary instigator for the MMR debate was a matter of his own ethos. Logical information that should have harmed his character did not much matter. He was a member of the institution he criticized; he offered MSM and caregivers a reason to believe that medicine had harmed children and did so in record numbers. He became an ally to the voice of the lifeworld. Contrasted with medicine's tendency to brush aside the matter because of a lack of scientific evidence, Wakefield took the time to cultivate media relationships and provide them with what he believed to be pertinent information. When reports began to question and attempt to harm his reputation, Boyce (2007) observed that media reports framed him as the victim, "a doctor fighting against the government and establishment science for the truth to be told" (p. 23).

The physical violence that has threatened some at the CDC is not common in this type of war. Caregivers draw upon a more metaphorical kind of warfare instead. MSM focus on caregiver accusations and stories, which I argue are akin to guerilla warfare. A small army of caregivers, who have much less power than the biomedical establishment, use their words to continually chip away at the existing power structure. Their weapon of choice is something that many medical professionals do not possess—the experience of living with autism every day.

Actress Jenny McCarthy has grown to be one of the most prominent leaders of this guerilla warfare. In 2007 she wrote a book about her son's autism and has since visited many MSM outlets with her message. McCarthy's celebrity status granted her special access to MSM that many other families did not have. One of her most

noteworthy appearances was on *Oprah*, where she shared her story in great detail. Of the many recurring themes on the show that day, the most prominent was her criticism of biomedicine and the MMR vaccine. McCarthy explained herself in the following way when Oprah asked her what caused autism in her son, Evan:

McCarthy: I do have a theory. Uh—

Oprah: Mommy instinct?

McCarthy: Mommy instinct. Everyone knows the stats, with it being one in 150 children have autism.

Oprah: And it used to be one in 10,000.

McCarthy: Yes. And, you know, what I have to say is this. What number does it have to be? What number will it take for [biomedical experts and practitioners] just to start listening to what the mothers of children who have autism have been saying for years? Which is, we've vaccinated our baby and something happened. That's it. And we don't know why, including myself. But I told my pediatrician, "Something happened." And the reaction I get was of making me feel dumb, and stupid, and I feel very alone in this.

Oprah: How were you made to feel alone and stupid?

McCarthy: Um because I was—you know right before his MMR shot, I said to the doctor, "I have a very bad feeling about this shot. This is the autism shot, isn't it?" And he said [McCarthy projects a

punishing tone], “No. That is ridiculous. It is the mother’s desperate attempt to blame something on autism.” And he swore at me, and then the nurse gave him the shot. And I remember going, “Oh, God, I hope he’s right.” And not soon thereafter, I noticed that change in his pictures. Boom! Soul gone from his eyes.

In McCarthy’s brief narrative, she strategically contrasts her role as the mother with that of her doctor. She possessed an intuition about the dangers of the vaccine and this prophecy was later fulfilled. Meanwhile the voices of medicine, her physician and nurse, embodied the arrogance of power. They dismissed her concerns because they believed that they knew better.

Through other MSM appearances, McCarthy broadened her enemy to the larger medical community. She repeated the common charge that the country’s medical institutions covered up the evidence of harm from vaccines. In an editorial on CNN.com in 2008 McCarthy and her partner wrote:

We think our health authorities don’t want to open this can of worms, so they don’t even look or listen. While there is strong debate on this topic, many parents of recovered children will tell you [the authorities] didn’t treat their child for autism; they treated them for vaccine injury. Many people aren’t aware that in the 1980s our children received only 10 vaccines by age 5, whereas today they are given 36 immunizations, most of them by age 2. With billions of

pharmaceutical dollars, could it be possible that the vaccine program is becoming more of a profit engine than a means of prevention?

On *Oprah*, McCarthy also argued negligence on the part of the CDC:

The fact that the Center of Disease Control [sic] acts as if these vaccines are one-size-fits-all is just crazy to me. Let's say there is no correlation. Let's say there isn't. The fact that they believe it's one-size-fits-all drives me crazy. Something needs to be done, and people need to start listening to what the moms have been saying.

Oprah then read a counter-statement from the CDC, in which the organization stated that they do not know what causes autism, and they believe from previous research that vaccines are not responsible. The CDC said they would continue to support more research and pursue the possible correlation between autism and vaccines. McCarthy dismissed this comment from the CDC, instead reasserting her voice of the lifeworld: "My science is named Evan. He's at home. That's my science."

McCarthy's equation of experience and science is an important one in the overall MSM reporting on the vaccine debates. The kind of warfare waged by caregivers like McCarthy has successfully challenged the existing power structure. Nowhere is this clearer than in the types of evidence appropriate for debate, especially in MSM.<sup>19</sup> The

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<sup>19</sup> This value shift in the appropriate type of evidence is also evident in the U.S. court system. In the summer of 2007, the U.S. Court of Federal Claims agreed to hear the cases of 5,000 families and their allegations against MMR, thimerosal or both. The families seek validation and financial compensation. The court will not base their judgment on scientific standards of evidence but instead on a "legal standard of plausibility—what one lawyer for the families called '50 percent and a feather'" (Vendantam, 2007, A6). In the opening statements of the first test case, attorney Thomas Powers focused on the significance of the families and their testimony. He said, "Numerous obstacles have been placed in the path of the petitioners seeking that fair and generous compensation that they are entitled to" (Harris, 2007, p. 21). As

dominance of biomedicine in our culture has traditionally meant that practitioners and scientists have the last word on medical issues. If it were up to scientists, there would be no debate about dangerous vaccines because no evidence exists to support the claims. Instead, because so many have challenged the existing power structure, MSM has shifted in whom they believed to be the experts on autism. The *New York Times* quoted Melinda Wharton, deputy director of the National Immunization Program, as saying they have entered “an era where it appears that science isn’t enough” (Harris & O’Connor, 2005, p. A1). Caregivers with stories about the harm done by vaccines have become just as or even more important than scientists and physicians.<sup>20</sup>

Moreover, science has become a key site of public contestation. Boyce (2007) concurred in her analysis, writing, “Journalists frequently equated public opinion with scientific arguments, making it appear as if claims made by both sides were equally valid. However, this style of reporting consistently puts science on the defensive” (p. 191). For example, in 2005, the president of the Institute of Medicine (IOM), Harvey Fineberg, and journalist David Kirby discussed the thimerosal controversy on *Meet the Press*. A 2003 report released by the IOM compiled 215 studies and found no causal

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noted in the *New York Times*, the court has gone to great lengths to demonstrate their commitment to the parents’ cause, even allowing parents to listen in on the hearings via conference call (Harris, 2007). Hope grew for the families when, in early 2008, the Department of Health and Human Services awarded money to a family who claimed that vaccines had caused a brain disorder in their daughter (Young, 2008). Officials decided that a series of vaccines she received as a toddler caused mitochondrial disorder—not exactly autism, but a disorder with autistic features.

<sup>20</sup> The 2008 presidential nominees offered their opinions about the link between autism and vaccines. In a blog post appropriately entitled “John McCain Enters the Autism Wars,” ABC reporter Jake Tapper (2008) described a moment on the campaign trail when a mother of a boy with autism asked John McCain about the vaccine debate. McCain responded by saying there was “strong evidence” that vaccines caused autism. Democratic nominee Barack Obama, on the other hand, called on scientists to produce more research on the subject matter at an April rally (Dobbs, 2008).

link between thimerosal and autism. Kirby objected to this seemingly comprehensive study, arguing:

You need to look at the biology, the toxicology; you need to look at the cellular level. You need to look at immunology, and I would say that's what the IOM did last year—I was at that meeting on February 9. Virtually half of the evidence against the theory, that was presented against the theory, was epidemiological .... The other half supporting the theory was largely biological. And yet the committee gave a preponderance of evidence or emphasis to the epidemiological evidence and rather, I would say, gave short shrift to the biological evidence.

In short, Kirby argued that the IOM valued the wrong kind of science when they determined that thimerosal caused no harm. The epidemiology, which examined the patterns of autism during the time when thimerosal was present in vaccines, was not enough. Kirby's argument also raised questions about trust, indicating that the committee strategically selected the epidemiological research—the wrong kind of science—over the other types of research available to them.

Professor, attorney and President of the environmental advocacy group Waterkeeper Alliance Robert F. Kennedy, Jr., in *Rolling Stone*, stepped up the accusations of corruption in the thimerosal case. Kennedy alleged that an epidemiologist at the CDC, Tom Verstraeten, found a link between thimerosal and autism. Panicking, the CDC organized a private meeting among industry officials. Kennedy wrote:

The CDC paid the Institute of Medicine to conduct a new study to whitewash the risks of thimerosal, ordering researchers to “rule out” the chemical's link to

autism. It withheld Verstraeten's findings, even though they had been slated for immediate publication, and told other scientists that his original data had been "lost" and could not be replicated. And to thwart the Freedom of Information Act, it handed its giant database of vaccine records over to a private company, declaring it off-limits to researchers. By the time Verstraeten finally published his study in 2003, he had gone to work for GlaxoSmithKline and reworked his data to bury the link between thimerosal and autism.

A cartoon illustration accompanied the essay. In it a woman (presumably the mother of a child with autism) holds an infant while struggling to keep a door open. Three men in suits (symbolizing biomedicine) stand on the other side of the door, fighting to keep it shut. The illustration once again attacks the credibility of the scientists, suggesting that they have purposely refused to include—or purposely left out—the caregiver perspective. It also ascribes the power to the mother who, while holding an infant, manages to keep the door open versus the three men on the other side, trying to keep it closed. Indeed, many of the conflict narratives presented in MSM have in common praise for the caregivers involved in the debate. Like the woman in the illustration, they are portrayed as the heroes, the people with the power. In doing this, MSM accounts remove control from the voice of medicine and reassign it to the voice of the lifeworld.

The MSM coverage of the vaccine debates begins to illustrate a new articulation of a military metaphor. The military metaphor of past medical crises emphasized the tenacity of biomedicine. A new interpretation of this metaphor has taken shape in MSM to explain the part of the autism war as battling the medical establishment. This new



frame has challenged the role of medical institutions and practitioners. Under the traditional conception of the military metaphor, practitioners were the heroes. They had the control, and patients willingly submitted to the healing power of the health practitioner. Now, in light of the vaccine debates, biomedicine has become the enemy to progress. Caregivers, who appear to be fighting for important values like truth and justice, have readily taken on the responsibilities as the protagonists.

I turn now to another new aspect of the military metaphor. In the instances provided below, caregivers retain their role as protagonists. This time they battle autism itself.

#### FROM THE FRONT LINES

Biomedicine dictates that diseases are discrete entities, independent from our physical bodies (Cassell, 1976). As Chapters II and III demonstrated, professional literature now considers mental health disorders like autism to be discrete entities, located somewhere (or many places) within the brain. It is because of this view of disease, also known as disease or germ theory, that a military metaphor exists. Golub (1997) explained that "...before the acceptance of germ theory, healing was not a battle against some defined 'enemy,' but with the realization that disease is specific, it became a foe we could deal with as we do any other foe" (p. 215). Oftentimes the military metaphor guided medical language towards describing one primary foe: death. Segal wrote (1997): "In the practice of western medicine ... the enemy is not disease but death itself, which must be kept at bay at any cost" (p. 223).

With autism, death is not an urgent threat. Instead, as the epidemic panic and vaccine debates illustrate, the threat comes from the lack of preventive measures and cures. Segal (1997) wrote that, “In North America, biomedicine aggressively patrols the border between life and death...” (p. 224). Segal’s statement needs amendment with regards to autism. MSM accounts portray a society that also patrols the border between normal and abnormal or, more specifically, autistic and neuro-typical.

In part, the autistic/neuro-typical border needs patrolling because autism *invades* children. Currently, however, no patrol can prevent the invasion. It often happens quickly, sneaking up on a seemingly normal child. The introduction to Oprah’s show on autism began by describing the sneak attack perilously:

Oprah: If your child stopped speaking, wouldn’t look you in the eye, completely ignored the world around them, what would you do?

[The show cuts to Jenny McCarthy]

McCarthy: When the doctor said, “I’m sorry, your son has autism,” I just remember closing my eyes and dying inside.

Oprah: In their first television interviews, actresses Jenny McCarthy and Holly Robinson Peete share the fight to save their sons. When autism strikes, a wake-up call for all parents. (Rakieten, 2007)

From the outset of *Oprah*, autism becomes a frightening foe. It *strikes*, causing a seemingly normal child to stop speaking, to avoid eye contact and to ignore the world around him.

This autism invasion is an important focal point for an autism narrative. It sets up a contrast, in many cases, between the past and the present. The contrast is only heightened because autism (the present) is so scary. In a *Good Housekeeping* article about autism, the author borrowed home video footage to demonstrate the difference. In the video, a two-year-old boy talked with and was affectionate towards his baby brother. The article continued:

Now four and a half, Christian is profoundly different from the irrepressible charmer in the video. He still has the beautiful blue eyes and kissable pink cheeks. But the connection to his surroundings is gone. Instead, he flutters around the room, moving from the VCR, which he robotically pats, to the window, which he bangs, then to his mother's hair, which he gently caresses—a baffling round that he repeats dozens of times. He makes sounds but no eye contact as he rushes around, with Katie ever at his heels, trying to redirect him, as she also keeps an eye on Mattias, now two and a half. “It’s hard to watch the video and see how Christian used to be,” says Katie, wiping her eyes. “But I’m so glad we got to know him before we lost him.” (Polaneczky, 2006, p. 112)

On *Oprah*, the show employed home video and still photographs to depict the contrast between McCarthy's normal son Evan and Evan with autism. The first of the home video footage showed McCarthy with her son immediately after giving birth to him. Its usage in this context seems to imply that Evan was healthy at birth because of the absence of any apparent abnormalities. The second set of footage continued in this vein, depicting baby Evan as normal as he stared into the camera and cooed. The show then

cut to McCarthy in her home as she looked through old pictures. She said, “Looking back at Evan’s baby pictures, I can see how he had this light and this soul in his eyes.” She then held up several pictures for the camera of Evan looking and smiling into the camera. She continued, “And then, all of a sudden, gone. Something happened just before that second-year-old birthday. He wouldn’t smile; it was really hard for him to look into a lens.” The pictures she showed supported her claim. In these pictures Evan looked away from the camera, somewhere off into the distance, and did not smile.

In both examples provided above, the contrast signaled to the frightening difference between normal characteristics and autism characteristics. The testimony and pictures suggest that autism robbed the boys of their humanness. Christian’s mother said, “I’m so glad we got to know him before we lost him,” as if, after the invasion, he was no longer a person. McCarthy described normal-Evan as having light and soul in his eyes, two characteristics that humans believe unique to them. These characteristics disappeared after the autism invaded. The pathos of the past-present description is enhanced when considering that the caregivers were powerless against the autism invasion in the first place. The healthy children could not protect themselves, and the caregivers could do nothing to prevent autism either. Even McCarthy, who recounted her interaction with her practitioners before her son received his MMR vaccine, had the intuition, but not the authority, to prevent it from happening.

Sometimes the contrast between normal and abnormal in a person with autism is extreme. The most striking of the behavioral symptoms for autism is the tantrum. The invasion comparison here is particularly apt, because often people with autism will

appear to behave normally and then, without warning, burst into a violent tantrum. With a tantrum, even a young child can harm loved ones. When caregivers encounter this behavior, they must engage in very physical fights. The story of Ben Royko, narrated in both an episode of NPR's *This American Life* and in the *Chicago Tribune Magazine*, contained scenes that can be best described as coming from the "front lines" of the autism battle. The plot of the Royko family story centered on a problem that many families coping with autism must face. Their son with autism, Ben, had become too large and difficult for the family to handle. The *Tribune* (2007) photography that accompanied the story set up the contrast, calling it "the two faces of autism." The description compared the human side of Ben with the inhuman side: "At left, Ben shows his affectionate side as he horses around his father" ... and "[a]t right, he is constrained in the family van by his father and brother, Jake, after an outburst that caused him to strike his mother, Karen" (p. 15). The Roykos had to come to terms with sending Ben away to a home. Indeed, the family regularly dealt with the violent side of autism, and it had become a significant source of stress. Ben's father, Dave, explained:

On a typical day, our son Ben empties the contents of cereal boxes and egg cartons onto the floor. He opens car doors while we're driving, he walks into traffic, throws himself up against a sliding glass door in our den. Luckily he's never smashed through, but he has put his hand through the windows in his room. By the time Ben was 12, he was nearly six feet tall and 250 pounds—a toddler in a giant's body. He dwarfed everyone in our house but me, which is

why my wife Karen's arms are covered with bruises, scratches and scars. I've come to call all the various wounds he inflicts "Benjuries." (Glass, 2007)

These battles that Royko and other families describe evoke a warfare that pits the family against the person with autism. But the Roykos do not physically fight back because Ben is their son. Rather, they endure the battle, trying their best to protect themselves and Ben from himself. But Ben does not always behave this way: "Most of the time he is as sweet a creature as you have ever known. He has a radiant smile and can be unusually affectionate for an autistic boy. Enormously lovable, with a delightful personality. Those who work with Ben tend to adore him" (Royko, 2007, p. 13). So Dave and Karen resist the suggestion of sending Ben to a home for months despite their physical battles. Dave recalled feeling that if he agreed to send Ben to a home, he would be a horrible parent (Glass, 2007).

The whole Royko family had a change of heart after one particularly grueling night. Ben's twin brother, Jake, described it thusly: "That one night with the banging and the hitting and the screaming and the sobbing and the more sobbing and the scratching and the banging and the pounding through doors" (Glass, 2007). Dave reported that, during this fight, he considered calling 911. He wrote:

I was concerned that Ben would smash his bedroom window (he's done so more than once, but not while raging). Maybe a 911 call would bring a paramedic with a sedative to inject. I kept listening for the sound of shattering glass, but it never came. At last, close to 1 am, the room got quiet. I looked in. Ben was asleep, knees on the floor, head on the bed. I was wrung out, on the verge of tears

myself, but relieved it was finally over. It wasn't. When I walked in, my nose told me that Ben had a load in his underpants. Excrement can serve as Ben's trump card. The last word. As one of his therapists said, "The message is clear: [Expletive] on you!" (Royko, 2007, p. 14-15)

The battle scenes described by the Royko family portray the invasion of autism as a sometimes violent one. This in light of the fact that Dave has also characterized his son as "enormously lovable."

The Royko's story, and two faces of autism, is not uncommon. In the 2006 CNN special *Autism is a World*, the Rubin family narrated the story of Sue and her life with autism (Wurzburg, 2005). Sue's mother experienced similarly violent behavior in Sue: "As a parent it is the most painful thing you can imagine, to see your child hitting herself and throwing her head against the car window or throwing her head against the table or on a concrete floor. It is horrible to have to watch your own child hurt herself that way." Through writing, Sue recalled how she felt: "When I wasn't able to communicate, actually I was a non-person..." The lack of humanity—whether due to violence or the inability to make eye contact—called forth the intervention. It is interesting to note that the language Sue uses contrasts with the caregiver explanations, which underscore difference through the use of alien or foreigner metaphors. Despite their use of these metaphors, caregivers still consider children with autism to be very much human.

Despite the apparent powerlessness against an autism invasion and subsequent bouts of extreme physical violence, rigorous intervention can help remove some of the autism from a child. Caregivers may not be able to prevent the initial invasion, but they

can tirelessly work to re-establish preexisting borders. This fight for normality has existed for decades, even outside MSM. Clara Claiborne Park (1967), narrating her experiences with having a daughter with autism during a time when few knew much about it, famously called her book *The Siege*. “We must intrude, attack, invade, not because she was unhappy inside [her world], but because the equilibrium she had found, perfect as it was, denied the possibility of growth” (p. 12), she wrote. McCarthy made a similar declaration about her son on *Oprah*: “He’s trapped inside. And all these little characteristics that I thought were Evan personalities was autism. So who is my kid, if it’s not the little characteristics of autism? He is locked, and I said it to myself, ‘I’m gonna get him out. I’m gonna get him out.’” Actress Holly Robinson Peete appeared alongside McCarthy on an episode of *Larry King Live*. Peete explained that it took her many years to go public with the story of her own son’s autism because her family was “in the trenches working to get this kid out of this window” (Douhit & Whitworth, 2007). These explanations ascribe significance and power to the voice of the lifeworld.

The Royko family remained humble about their lives with autism. They denied their role as heroes, assuring the audience that anyone in their shoes would behave similarly (Glass, 2007). They communicate this despite the fact that their story clearly places them as the protagonists in the (often physical) battle to help their son. Other parents, however, are willing to make the heroic comparisons. On *Oprah*, Peete explained: “Autism is like a wall around your kid. It’s a wall, and you have to be like a superhero and like Foxy Brown and kick that wall down. And make cracks in that wall to bring your child through” (Rakieten, 2007). Throughout the show, Peete used strong



female film characters to compare hers and McCarthy's struggles with autism. Peete described herself as Foxy Brown, a character out for revenge in a famous blaxploitation film by the same name. She called McCarthy Norma Rae, in reference to the film about the woman who fights for unions in her small town. Oprah agreed, remarking, "You're mother warriors, is what you are."

Sometimes these heroic efforts pay off. Caregivers have reported success in pushing the autism out. MSM are drawn to these narratives of victory because, in that moment of time, normality seems to be reestablished. In some extreme cases like McCarthy's, people report a full recovery from autism. McCarthy, for example, called her own story one of "hope, faith and recovery" (Rakieten, 2007) because she found several treatments that helped her son dramatically. The use of a special diet enabled McCarthy to draw her son from behind the wall, and it transformed him into a more typically developing child. More still photographs, shown throughout the show, were again supplied as evidence—this time of Evan's return to normal. Compared to the pictures of when autism had first invaded, these pictures show him again looking at the camera and smiling. Home video footage documented more normal behavior, as McCarthy and Evan played with his toys.

More frequently, MSM reported moment-in-time victories, where children briefly surmount autism's barriers. Jason McElwain's story is perhaps the most publicized and memorable of the moment-in-time success stories. On February 15, 2006, during the final regular-season Varsity basketball game at Greece Athena High School in Greece, New York, the coach allowed McElwain, the team's manager, to enter

the game with four minutes remaining. McElwain, who has autism, surprised his teammates, opponents, and the crowd by scoring 20 points in under four minutes, most of them from beyond the three-point arc. He was not particularly talented at basketball; though he enjoyed the sport, he had tried out and failed to make the team several times. Someone in the crowd videotaped the game, and the footage soon reached national telecasts and was archived on websites like CNN and Yahoo! News. McElwain's story appeared in almost every major MSM outlet; he received congratulations from President Bush and also received offers from movie studio executives who wanted to make a film about his life. After his 15 minutes of fame were complete, McElwain returned to his life with autism. He was not able to finish high school and does not have any aspirations for becoming a full-time athlete—instead, he works at his town's local grocery store (Roberts, 2006). But the story of a person with autism becoming a superior athlete for four minutes was victory enough. He had transcended autism to achieve something that many boys only dream about. McElwain's mother compared the basketball game to the ending of the Cold War—this was the moment that finally cracked his Berlin Wall (Harvey, 2006).

Another notable moment-in-time victory is the HBO documentary called *Autism: The Musical* (Chiles and Regan, 2007). The film followed a mother and her son with autism and her dream to carry out the Miracle Project, a musical she hoped to develop with the help of several children with autism in the community. There were many barriers to producing the musical. The Miracle Project relied on the children with autism to create the storyline and the music, but the project suffered because of autism.

Sometimes the children were not focused, they could not perform their roles or they misbehaved. Furthermore, parents argued about their children and their level of participation in the project. The film also focused on the struggles that each of the families experienced in the daily lives outside of the Miracle Project workshops. Ultimately, the Miracle Project succeeded. The children learned to cooperate and make friends. Parents found advocates in one another. On the night of their performance, the children seemed to leave the negative consequences of autism behind momentarily as they sang and played instruments, however imperfectly, in front of an audience of proud family members.

Despite the difficult path traveled by the Royko family, their MSM narrative also ended on a victorious note. The autism in Ben seemed to have retreated as a result of his life in a group home. On Ben's first visit home to see his family, the Roykos saw some remarkable changes:

Ben walked into the house and stared momentarily at things that had changed—like the new couch in the living room. Soon we were in the backyard, and he swung on the bench swing for two hours, as happy and relaxed as I had ever seen him. He spent the rest of the day with us, and when it was time to go, Ben and I got in the car and headed back to his home. A half hour into our drive, Ben said, “The letter D.” And it was my cue to say, “And D is for...”. Ben countered with “D is for dump truck.” And then he said, “D is for Daddy.” I glanced in the rear view mirror, and Ben was looking right at me—a rarity—and smiling. I reached back and, patting his leg, said, “That’s right, Ben. D is for Daddy. And Daddy

loves you so much.” He beamed. And, choking back tears, I said, “You’ll always have Daddy.” (Glass, 2007)

Their victory is not quite as hopeful as McCarthy’s—it is clear that Ben will never fully recover from autism. The new contrast depicted in the MSM narrative between how Ben was and how he transformed suggested that Ben was a few steps closer to having a normal life.

The MSM articulation of a military metaphor for autism differs from the typical iteration. Instead of death, the threat is the initial invasion, followed by a life lived somewhere between nonhuman and typical behavior. Accordingly, MSM explanations portray caregivers as heroic warriors, patrolling the border between autistic and neuro-typical. Caregivers are tenacious in their fight to save their children and sometimes must defend themselves against the violence that the autism can bring about. Though not all MSM stories about autism end hopefully, MSM respond positively to stories of victory. This positive response for stories from Jason McElwain and Jenny McCarthy educate and inspire the public. With all of the conflict that autism creates, it is perhaps a comfort to learn that victory is sometimes possible.

## CONCLUSION

An MSM explanatory model included many conflict narratives, often pitting the voice of medicine against the voice of the lifeworld. This conflict brought forward a military metaphor frame. The vaccine debate received a great deal of attention in MSM and, as articulated by MSM, re-characterized the role of medical institutions and health

practitioners. Caregivers became the heroes, using their personal experiences as weapons against medical knowledge and scientific evidence and, allegedly, data corruption. Caregivers also dealt with the invasion of autism, struggling for ways to return their children closer to the boundary of typical. Sometimes these conflicts brought forward stories of hope. These stories implied that victories were possible—people with autism could at least begin to return to normal.

The final chapter of this dissertation serves as an extensive summary. I summarize the major findings from each chapter and point to the various areas where I have contributed to the medical humanities and autism literatures. I also discuss some themes that require future research. I then answer the final research question posed in Chapter I about the overall autism explanatory model. In answering this question, I examine the primary differences among the three smaller explanatory models. I conclude by considering two places of unfortunate disconnection in the overall explanatory model.

## CHAPTER VI

### SUMMARY AND CONCLUDING REMARKS

In Chapter I, I wrote that this project relied on rhetoric as both a guiding worldview and a method by which to conduct my analyses. More and more, scholars of rhetoric have turned to the subjects of health and medicine because they are suited to a rhetorical mode of inquiry. Uncertainty abounds in medicine and so does deliberation. I made the argument, first introduced by scholars outside the discipline of rhetoric (Kleinman, 1988a; Tilly, 2006), that rhetoricians can look for persuasion in certain symbolic constructions known as explanations. These explanations help people to make sense of their world and to reduce uncertainty. Autism was well-suited for this study because so much uncertainty—and so many explanations—exist.

This project has also demonstrated that there is more to autism—and illness in general—than the professional expert's explanatory model. Medical humanities scholars like Arthur Kleinman (1980, 1988a) were among the first to suggest that scholars look beyond the biomedical account to the patient and even family account of illness. I expanded upon this argument by introducing an autism expert explanatory model, a caregiver explanatory model, and a mainstream media (MSM) explanatory model. In addition to the biomedical terminology that has constructed autism, I introduced various underlying social and psychological aspects of autism.

Ultimately I hope that readers will take away three broad lessons from my project. First, illness explanations are fruitful for those studying medical rhetoric. By incorporating the concept of the explanatory model into my project, I hope to encourage other medical rhetoric scholars to consider studying both the model and other rhetorical concepts that exist outside of the rhetorical studies literature. As a corollary to the first lesson, I also wish to encourage the marriage of medical humanities literature to the literature in rhetorical studies. Elliot Mishler and Arthur Kleinman are two of the many rhetorically savvy authors whose work need much more consideration and study. I also want to impress upon scholars that there are many kinds of illness explanations in need of further study; professional and patient explanations are only the tip of the iceberg. This final lesson speaks more to the broader health communication community, where the practitioner-patient encounter continues to be major focal point for research.

Major rhetorical lessons aside, I now move to outline the many smaller lessons readers can also take away from this project. I begin by summarizing some of the major findings from each chapter. Following this summary, I provide some areas that require future research. I then answer the final research question posed in Chapter I about the overall autism explanatory model. In answering this question, I examine the primary differences among the three explanatory models. I conclude by considering two places of unfortunate disconnection in the overall explanatory model. Citing two specific topics originating in the caregiver explanatory model, I argue that they ought to appear in the expert and MSM explanatory models as well.

## SUMMARY OF EXPLANATORY MODELS AND FUTURE RESEARCH

### The Autism Expert Explanatory Model

The first research question asked about the rhetorical strategies used to communicate the autism expert explanatory model. I argued that experts used one primary metaphor as a guide from the 1980s onward. It took several decades prior to the 1980s for the discipline to establish this metaphor because the discipline lacked rhetorical unity.

In Chapter II, I began by introducing autism as a fluid concept even within autism research. It was once embraced by the psychoanalytic tradition and considered a major symptom of schizophrenia. This psychoanalytic research tradition gained popularity in the middle of the 20<sup>th</sup> century but soon lost power because it failed to meet the basic requirements of science. Many within psychiatry valued science and hoped to include its principles within the research tradition, affording a new-found legitimacy for the discipline. Gradually, the movement towards biomedicine gathered steam and biomedical psychiatrists became a force within the psychiatric community. Under their direction, in 1980 the APA released the *Diagnostic and Statistical Manual of Mental Disorders-III*, the discipline's new charter document.

Previous research about the composition of the *DSM-III* established that the release of the charter document symbolized a paradigm shift in the psychiatric research community (Berkenkotter, 2001; McCarthy, 1991; McCarthy & Gerring, 1994). In Chapter II, I used this pre-existing research and evidence from autism literature to assert that a paradigm shift also occurred within the autism research community. Beginning with Leo Kanner's 1943 publication about "infantile autism," biomedical research began



its takeover. Although some of his arguments remained rooted in psychoanalysis, Kanner famously argued that autism was its own entity, identifiable by a host of physical symptoms. In his research on autism, psychologist and founder of Autism Society of America Bernard Rimland (1964/1985) posited that innate brain deficits caused autism, an idea very much ahead of its time. Rimland sparred with Bruno Bettelheim, one of the key psychoanalytic figures of the time period, about autism causation and the seeming lack of science in Bettelheim's arguments. The 1980 release of the *DSM-III*, in which the APA officially recognized autism as a distinct disorder, was significant in that it formally established a biomedical research trajectory for autism. The autism entry eradicated most of the psychoanalytic language previously used to describe autism and redefined autism according to its observable manifestations, a thoroughly biomedical practice.

Chapter III delved deeper into the biomedical perspective, uncovering further evidence of a strategic paradigm shift. Following the well-supported argument of the scientific article as rhetoric (Bazerman, 1988; Gross, 1990), I examined the autism research community's meta-dialogue about its research trajectory through autism's flagship research journal, the *Journal of Autism and Developmental Disorders (JADD)*, from its first issue in 1971 to the latest in 2008. I also relied on research articles from other journals and key books for additional insight. During the height of the biomedical takeover in the 1970s, the journal's articles focused mostly on achieving rhetorical unity; the journal editors encouraged contributions from a variety of sub-disciplines in an effort to connect the many disparate voices of autism research. Articles also united around

their criticism for the psychoanalytic research tradition, further emphasizing its lack of evidence-based research. By the end of that decade, near the time of the APA's release of the *DSM-III*, psychoanalysis—even the criticism of it—no longer appeared in the journal. It was replaced by competing biomedical theories about autism.

First documented by other autism researchers (e.g., Loveland, 2001; Nadesan, 2005), cognitive studies took control of the research agenda because of its legitimacy within the discipline and its compelling, cutting-edge computer-as-brain explanation for autism. The adoption of this mechanical metaphor stemmed from a longstanding tradition in medicine of viewing the body as a machine (e.g., Daugman, 2001; Osherson & AmaraSingham, 1981; Payer, 1988). Following Nadesan's (2005) previous work on the subject, the majority of Chapter III set out to examine the benefits and drawbacks to the prominent use of the computer metaphor. The metaphor allowed autism research to flourish in a number of directions, placing these researchers on the cutting edge of brain research. Three theories about autism—Theory of Mind, Weak Central Coherence and Executive Function—currently take up much of the space in the professional literature. The acceptance of the computer metaphor has moved autism research substantially beyond the basic description of symptoms. Drawing on observable autism behaviors, I argued that the metaphor attempts to explain those behaviors through specific mental functions or dysfunction. The computer metaphor afforded experts an endless avenue for generating hypotheses about brain structures. In this chapter I also examined some of the limitations of the current biomedical explanation for autism. The computer metaphor—and a biomedical approach to autism in general—directs expert attention to a

single body part, preventing holistic explanations of autism. The computer metaphor often receives a literal interpretation, further dehumanizing the person with autism; mechanical parts replace the human brain, diminishing the humanness of the person.

### The Caregiver Explanatory Model

The second research question asked about the rhetorical strategies used to communicate the caregiver explanatory model. To answer this question in Chapter IV, I departed from traditional rhetorical practices by interviewing parental caregivers to children with autism. This deviation from traditional rhetoric occurred particularly in my choice to conduct interviews rather than use publicly available caregiver narratives. The rule of thumb seems to be that “qualitative researchers” conduct interviews; rhetoricians do not unless it is to supply background information for an analysis.<sup>21</sup> I hope to encourage others rhetoricians to consider using “qualitative” methods to obtain texts and, ultimately, I envision a future for medical rhetoric where these types of boundaries do not exist.<sup>22</sup>

In Chapter IV, I also shifted from a biomedical to a biopsychosocial approach to autism on the recommendation of other medical humanists (Engel, 1977; Kleinman, 1988a; Mishler, 1981) who encouraged use of this approach when considering a patient

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<sup>21</sup> See the following other projects that blur the line between rhetorical and interpretive study: Sharf, B.F. (1990). Physician-patient communication as interpersonal rhetoric: A narrative approach. *Health Communication*, 2, 217-231; Vanderford & Smith (1996); Sharf, B.F. (2001). Out of the closet and into the legislature: The impact of communicating breast cancer narratives on health policy. *Health Affairs*, 20, 213-218; Vanderford, M.L., Jenks, E.B., & Sharf, B.F. (1997). Exploring patients' experiences as a primary source of meaning. *Health Communication*, 7, 13-26;

<sup>22</sup> I think this particular belief stems from a conversation I had with a friend and colleague at a recent rhetoric conference. I described to her some of the work that goes into conducting and transcribing interviews, and she said something along the lines of: “I’m so glad I’m a rhetorician and don’t have to do that.”

explanatory model. I argued specifically that caregivers overwhelmingly explained autism in terms of its social problems; autism was a social pathology. For caregivers, social problems stemmed from the difference and distance between their children with autism and neuro-typical people. They regularly drew on tropes to convey this difference and distance. I aligned these explanations with publicly available explanations of a similar ilk, especially Oliver Sacks's and Temple Grandin's (1995) descriptions of Grandin, a high-functioning person with autism, as an "anthropologist on Mars." The phrase explains both the perceived difference between Grandin (an anthropologist) and a neuro-typical person (Martians) and the sizable distance between herself (Earth) and others (Mars). Chapter IV supported Grandin's and Sacks's explanations, arguing that parents drew on similar tropes to explain their children. For example, as narrated by parents, language barriers prevented the mother from meeting her child's needs. Language difficulties also prompted parents to describe communicating with their child to be like communicating with a foreigner. Parents reported that their children with autism preferred to keep their distance from others; desiring isolation rather than friendship, children with autism played on the other side of the room from neuro-typical children.

Emanating from their view of autism as a social pathology, caregivers produced an autism treatment narrative that departed from traditional biomedical interventions. Caregivers described themselves as the primary ones delivering these interventions with the assistance of special educators at school. Their explanations concurred with previous research on the subject (e.g., McGrath, 2006). Caregivers and special educators used

social interventions to assist in treating the social pathology. Accordingly, caregivers described their role in treatment as cultural liaisons, attempting to assimilate their children with the neuro-typical world and vice versa. Treatment encouraged children with autism to stop negative behaviors and to converse and act more like neuro-typical people. Caregivers also expressed much frustration with the attitudes and behaviors of neuro-typical people who knew little about autism; consequently, parents said that they also hoped to assimilate neuro-typical people into the world of autism. In the end, caregivers worked daily at social interventions to prepare their children for a social, independent adulthood in the neuro-typical world.

#### The MSM Explanatory Model

The third research question asked about the rhetorical strategies used to communicate the MSM explanatory model. To answer this question in Chapter V, I analyzed MSM explanations of autism by reading recent newspaper, magazine and internet articles; watching television specials; listening to radio reports and reading radio and television transcripts from the year 2000 onward. I argued that a military metaphor guided many MSM accounts of autism. To help make this argument, I further expounded on the biopsychosocial approach. MSM acknowledged the construction of autism as both a biological pathology and a social pathology and welcomed both perspectives. Often, however, these perspectives did not co-exist peacefully, concurring with Mishler's (1984) research on doctor-patient interactions. The "voice of the lifeworld," the psychosocial, met and clashed with the bio, the "voice of medicine" (Mishler, 1984). As

a result, I found the MSM explanatory model laden with conflict, weapons, heroes, villains and a commonly used metaphor to frame it all. The rhetorical language conveyed aggression, something that biomedicine—especially American biomedicine—has long encouraged (Payer, 1988). Though previous literature has examined the biomedical war metaphor many times over (e.g., Kleinman, 1980; Montgomery, 2001; Rollins, 2002; Sontag, 1978, 1989; Segal, 1997, 2005), in Chapter V I described the various ways in which the MSM accounts of autism articulated the war metaphor in new ways; the direction of the aggression (toward whom, from whom) changed considerably.

Chapter V's analysis began with some context. The question of a possible autism epidemic set the tone for all other autism coverage. MSM reported that, based on new epidemiological studies, autism diagnoses rose significantly since the 1990s, from one in 10,000 to about one in 150 (CDC, 2007). This statistic raised more questions rather than answers, prompting MSM to describe autism as a puzzling disorder that required urgent attention. The epidemic coverage laid the groundwork for the war metaphor to thrive in MSM explanations for autism. The vaccine controversy, as others have noted (Boyce, 2007; Offit, 2008), continues to receive a lot of media attention. Unlike traditional articulations of the war metaphor in which the health practitioners are the good guys fighting off the evils of disease, MSM coverage of the controversy established the parents as the heroes, the voice of the lifeworld, fighting against the powerful but villainous biomedical practitioners, the voice of medicine. Using very public platforms like *Oprah*, parents accused the biomedical establishment of suppressing evidence that vaccines cause autism in some children. Parent narratives

became their weapons, and MSM used them to show how autism invaded normal children post-inoculation. Biomedical practitioners, through MSM, vehemently disagreed and tried to fight back with scientific evidence. However, in an apt *New York Times* quotation that summed up the changing role of biomedicine, Melinda Wharton, deputy director of the National Immunization Program, said they had entered “an era where it appears that science isn’t enough” (Harris & O’Connor, 2005, p. A1).

In most biomedical contexts, the war metaphor typically appears when patients and practitioners unite to fight against the possibility of death. Autism does not pose this kind of danger. Parents, still the heroes of the MSM narrative, instead fought off another aspect of the pathology, the autism invasion. MSM accounts described the autism invasion and the frightening behavior changes brought upon by it. Playful, social children became distant and disconnected. Loving children, when taken over by autism, became violent, even towards their loved ones. Parents battled to reestablish normality and humanity in their children, using military and/or empowered language to describe the fight. Sometimes these fights were successful. The final part of Chapter V described the circumstances in which MSM claimed victory for parents and their children with autism. Successful treatments and remarkable events magically transformed the person with autism back into a normal person, bringing peace back to families. In a rhetorical move that balanced out the gloom and doom narratives of autism, MSM regularly covered such victories, often failing to note the lifelong battle that is life with autism.

### Future Directions for Research

There are many more directions in which autism explanatory model research can head, and all of them will enlighten the current project. Throughout the writing process, I made innumerable decisions about what to keep in the analysis and what to keep out. It always came down to the matter of whether the material-in-question flowed with the overall arguments of the chapter; if it did not flow—or, as I often put it, if it opened up a new can of worms—I left it out. Such is the challenge when doing any kind of writing. Countless decisions were made in this project because there was so much material that beckoned my attention. In the next few paragraphs, I outline a few areas of research that do indeed open up new cans of worms, but still left me sorry that I could not include them. I consider these topics as potential areas for future research and important extensions to my current project as well as that of others working within the autism research community.

I devoted two chapters to autism's biomedical perspective. Even so, there is more to the story than space afforded me in these two chapters. Much of the autism research agenda adheres strictly to biomedical research principles, but some autism experts believe that these principles should not guide all of autism research. The lack of scientific proof for most autism interventions has raised questions about whether a thoroughly biomedical approach is the most appropriate avenue for investigation. Applied Behavior Analysis remains the only intervention that is evidence-based. Many other approaches, developed by some of the key figures in the autism community, do not have the backing of science. At the moment, this lack of proof demonizes some



approaches to treatment that, anecdotally, are considered beneficial (Schriebman, 2005). Eric Schopler (2005), psychiatrist and founder of TEACCH, criticized the autism research community's demand for randomized control trials. In order to conduct these trials, he wrote, researchers must study a uniform group of people with autism. This, he argued, is difficult and unrealistic. Autism co-exists with other problems such as learning disabilities and mental retardation. Furthermore, because autism exists on a spectrum, researchers need to limit their subjects to the same location on the spectrum. Both issues prevent researchers from studying autism treatment as it exists in reality—a tool that is adaptable to the many faces of autism. Schopler suggested an alternative research practice to replace the randomized control trial and stop the deadlock in this area of autism research. With regards to intervention outcomes, “expectations of ‘normal’ are replaced by ‘optimum adaptation, or improvement in quality of life’ . Interventions would involve multiple aims such as teaching new skills, changing attitudes, improving self sufficiency, to name but a few” (p. 710). In the cases of individuals with high-functioning autism, Schopler recommended social appreciation of their contributions, much like Temple Grandin has received accolades for her work on cattle chutes. Additional research needs to continue to explore the problem that many legitimate modes of treatment lack—the proper scientific backing. Questions like, what standards are currently applied for autism treatment research? and What alternative research paradigms exist? will help experts to get there.

Contrasted with high-profile programs like TEACCH are the fringe methods of intervention. These could include the use of tinted glasses to correct learning problems

in children with autism, vitamin therapies and allergy treatments to reduce unwanted behaviors and improve social skills. They also lack scientific evidence but the primary difference from those suggested by Schopler is that they also lack the endorsement of major figures within the biomedical research community. Paul Offit (2008) recently cautioned people about the dangers that some of these therapies can pose, explaining that parents desperate for solutions are vulnerable to therapies with no scientific backing or bad science. However, because so many methods of treatment lack evidence-based research, they all fall in together into the same category of treatment vaguely defined as possibly beneficial, but lacking appropriate scientific confirmation.

The problems that plague autism treatment parallel the barriers that advocates for complementary and alternative medicine have sought to overcome (Derkatch and Segal, 2005). Future research needs to heed the call of Derkatch and Segal (2005) and investigate the various modes of persuasion that practitioners use to justify the legitimacy of their autism intervention. Issues in question can include the selected research methodology (if any) and the rhetorical devices employed to establish *ethos* for the treatment. Findings could further assist practitioners and caregivers with adopting their own evaluation strategies for treatment.

Second, I admit that I unintentionally subverted an additional character, special educators, in this project. Their prominence in the caregiver explanatory model alerted me to this problem. The Individuals with Disabilities Education Act first shifted treatment responsibilities from public and private biomedical institutions to the public school districts. Thirty years later, autism diagnoses climb higher than ever before and,

as the California Department of Developmental Services (1999) report first noted, more people than ever are reaching out to the state for services. Helps, Newson-Davis and Callias (1999) wrote: “Teachers work closely with children at a time (early childhood) and under circumstances (new environment and demands, close peer contact) when typical features of autism are most obvious” (p. 288). Previous research has already established the importance of educational programs in the successful treatment of autism (Howlin, 1998; Rutter and Bartak, 1973; Schopler, et al., 1971). In the years to come, special educators will grow in prominence as they continue to establish themselves as experts in autism. If I had known just how important they were when I began the project, I would have also included a chapter on the educators’ explanatory model. How does this explanatory model translate to their approach to treatment? It would be very interesting indeed to contrast this model with those of professional experts and caregivers.

#### FINAL THOUGHTS: DIFFERENCES AND DISCONNECTIONS

A closer look at my research questions in Chapter I reveals certain expectations I had before I began my analyses. Based on previous research about explanatory models (Good, 1977; Kleinman, 1980, 1988a), I expected in the first three research questions that autism expert, autism caregiver and MSM explanations of autism would constitute three separate explanatory models. Because I based these questions on previous research, my expectations proved correct. In considering my fourth research question, on the other hand, my expectations fell short. I anticipated that I could examine all three

explanatory models side-by-side and see obvious points of similarity and difference. In particular, I thought I would see many connections; I expected some of the puzzle pieces to fit together.

Rather than finding connections, I found far more differences and disconnections as I examined the three explanatory models together. This occurred because of the very different rhetorical forms guiding each of the explanatory models. Each particular form encouraged the prominence of certain characters and topoi while suppressing other characters and topoi. So to tackle the fourth research question, I first located the primary differences in three major characters—biomedical experts, caregivers and people with autism—in Chapters II through V. Along these lines I also examined the topoi as they varied from chapter to chapter. After laying out these differences, I move to conclude with a brief editorial section in which I address some of the major disconnections across explanatory models. I argue that, in the caregiver chapter, some of the topoi raised there ought to be more prominent in the MSM and the autism expert explanatory model.

#### Differences in Explanatory Models

Biomedicine dominated the autism expert explanatory model. The psychiatric and autism research communities encouraged its dominance. Their new charter document, released in 1980, first articulated a coherent biomedical turn. More specific to autism research, the biomedical scholars within the research community welcomed the cognitive studies approach and its attendant computer metaphor. Today's autism expert explanatory model still draws on the computer metaphor, usually in one of two ways.

Top-down research uses observable autism behaviors and attempt to explain those behaviors through specific mental functions or dysfunctions. Terms like decoupler, information processing and CPU are just a few of the many that explain autism as a product of the brain and mind. Bottom-up research focuses on physical brain structures, both their function and dysfunction, in order to explain autism behaviors. Both perspectives encourage intense focus on the brain, subsequently reducing the role of the two other characters, people with autism and their caregivers. People with autism—or rather, their brain—become the objects under scrutiny. As Waltz (2005) wrote: “these children have become disembodied brains: ‘cases’ without names or faces. They are labeled as members of a group (‘AD children’ or ‘AS children’) rather than individuated” (p. 428). Over the years, the *JADD* encouraged first-person accounts from people with autism and caregivers. In Chapters III and IV, I referred to some social scientific research about specific caregiver issues, including social support, stress management and marital stress. These studies hint at some of the social problems caused by autism, while not explicitly drawing on the biopsychosocial approach. Nonetheless, these narratives and social scientific studies continue to operate outside of the computer metaphor-driven research paradigm and, as such, they will continue to remain on the sidelines of the overall explanatory model.

In Chapter IV, the caregiver explanatory model and its tropes of difference and distance reshuffled the character order established by the computer metaphor. People with autism became the primary subject of the narrative. Caregivers drew on tropes of difference and distance to construct autism as a social pathology. Their explanations

emphasized the difficult human side of autism—the narrative shifted from the topic of brain dysfunction to the dysfunctional aspects of everyday life. Parents and children struggled to communicate their needs to each other. As children with autism grew up, they struggled to develop social relationships with their peers. In reaching adulthood, caregivers described the ways in which it would be difficult for their children to become independent. Caregivers also constructed an alternative treatment narrative, placing themselves and special educators as the figures of prominence. Biomedicine, described as mostly uninformed and unnecessary, fell to the background. Caregivers and special educators took on the roles of social liaisons, helping to assimilate children with autism into the neuro-typical world. Mothers in particular reported devoting their lives to their new roles in hopes of best preparing their children for adulthood. Caregivers also spoke about educating and assimilating the neuro-typical world; they described this world as mostly ignorant and critical of children with autism.

Chapter V once again reshuffled the roles of the three main characters. The war metaphor used in MSM explanations of autism pitted caregivers and their children against biomedicine; it also pitted caregivers against the pathologies of autism. These battles brought forth topoi only mentioned in passing in the other two explanatory models. The epidemic issue, as reported in MSM, alerted the public to rising autism diagnoses and the fact that no one knew why or how the rise in diagnosis came to be. Vaccines became a subject matter over which the biomedical establishment and caregivers battled. The biomedical establishment's refusal to consider vaccines a possible cause created much suspicion in MSM accounts. They became the enemy in

this narrative. Caregivers accused experts of using bad and manipulated science. They drew on stories of how their children fell ill after a vaccination to counter biomedicine's scientific claims. The biomedical perspective was acknowledged, but lost its authority. Once relied upon to give the last word on a topic, science now fell behind caregiver testimony in status. Heroically fighting biomedicine to uncover the truth about vaccines, caregivers also heroically fought autism itself. In celebrating the role of the caregiver, however, MSM explanations of autism weakened the role of the person with autism. Autism invaded their bodies, and children could not protect themselves from it. Caregivers could not protect their children from invasion either, but MSM reported how many of them fought back to restore some degree of normality. The bodies of the children with autism, both metaphorically and literally in the MSM explanatory model, were under siege. They became the sites over which all of the conflict took place.

As I explained earlier, I expected to see some similarity or connection between explanatory models. Without any major similarities, I instead outlined the differences in characters and topoi. To continue further, I also posed a new question: Where should there be connections? This final section is my own personal attempt to make sense of the autism puzzle as I see it, encouraging certain pieces to go in places where they currently do not exist. The disempowerment of the person with autism in both the MSM and expert explanatory models is an important issue that, in my opinion, needs further attention. This problem represents the overall disconnect I saw between the caregiver explanations and the others.

### Concluding with Disconnections

I initially hesitated to include my own thoughts about the explanatory models I examined. Up until this point, I have tried to keep the research in this project value-free (an impossibility, I realize). But in the spirit of incorporating all perspectives about autism into the dissertation, in the end I felt comfortable adding my own as well. After all, when people asked me about the topic of my dissertation, they typically asked me for my opinion. “Oh, autism,” they would say, “Well, what do you think about...?” Do I think that vaccines cause autism? What do I think causes autism? Why are there so many people with autism nowadays? And so on.

I worked with a woman who was very interested in autism. She had three sons under the age of six, all of them neuro-typical during the time we spoke. However, because two of her boys were still very young, she wanted to do whatever she could to prevent the possibility of autism. She asked me one day about the topic of my dissertation, and when I told her, she started asking me many questions, much like the ones I just included in the paragraph above. She asked me if I had seen the story in the local paper about Bisphenol-A, a chemical found in clear plastic containers like baby bottles. Newly publicized research suggested that small amounts of the chemical leaked into the plastic containers and consumption of the chemicals over time could cause, among other things, neurodevelopmental problems. I told her that the study had caught my attention, though no one, myself included, could say that it was related to autism. Several months later she stopped me again to ask about autism and vaccines. She had just returned from her pediatrician’s office where they had discussed the possibility of



administering the Measles-Mumps-Rubella vaccine in single doses and removing the chicken pox vaccine altogether from her son's schedule. She then reached into her briefcase and pulled out a folder of newspaper clippings and brochures all pertaining to the various environmental chemicals that could potentially harm her children. Digging through the pile, she found the brochure containing all of the ingredients listed in the chicken pox vaccine. Her pediatrician confirmed that one particular ingredient referred to either a human or animal embryo. For religious reasons this upset her. She also felt uncomfortable injecting other genetic material into her son. Few people outside of the vaccine community knew about this ingredient and that made her suspicious. She distrusted the biomedical community—she thought they were purposely hiding information from her—and did not want to take any chances with her son. So she asked me again, like almost everyone else, about my own perspective about autism. Did I agree that we should concern ourselves more with environmental toxins? Do I think there is a link to autism?

I told her that I was impressed with her research and her willingness to talk openly with her pediatrician about her concerns. I was also impressed that her pediatrician understood her concerns and helped her access information she could not get on her own.<sup>23</sup> But, because she also expressed concern about autism as an emerging public health issue, I encouraged her to shift her thinking about autism and its crises to some other issues of import that she had not considered.

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<sup>23</sup> In fact, my co-worker told me that she interviewed many pediatricians for her children and finally settled on one that was open to listening to her needs.

I include this story because it revealed a lot to me about the general dialogue about autism and the directions it has taken. First, my co-worker's concerns pertained mostly to biomedicine, although she questioned the extent of this authority. Furthermore, she expressed specific concern with autism as it pertained to early childhood. She worried about vaccines and other potentially harmful toxins and their affect on her young children. Her worries were also situated in the short-term. As she saw it, young children were vulnerable to toxins during a short period of time.

I could not offer her any help regarding her concerns, but I hoped that I could explain to her a more expansive picture of autism. What about adults with autism? What about some of autism's long-term issues like institutionalization and social acceptance? I found these issues ever-present in my conversations with caregivers, but absent from my conversations with the general public; I also found them absent in the MSM and autism expert explanatory models. These are the two disconnections I would like to address here.

I am not the first person to suggest that more attention be paid to adults with autism. In this project, however, the absence of the topic from the MSM and autism expert explanatory models was evident. Caregivers addressed the issue, although sometimes more implicitly than explicitly. The work they do daily for their children, in the end, prepares them for adulthood and some kind of independence. All the caregivers I interviewed believed that assimilation with the neuro-typical world was critical while acknowledging that true independence was probably not possible. For the most part, they defined independence through common neuro-typical benchmarks such as college,

employment and marriage. Two parents said that their children were currently employed part-time and enrolled in college part-time. Two other young adults did not attend college but did find employment in local food establishments. All four of these parents worked very hard to help their children reach these benchmarks and experienced particular struggle with finding employment where the employer and the job itself were flexible enough for a very different kind of person. Ultimately caregivers hoped for some type of assimilation in order to prevent the opposite: continued isolation, whether inside their home or within an institution.

As discussed in Chapter III, the autism expert explanatory model does not lend itself to a non-cognitive studies topic such as autism and adulthood. Adults do appear regularly as research subjects; experts have shown great interest in examining how autism symptoms change over time (e.g., Baron-Cohen, Wheelwright, & Jolliffe, 1997, for Theory of Mind adaptations; Howlin, 2003, for language changes). But the dearth of research on the *lives* of adults with autism was recently confirmed by an article in *JADD*. The authors (Eaves & Ho, 2008) wrote:

Few studies examine the outcome into adulthood, and most of these were done years ago or focused only on higher functioning individuals. Thus planning and prognoses within the wider autism spectrum are limited. Little is known about transition to the adult world, but it is thought to be a “confusing maze of misinformation, limited opportunities, insufficient resources and inappropriate or time-limited services” (Gerhardt & Holmes, 1997).

In Chapter III, I discussed the prospect of a future expert explanatory model that welcomes alternative or compatible viewpoints that extend the focus of research beyond the brain. The inclusion of the above study in *JADD* shows promise for additional research on the subject. It also shows a willingness on the part of a journal, oriented toward cognitive studies research, to consider other areas of research. I encourage autism researchers to push this research topic into the mainstream research trajectory. It seems that some researchers have started to pave this path. As I was writing this section, I heard story on the radio about Virginia Commonwealth University receiving a \$1.75 million grant to study vocational training for people with autism (“VCU gets autism”, 2008). It will also assist people with autism in finding jobs in the state of Virginia once their school district training ends.

Moving to MSM coverage of autism, adults with autism are not completely absent. Consider this quotation from a 2006 *Newsweek* article on the subject, particularly as it fits with the MSM military frame described in Chapter V:

Autism strikes in childhood, but as thousands of families like the Boronats have learned—and thousands more are destined to learn—autism is not simply a childhood disorder. Two decades into the surge of diagnoses that has made autism a major public health issue, a generation of teenagers and young adults is facing a new crisis: what happens next? (Kantrowitz & Scelfo, 2006)

The topic certainly lends itself to the current tone set by the war metaphor and its accompanying tropes. A story this summer on NPR’s *Morning Edition* (Davis, 2008) also outlined the uphill battle parents face as their children with autism becomes adults.

The story featured a wealthy family who went to extreme lengths to ensure a high standard of care for their two daughters who could not care for themselves. The family purchased a 10,000 square-foot former convent in their home town in hopes of converting it into a fully staffed group home. The story outlined the struggles a family with no financial limitations, implying the even greater struggles for most other families in this country.

The problem with MSM accounts of autism is that the topic of adults with autism gets buried under all of the coverage about the early childhood autism invasion and the vaccine debate. These typical accounts are quite dramatic for readers. Autism exposes the vulnerability of children and parents, seemingly striking unsuspecting families. It also exposes a gap in understanding between the biomedical establishment and parents. But as autism awareness continues to increase, I hope that adults with autism will become more visible. According to the *Newsweek* article I quoted above, autism advocacy groups, who recently succeeded in securing federal funding for childhood issues such as causes and early diagnosis while also garnering significant media attention for these issues, will turn their sights to the need for funding for adult services next. MSM coverage will likely follow the advocacy group agenda and expand their military frame to include this topic as well.

The absence of adults with autism, to a certain extent, is a problem of accepting autism. Pathologized by biomedicine and demonized by MSM, the public gaze is directed to autism's dysfunction and horror. The caregivers I interviewed agree that autism can be a bad thing; for example, all the parents described to me the mourning

they felt after their children were diagnosed. But rather than continue to focus on the horrors, I think the dialogue needs to move on much in the way the caregivers did. Autism exists, and people must accept its presence in children and adults.

Tangential to this lack of acceptance is the general public's inability to understand autism. Here is radio personality Michael Savage (Aronow, 2008) rearticulating a problem that so many caregivers described to me in our interviews: "Now, the illness du jour is autism. You know what autism is? I'll tell you what autism is. In 99 percent of the cases, it's a brat who hasn't been told to cut the act out. That's what autism is." Savage's comments are nothing new to families with autism. Misunderstandings or, better yet, misinterpretations occur all the time. Parents I spoke with told me that their children were formally suspended from school, accused of stalking, charged with assault, described as insubordinate and criticized for their behavior in public because the neuro-typical world did not understand the world of autism. None of these incidents, parents agreed, would have happened if neuro-typical people had learned about autism and its many differences. Savage probably hoped for controversy in his comments about autism; instead, he simply rearticulated, in a more public forum, neuro-typical ignorance.

Much like the topic of adults with autism, the issue of acceptance and understanding ought to appear more in the MSM and expert explanatory models. When I first read about Savage's comments, I was hopeful that he had unintentionally initiated more dialogue about acceptance and understanding. Indeed, he has become somewhat of a villain already in MSM (e.g., Childs, 2008; "Michael Savage", 2008; "Protestors

Decry,” 2008). I urge the general public, researchers and journalists to consider the importance of this issue and what they might do to push issues of understanding and acceptance forward. Right now, the general dialogue about autism seems to concern itself with biomedical uncertainties and early childhood uncertainties pertaining to autism. What is certain is that children with autism will grow up and a totally different puzzle awaits them. Our explanations may not be able to solve the whole autism puzzle, but I believe that they can determine its degree of difficulty.

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## APPENDIX A

## INTERVIEW PROTOCOL

## Icebreaker/Introductory Questions

1. What words would you use to describe autism?

## The Nature of Autism

2. How does autism manifest itself in your child?
3. What treatments have proven effective for your child?
  - Possible probe: What about ineffective treatments?
4. What do you believe caused autism in your child?
  - Possible probe if anyone answers “genetic”: Who is responsible?

## Impact on Family

5. What has your life been like since your child was diagnosed with autism?
  - Possible probes:       With your own child?  
                              As a parent to other children?  
                              Within your marriage?  
                              How you see yourself (changes in self image)?

## Expectations for the Future

6. What are the chances for a cure for autism?
  - Possible probes: Do you believe the pursuit of a cure is ethical? Why/why not?
7. What are your hopes and fears for your autistic child as s/he grows up?

## Understanding of Autism

8. Do you have any favorite autism researchers?
  - Possible probes: How about autism books?
9. What types of religious perspectives, if any, have you used to help explain your child’s autism?
  - Possible probes: How has religion become a bigger part of your life since your child’s diagnosis?  
                              How has religion become a smaller part of your life since your child’s diagnosis?



Miscellaneous

10. Is there anything else you would like to discuss about autism?

Adapted from Kleinman (1988a)

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