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# Autism Literacy: A Rhetorical and Social Inquiry Through Archival Research

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AUTISM LITERACY: A RHETORICAL AND SOCIAL INQUIRY THROUGH ARCHIVAL  
RESEARCH

by

KRISTEEN CHERNEY

Under the Direction of Lynée Lewis Gaillet, Ph.D.

ABSTRACT

Over the past two decades, the term “autism” has become ubiquitous in American culture, with an even bigger effort by activists, advocacy groups, and non-profit/for-profit organizations to “spread awareness” about this supposed epidemic. To better understand the phenomenon of autism awareness, I utilize archival research methods to trace the exchange of autism-related information to its foundation during the 1960s and 1970s. These include the papers of Margie Pitts Hames, the late Atlanta-based Civil Rights attorney, the late radio and film writer Allan Sloane, and a parent-based advocacy organization called the Autism Society of

Northwest Ohio. Couched within scholarship of Disability Studies and Literacy Studies, I refer to the exchange and acquisition of such information as Autism Literacy.

The project at hand is not a commendation of the increase in autistic rhetorics that tend to stem from a eugenics approach to find “cures,” but is rather a response to the influx in rhetorical strategies that continue to place people with autism at a cultural disadvantage. Due to a nationalist-leaning culture that further isolates people with disabilities though, I argue that the need to understand Autism Literacy is more important than ever. I trace the emergence of Autism Literacy’s more widespread cultural beginnings, which appeared during the 1960s across the U.S. My discussion of these archival findings focus on the rhetorical contexts in which people wrote about autism at the time, as well as their intentions. Such a project also lends itself to the growing need for archival research within Disability Studies conversations in the field of Rhetoric and Composition more broadly.

INDEX WORDS: Autism Literacy, Autism rhetorics, Disability Studies, Archival research,  
Literacy Studies

AUTISM LITERACY: A RHETORICAL AND SOCIAL INQUIRY THROUGH ARCHIVAL  
RESEARCH

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KRISTEEN CHERNEY

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

in the College of Arts and Sciences

Georgia State University

2018

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2018

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RESEARCH

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December 2018

## **DEDICATION**

To Dominik, who continues to be my inspiration and helps me become a better human being every single day.

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## 1 INTRODUCTION

**Overview:** In the Introduction, I make a case for the need to explore Autism Literacy as a new intersection within Rhetoric and Composition Studies. I also clearly identify my positionality, as well as provide a brief overview of the subsequent chapters and the three archival research projects that ground the work of the project at hand.

In 2012, my then almost-four-year-old son was diagnosed with autism. His diagnosis came around the same time that the seemingly powerful forces in charge of creating medical labels and diagnoses decided to create what was called a “spectrum” of autism disorders. Since then, the use of the term “autism spectrum disorder” (ASD) has pervaded our society over the simplistic “autism.” After all, the latter doesn’t imply the “disorder” that ASD clearly ought to be, according to our normative culture.<sup>1</sup> Since the term ASD has become more prevalent, other labels for autism have emerged, including “on the spectrum,” “neurodivergent,” and “high-functioning.”

By the time my son was born, I knew what the word “autism” meant to society, but I did not fully understand what “autism” *was*. Our culture teaches us that autism is a “thing” you get, which has negative implications, such as catching a cold or the flu virus. Based on the discourse surrounding autism, people who are unfamiliar with the disability knows that it is definitely *something* that is unwanted and undesirable. Autism creates a burden to families and friends. Autism inherently means that someone on the spectrum will automatically have a difficult life because they are not “like” other “normal” people. Autism represents something “off” or

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<sup>1</sup> In this project, I prefer the use of the terms “autism” and “autistic” rather than ASD, since the latter focuses on autism as a disorder, as opposed to a disability.

missing, which is captured visually via artifacts, such as Autism Speaks' logo of the missing puzzle piece.

As I write this in 2018, autism as a rhetorical entity has overshadowed autism as a medical diagnosis, though much of the definitions and related discourse remain clinical in nature. Information on autism is readily available online, in schools, and in doctor's offices, and so-called "experts" and "advocates" are on hand, ready to bestow their knowledge onto newcomers. Indeed, autism has become a hot-topic of conversation among new parents looking for advice on how to "detect any signs" of the disability. It is also talked amongst our youth, who are in a gray area between understanding autism in negative terms, but who also know others or identify themselves on the spectrum.

Like other types of disabilities, people with autism are often viewed with pity by their normative counterparts as the pervading "other" who cannot possibly understand what it is like to be "normal." Indeed, autism continues to somewhat of a taboo term—our culture does not encourage positive connections with an autistic identity, but rather drives us to fear it. Though autism itself is not a new phenomenon, the rhetorical nature of ableist societies have made it seem as such and have even classified autism as an epidemic. In turn, this epidemic is treated as something that ought to be prevented and destroyed for the sake of society at large.

The topic of Autism Literacy might perhaps become as ubiquitous as the disability itself. I write and hope to increase awareness for Autism Literacy, not in alignment with the supposed epidemic described by eugenicists, but rather as a response to the increase in autism activist groups that run on ableist agendas. Aside from addressing the rise in autism rates in the United States, this work is also a response to the increase in conspiracy theories behind supposed causes of autism that are particularly prevalent in the nationalist-leaning era that is our current state of

the culture. Also, from a pedagogical perspective, I hope to inspire more discussions about disability rhetorics and literacy in our classrooms.<sup>2</sup> Even those in the field of Rhetoric and Composition who are *not* in Disability Studies can benefit from the intersections explored in this dissertation, as well as their rhetorical implications on culture and language.

My mission in this project is to explore the ways in which people obtain autism information, and how exactly they do so. Who exchanges this type of information and why? How do they go about doing so, and to what end? What are the rhetorical contexts that drive this exchange? These are just some of the initial questions I considered from the outset. Before I identify the specific research methods used, it is worth laying out my own positionality to the subject at hand, as I am fully aware of the sensitive nature of autism studies.

## 1.1 POSITIONALITY

I am neither an individual with autism, nor am I a psychologist or a neurologist. I am, however, a mother of an autistic son and a Disability Studies scholar. During pregnancy, I was warned about vaccinations and how they could “cause autism.” I remember bursting into tears. It was not so much that the notion of a vaccine could cause autism that was upsetting, but the fact that I was made to feel burdened for possibly birthing a child who could inherently “catch” this unwanted disease. Such warnings were also a wake-up call about what was considered desirable and undesirable in terms of newborns. Not only should the baby be in good health, but a baby catching a disability like autism was also forbidden.

To make it clear: no, I do not believe that vaccines are the “cause” of autism. I also suspected early on that my son was “sensitive” and neuro-atypical before he was even exposed to

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<sup>2</sup> In the conclusion, I discuss a proposed course on Autism Literacy in the college classroom.

any vaccinations. As Uta Frith, a Professor of Cognitive Development at the Institute of Cognitive Neuroscience notes:

Autism is not a modern phenomenon, even though it has been recognized only in modern times. In view of the short history of psychiatry, and the even shorter history of child psychiatry, we know that a disorder recently described is not necessarily a recent disorder. An increase in diagnosed cases does not necessarily mean an increase in cases.

There are tantalizing hints of autism in the medical records of history. (34)

Such an explanation from a neuroscience scholar is important in driving our current understanding of the increase in autism rhetorics. As Frith argues, autism itself is not new at all. However, it has recently been identified and singled out “in modern times” only. Autism is not a “thing” that you can catch at all, though such logic is contrary to the persistent fear of disabilities in our culture.

In my own experience, autism was an identity that evolved in my own household. My son did not just suddenly “catch” this disability. On the contrary, he was suspected of being on the spectrum for almost two years before getting the official diagnosis at the age of four, despite the fact he was in an autism preschool. In the meantime, we were subjected to friends and family trying to reassure us that he was “not a problem,” and that he likely “had a touch of something,” as if we really needed reassurance. Finally, after all the tests were completed, I received the doctor’s phone call while we were playing at the park. Right away, her tone was full of regret. “Well, the tests do say autism...” she trailed off, and seemed to stiffen, as if awaiting an outburst from me. I calmly replied, “And?” The doctor did not know what to say; I refused to produce the reaction that was expected of me as a parent with a child with autism: fear, guilt, anger, and the incessant need to “fix” my son, all these items that are so inherent in our ableist culture evolved

from rhetorical constructions to make all of us feel the need to achieve normalcy. As Autism Rhetorics scholar Anne McGuire argues, “Autism advocacy is therefore not simply a response to autism but a productive force that generates and governs what autism is and can be” (43). While I understand McGuire’s criticism of advocacy, I do not discredit advocates entirely—after all, it is only natural for any parent to advocate for their children. Yet the ways in which we advocate for others with disability constantly evolves based on social constructs so that we maintain “good” citizenship.

As I reflected on the evolution of my son’s autism identity, I also realized that the best way to explain Autism Literacy was to look for material evidence as far back as possible. Such inquiries led me to conduct archival research into the history of Autism Literacy. Autism and related medical information is relentless and often overwhelming. To understand how our culture develops Autism Literacy today, it is important to look in the past at how such literacies came to fruition. My combined scholarly and personal experiences have led to the project at hand today.

To be clear, while I admit at having some personal experience in the world of autism and Autism Literacy, this project is not about me and my son. Instead, I use my experiences as a mother of a child of autism, and one that has often been criticized for not feeling the way I am supposed to feel as my positionality, as well as a way to couch the existing secondary research available on autism rhetorics and advocacy. I question the rhetorical constructs surrounding autism, and my definitions of Autism Literacy stem from my experiences with autism coupled with my theoretical grounding in Disability Studies. Furthermore, my experiences and early research thus far have led me to question the rhetorical methods by organizations with widespread influence (such as Autism Speaks) to provide literacy about autism to the public.

As both a scholar and a mother, I also refer to Lindal Buchanan's theories in *Rhetorics of Motherhood*. I often wonder how we can find common ground between feminist points of view about motherhood, as well as the ideologies of taking ownership of our children's disabilities, such as the notions of autism activism benefiting the mother, rather than the individual who actually identifies as autistic. Buchanan writes, "Rhetorics of motherhood, I argue, not only benefit women, giving them authority and credibility, but also impede them, always/already positioning disadvantageously within the gendered status quo" (5). I wondered, throughout my own project, how such a position can apply to mothers of children with disabilities. As I came to see in the archives, both the mother and father played large roles in the development of Autism Literacy, with the mothers leading the reigns onward into the 21<sup>st</sup> century.

## 1.2 RATIONALE

Before I introduce the research behind this dissertation, it is important to first discuss the meaning of literacy within the intersections of Rhetoric and Composition. We often view literacy in terms of reading and writing skills, as set forth in a traditional education studies context. Literacy is advocated as a "thing" to achieve, and one that is controlled within a power structure within society at large. In his 2007 book *Literacy: An Introduction to the Ecology of Written Language*, David Barton instead posits "literacy as a form of empowerment, as a right, as something which people do, a process rather than a thing" (12). He goes on to note other metaphors people often use when people are perceived to have literacy deficits, such as "handicap," "ignorance," and "incapacity" (13). People with autism—according to our society—are not equipped to possess traditional modes of literacy, where "according to definition and convention, the degenerate and the defective could not function as full and literate citizens of society" (Kliwer 168).

Still, the question isn't whether people with autism can be literate—indeed, there is a multitude of evidence to support that they are. For example, Van Gerstle and Lynda Walsh's edited collection *Autism Spectrum Disorders in the College Composition Classroom: Making Writing Instruction More Accessible for All Students* provides accessibility tips for composition instructors with the presumption that yes, autistic students are very much literate. Educational scholars have long-ago debunked the theory that people with autism cannot read or write. Furthermore, Disability Scholars have since defined the idea of illiteracy in disabilities as a rhetorical method of power, where literacy is reserved for the most able-bodied and able-minded. Instead of further proving autistic abilities in the realm of reading and writing, what is really up for investigation here are the literacy *experiences* in relation to literacy. My focus here is *not* on using literacy in its most basic and literal terms—reading and writing skills—but as a metaphor for autism knowledge acquisition instead.

Literacy Studies offers the appropriate context for researching such experiences. To date, there has been much research conducted in the realm of literacy, particularly by scholars who identify with the New Literacy Studies movement, including Brian Street and James Gee. In considering my duties in academia, I echo Rebecca Jones's position in Kahn and Lee's edited collection *Activism and Rhetoric: Theories and Contexts for Political Engagement* that “our work should, at least some of it, directly connect to social issues, especially considering how many citizens matriculate through our classrooms” (186). Considering the growing numbers of autism diagnoses and the perceived isolation that often follows, it is worth studying the history, theories, and practices that scholars have explored thus far to better understand the need for research within the intersections of Autism Rhetorics and Literacy Studies.

The concepts of literacy Barton poses and the power structures it depends upon has been expanded to other forms of literacies in our culture. To be technologically literate means one would have extensive knowledge and experience with computers and other advanced technologies. Rather than discuss the medical definitions and various “causes” of autism, this dissertation focuses on the ways we learn about autism from culture and society, and the practices of non-autistics teaching others about autism. I define this process as *Autism Literacy*. Throughout this dissertation, I explore the intersections between Autism Rhetorics, Disability Studies, and Literacy Studies, while further defining Autism Literacy, as discussed in the following chapters:

### ***Chapter 2. Autism History, Definitions, and Archival Research Methodologies***

The next chapter provides historical context based on a combination of archival and secondary research to fully explicate my understandings of Autism Literacy. I further define Autism Literacy as the ways we learn about and the practices we use to transmit information about autism. I also explore the different types of modern autism definitions that are available as a means to unpack the rhetorical strategies used to transmit certain information about the mental health disability to particular audiences.

First, though, I offer a brief history of how autism evolved into its own classified disability. The term “autistic” itself was coined by Swiss psychiatrist Eugen Bleuler in 1908. Waltz discusses some of the Greek influence of the word autistic, too. Still, autism awareness didn’t really take off until the 1970s. The *Journal of Autism and Developmental Disorders* was established in 1971, but autism itself did not become its own category in mental health diagnoses until 1980. The 1990s saw increased awareness about autism through Jim Sinclair’s

Neurodiversity Movement, though autism awareness did not become mainstream until about a decade later.

In this chapter, I also review major contributions to the fields of Autism Rhetorics, Disability Studies, and Rhetorics of Health and Medicine, noting the intersections between these scholarly conversations. I also explain why archival research methodologies are key to the exploration of early evidence related to Autism Literacy, while briefly explaining the three archival research projects that were used for this dissertation.

### ***Chapter 3. Early Autism Literacy and Public Knowledge***

Chapter Three further defines Autism Literacy as a process and exchange of information between specific speakers and audiences. While Chapter Two couches this definition with the help of scholars in the fields of Autism Rhetorics, Disability Studies, and Rhetorics of Health and Medicine, Chapter Two includes a brief literature review of Literacy Studies, with a special focus on the New Literacy Studies movement as an intersection with Rhetoric and Composition. By understanding the theories of New Literacy Studies, I further help readers understand the definition of Autism Literacy as more of a practice and exchange of information, rather than the traditional concept of literacy as a measurement of knowledge.

In this chapter, I also introduce my first archival research project via the Margie Pitts Hames collection at Emory University. Hames, an attorney in Atlanta, primarily focused her work on Civil Rights, women's rights, and disability rights. While the majority of the materials reflected the exchange of autism information in a legal context, I found evidence of Autism Literacy in the collection nonetheless. Through the backdrop of legal actions and civil suits filed in the 1970s, I identify the emergence of information exchanges about autism, while also noting the presence of inquiry in shaping individuals' roles in the Autism Literacy process.

#### ***Chapter 4. Early Parental Advocacy and Autism***

Chapter Four explores the shift in Autism Literacy from knowledge acquisition to parental advocacy. First, though, I define what it means to be an “advocate,” as well as the potential benefits and drawbacks to parents speaking for children with disabilities. I then turn to my second archival research project, detailing my findings in the Allan Sloane Papers, stored at the University of Georgia. As I came to learn, Sloane was both a writer and a father of a son on the autism spectrum, who used his platform as a way to fulfill his creative instincts while also attempting to help children with disabilities. While Sloane’s writings are of interest, what is perhaps most telling is the wealth of response letters to Sloane’s work, which all encompass the wide range of Autism Literacy practices found across the country between the mid-1960s and early-1970s.

#### ***Chapter 5. Emergence of Autism Advocacy and Activist Groups***

Modern-day autism advocacy groups have gained a negative reputation, especially from the perspectives of many Disability Studies scholars. In Chapter Five, I briefly outline the historical beginnings of such advocacy groups, and how they formed in response to ableist clinicians who defined autism as a problem that required significant correction outside of the family unit. While many disability advocacy groups are criticized for self-serving interests and a slew of other ethical issues, it is important to unpack the initial rhetorical contexts in which autism advocacy groups first formed so that we can better understand their impacts on the evolution of Autism Literacy. I then turn to the third archival research project for this dissertation, which explores the papers of the Autism Society of Northwest Ohio, a collection donated to the University of Toledo. Such advocacy groups are crucial to the discussion of

Autism Literacy, as this form of activism has especially gained ground in modern-day autism discussions as the public grows increasingly suspicious of government-run health research.

***Chapter 6. Conclusion: Future Implications and Directions of Autism Literacy***

In the conclusion, I review my findings and reiterate the importance of understanding Autism Literacy in my research field of Rhetoric and Composition, as well as proposed future directions. Examples include other types of primary and archival research, as well as other research methods that I feel would build upon the concept of Autism Literacy. I also pinpoint specific areas of interest in my own archival research projects that could be built upon but did not necessarily serve as points for conversation in the context of the project at hand.

Additionally, I call for the need to explore Autism Literacy in other regions of the country to help further build the scholarly conversation.

## 2 AUTISM HISTORY, DEFINITIONS, AND ARCHIVAL RESEARCH METHODOLOGIES

**Overview:** Chapter Two provides historical contexts to set the groundwork for Autism Literacy. Here I discuss important scholarly contributions within the intersections of Disability Studies, Literacy Studies, and Archival Research, and how these conversations highlight the differences between medical definitions of autism, as well as socially-constructed versions.

### 2.1 A Brief History of Autism and Emerging Definitions

In the spring of 2018, I overheard a conversation at a conference about what type of “disorder” autism “really is.” On the one hand, autism was initially highlighted in the 20<sup>th</sup> century as a psychological disorder. The underlying argument was that autism was not a psychological disorder anymore, but rather a *medical* one. Indeed, both psychology and medical-based offer their own modern-day definitions of autism. Before I can define Autism Literacy, it is important to first explore both current and historical definitions related to autism. In their critique of research surrounding rhetorics of mental health, Jordynn Jack and Gregory Appelbaum’s “This is Your Brain on Rhetoric” notes how “in many cases, researchers did not define what was meant by key terms such as *emotion* or *reason*...what do the authors mean by a term like *emotion* if it is not defined?” (418). As such, I do not want anyone to assume I am speaking of the mere medical definition of autism in this dissertation. While some of the medical definitions can help reinforce the sociocultural implications throughout the discussion, these are not the focus of this work. As Tobin Siebers, the late author of *Disability Theory* describes:

The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve a full capacity as a human being...Unlike the medical approach, the emerging field of disability studies

defines disability not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment. (3)

Still, while autism itself is widely viewed by Disability Studies scholars as a socially constructed definition, it is beneficial to the discussion of Autism Literacy to unpack medical, psychological, and social definitions that are so widely accessible to those who acquire literacy about this disability. One such medical definition is offered by the National Institute of Neurological Disorders and Stroke (NINDS), who state that autism spectrum disorders are “a group of complex neurodevelopment disorders characterized by repetitive and characteristic patterns of behavior and difficulties with social communication and interaction.” A more psychological definition often involves further context. For example, the American Psychological Association’s *Encyclopedia of Psychology* declares, “**Autism** is the most severe developmental disability. Appearing within the first three years of life, autism involves impairments in social interaction — such as being aware of other people’s feelings — and verbal and nonverbal communication.” For a brief social definition, the U.S. Centers for Disease Control and Prevention simply states that “Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication, and behavioral challenges.” Other organizations have gone so far as to say that autism has become an *epidemic*, a word often synonymous with an infection or a plague.

Despite the slight variations in definitions, all three of these examples share similarities within their rhetorical consequences pertaining to disability. “Those with mental disabilities are always already defined as nonhuman, by dint of their failure to *make sense*,” warns Margaret Price, a noted scholar in Disability Studies in her book *Mad at School: Rhetorics of Disability*

*and Academic Life* (39). Indeed, the NINDS highlights the *difficulties* people with autism possess, while the CDC explains how this disability evokes *challenges*. While the American Psychological Association offers some more context, their definition isn't much better, as it highlights *impairments* and claims that autism is the *most severe* of all developmental disabilities. Certainly, there are variations across mainstream definitions of autism, but as these three examples reveal, all have the “nonhuman” predispositions that society has come to learn that disabilities like autism are defined. From a literacy standpoint, we can see how much of the information available to the public consists of such negative rhetorical strategies to further displace the disabled as “other.” (I discuss more of the evolution of public literacies and autism in chapter two and how these contribute to Autism Literacy.)

Also, while there are differences in definitions based on speaker and audience, all three definitions share similar underlying messages: Autism is a *disorder* and a *disability* that results in *impairments* and *difficulties*. Paul Heilker and Melanie Yergeau ask, “Is it a disease? A disorder? A disability? A diversity issue? All these things, and more? How meaningful—and to whom—is the concept of autism spectrum disorders (ASD) (and all that such a rainbow metaphor entails)?” (486). The classification of autism as a “spectrum” further adds to the confusion if one were to try to narrow down autism into one single definition. Again, for the purposes of my discussion of Autism Literacy, I define autism as a disability, rather than a medical or psychological shortcoming. According to Anne McGuire, “Disability—its meaning and thus its very materiality—is made and remade, rhetorically and interactionally, between all of us who have a body, and all who live and participate in the making of culture” (18). Just as the meanings of disability evolve over time, so have the meanings of autism. Understanding the formation of the

word autism is important in understanding the sociocultural evolutions of the disability, as well as its implications.

First, though, I offer a brief history of how autism evolved into its own classified disability. The term “autistic” itself was coined by Swiss psychiatrist Eugen Bleuler in 1908. Mitzi Waltz, a sociologist, discusses some of the Greek influence of the word autistic, too. According to Waltz, “‘autism’ is derived from the Greek word *autos*, meaning ‘self,’ coupled with the suffix *-ism*, which is used to denote a condition, generally one characterized by an excess of something” (51). In other words, Bleuler’s early 20<sup>th</sup>-century definition means to imply that autism means an excessive interest in the self, rather than a deficit of any sort. A few decades later, “two psychiatrists, Leo Kanner and Hans Asperger, published articles in the 1940s that identified infantile autism as a distinct syndrome” (Bumiller 969). In terms of history, Uta Frith writes on autism:

It originally referred to a particularly striking disturbance in schizophrenia, namely the narrowing of relationships to people and to the outside world, a narrowing so extreme that it seemed to exclude everything except the person’s own self. This narrowing could be described as a withdrawal from the fabric of social life into the self. Hence the words “autistic” and “autism,” from the Greek word *autos* meaning “self.” (5)

As autism was further researched, more “types” were created, including Asperger’s syndrome, which is also sometimes known as high-functioning autism (sometimes called “Aspies”). Not surprisingly, the more that autism is labeled and divided into different types, the more controversy there is. From my own observations at autism conferences, the underlying attitude about Aspies is that they are not “bad enough” or “autistic enough” to really identify as autistic.

Part of this criticism ties into the perceived superiority of Aspies in the Western culture. Another sociocultural issue is the rise in race and high-functioning autism, a problem that Paul Heilker calls “Aspie Supremacism.” In his essay “Autism, Rhetoric, and Whiteness,” Heilker writes, “In this discourse, autism is seen not as a problem to be fixed or to be overcome, but rather as a marked improvement over normal neurology...I admit that I find this rhetoric disturbing, since any discourse that invokes a reference to genetic or evolutionary superiority will, of course, immediately rise the spectre of racism” (4). It is important to note here that Heilker’s essay was published in 2012, right before Asperger’s was moved to the Autism Spectrum Disorders umbrella. I would argue that this movement of Asperger’s to the Autism Spectrum Disorder has led to contention on both sides of the aisle.

With the obsession for “curing” disabilities more prevalent than ever, much of the public literacies about mental disabilities like autism rely on clinical definitions. For example, Uta Frith, Professor of Cognitive Development at the Institute of Cognitive Neuroscience from London’s University College, explains in her acclaimed book *Autism: Explaining the Enigma*, of the medical science and advances in research based on clinical definitions and treatments of autism. What is interesting, though, is Frith’s exploration of the presence of autism in early literature and in medical records, which are featured early in the book. She also includes some of the stereotypical “signs” of autism and couches them in current neuropsychological research. In terms of Autism Literacy, Frith’s first chapter appropriately reflects a search terms one might use if he or she is unfamiliar with autism: “What is Autism?” In this chapter, Frith writes:

What is this puzzling disorder that is at once so subtle and so vicious in its effects: allowing so much developmental progress and yet cruelly preventing full integration into

the community? From the very beginning of awareness of such strange developmental patterns, people have attempted to answer this question. (5)

Such a definition of autism might seem neutral from a clinical perspective, but with a closer look, we can then hone in on the negative connotations, such as through the words she uses here: *vicious*, *cruelly*, and *strange*. Such connotations are closely tied with disabilities within a social context, including autism.

Another overarching issue is the rhetorical implications of the mainstream definitions of autism that describe the disability as a *disorder*, *deficit*, or *impairment*. Waltz's *Autism: A Social and Medical History* investigates the intersections between social and medical rhetorics surrounding autism, offering a historical background and discussion on how the clinical definitions of autism have subsequently dominated sociocultural attitudes about autism. She notes how during the 1800s, Victorians "viewed disabled people as a drain on the public purse" (26), while Social Darwinism "posited that it was natural and desirable for ill, disabled, or less intelligent people to be weeded out of the gene pool" (31). Such eugenics-inherent rhetorics are not as blunt in 21<sup>st</sup> century America, though there is certainly a more abstract desire to stop the "epidemic" that autism is often perceived to be.

Indeed, this view of autism as an undesirable state of being has fueled what autism is often referred to by 21<sup>st</sup>-century medical professionals: an epidemic. McGuire writes, "Epidemic implies a sudden widespread occurrence of an infectious disease. Epidemic evokes fear—something undesirable, often life-threatening, is spreading through a helpless population" (56). Autism-as-epidemic can lead to dangerous shifts in acquiring literacy about this disability. Indeed, an epidemic implies that you can "catch the autism" and that "normal" life as you know it would all be over. As such, one might instead acquire literacy related to the "prevention" and

“cures” for autism, rather than the knowledge neurotypical individuals might use to better understand with those who might be considered *neuroatypical*. “*Neuroatypical* is most often used to indicate persons on the autism spectrum, including those with Asperger’s syndrome (AS), but has also been used to refer to persons with bipolar disorder and traumatic brain injuries,” describes Margaret Price (*Mad at School*, 16).

Understanding the negative implications of autism and other mental health disabilities being perceived as “epidemics” is important to the investigation of Autism Literacy practices. While clinical definitions have fueled the ableist attitudes towards disabilities in mainstream western culture, it is also important to note that clinicians do not widely accept the theory that autism is an epidemic. Frith herself argues, “Most experts believe that the increasing prevalence figures that have been found over time do not reflect a real increase in cases. Not only have the diagnostic criteria been widened, but greater awareness of autism has meant that more cases are coming forward for diagnosis” (59). Still, the implications of the clinical definitions have led the way to ableism, the portrayal of autistic individuals as victims or deviants, and has also paved the way to conspiracy theories that fuel the incessant “need” for a cure. Before highlighting these implications though, I turn to a brief overview and history of the role Disability Studies has played in the current conversation of disability as sociocultural construct, rather than a medical one.

## **2.2 The Rise of Disability Studies**

Disability Studies is increasing in prominence as an intersection with Rhetoric and Composition, where Jay Dolmage, Paul Heilker, Margaret Price, Melanie Yergeau, and Tobin Siebers are among just a few of a growing number of notable scholars. Tobin Siebers was a late professor and scholar in the field of English Language and Literature, whose 2008 book

*Disability Theory* greatly influenced other scholars who followed. Siebers posits people with disabilities as a minority group in society, and he stresses the need for sociopolitical action and rights to prevent some of the perceived negative implications of minor as “other.” Additionally, as someone with a disability himself (polio), Siebers also interweaves some narratives throughout the book to establish his *ethos*, a methodology I that has emerged as a pattern during my own research with autism rhetorics and literacy.

Building on some of Siebers’s groundbreaking work, Jay Dolmage wrote *Disability Rhetoric* as a historical look into the terms that define disability that date back to the Greeks. Here, Dolmage primarily looks at the historical aspects of both disability and rhetoric tied back to ancient Greek civilization, even pointing out how some individuals (albeit men) were celebrated for their disabilities, such as the Greek god Hephaestus. In defining Disability Studies as an intersection with Rhetoric and Composition in English, he writes:

Disability studies is a coherent but interdisciplinary, multidisciplinary field of study, holding that disability is a political and cultural identity, not simply a medical condition. Disability studies challenges the idea that disability is a deficit or defect that should be cured or remedied, disrupts the idea that an individual with disabilities can be defined solely through her disabilities, and critiques representations of disability as pitiable, inviting charity, to be compensated for, made invisible, or overcome. (20)

Such a definition has paved the way for scholars interested in disability theory to consider disabilities as social constructs that have led to medical diagnoses and ableist discourse.

Dolmage also advocates for the understanding of how labels and definitions are created: “Instead of being an incomplete expression of language (or of subjectivity, or of humanity), instead of

being an unsuitable vehicle for rhetoric, disability should be understood instead as the very possibility of meaning” (287).

Still, early scholarship of disability theory and rhetoric primarily focused on more physical (or “visible”) disabilities (also see Walters’ *Rhetorical Touch*). Catherine Prendergast’s essay “On the Rhetorics of Mental Disability” and Cynthia Lewiecki-Wilson’s article “Rethinking Rhetoric through Mental Disabilities” are examples of early Disability Studies scholarship that discuss traditional mental health diagnoses, such as schizophrenia, as mental disabilities. Prendergast argues that “to be disabled mentally is to be disabled rhetorically” (202), meaning that people with mental disabilities have little sociocultural power. She goes on to note how “the mentally ill are the most reviled of the disabled” (203) because of the lack of understanding, or the more likely scenario of an unwillingness to understand. Indeed, invisible disabilities like mental illnesses as well as the neurodiversity seen in autism can fuel this sort of ignorance. Lewiecki-Wilson also touches on the subject, noting how “mental impairments are also the hardest test cases in thinking through the relation between nature—what exists in the world—and social construction—how cultures (re)make the world” (157). Both Prendergast and Lewiecki-Wilson would consent to the fact that impairments are markers of mental disability, but the agency of those affected are oppressed through cultural norms. In fact, Lewiecki-Wilson further notes:

Those in disability studies argue that what is disabling about impairments resides in culture rather than in natural consequence of an impairment. This move does not mean that impairments do not exist but that the disability is always experienced through the attitudes, social arrangements, and technologies of a particular culture. To many, however, the cultural construction of disability makes sense in regard to the physically

disabled, but seems less persuasive in the case of people with severe mental disabilities.

(158)

In the last decade, Margaret Price has emerged at the forefront of rhetorical research in mental disabilities. Her book *Mad at School: Rhetorics of Disability and Academic Life* explores the sociocultural perception of “madness” coinciding with violence, and how violent tendencies are mistakenly used interchangeably with mental disability<sup>3</sup>. An important key to Price’s discussions is her use of *ethos*, and how she includes personal stories, arguing “I believe stories are one way of accessing theory” (21). Through my readings and personal interactions with Disability Studies scholars, the power of personal experience as an establishment of *ethos* and positionality is evident—many have disabilities themselves, or know someone with a disability (See Price, Siebers, and Yergeau). Some are also parents who use their scholarship not only as a framework for academic research (see Heilker, Lewiecki-Wilson, and Cellio), but also as a method to make the world a better place for their own children. The growing scholarly research interweaved with narrative experiences is indeed a growing framework in Disability Studies, and I argue it is crucial in our understanding of Autism Literacy.

### 2.3 Autism Rhetorics and a Challenge to Normative Cultures

Disability Studies scholarship has also paved the way to research in rhetoric and autism, in which Melanie Yergeau is at the forefront because of her identification as both a Disability Studies scholar and a person with autism. In an essay co-written with Paul Heilker, a father of a

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<sup>3</sup> Price and I also explore sociocultural attitudes towards mental disability in our chapter, “Student Profiling and Negative Implications for Students with Disabilities” in *The Wiley Handbook on Violence in Education: Forms, Factors, and Preventions*, edited by Harvey Shapiro, 2018. Specifically, we explore the ways in which our culture has taught us how to “profile” individuals with mental health disabilities as threats against the populace, even though there is no direct association between the two.

son with autism, Yergeau calls for a reworking of the rhetorical triangle, stating that “rhetorical listening allows us to generate a more productive discourse about autism and the rhetorical triangle” (491). Yergeau and Heilker have perhaps produced the most credible work to-date in the realm of rhetoric and autism because of their positionalities. Yergeau remains at the forefront of autism rhetorics within Disability Studies (see her works in “Clinically Significant Disturbance,” “Circle Wars: Reshaping the Typical Autism Essay,” her dissertation on *Disabling Composition*, and an edited special issue on *Kairos* titled “Multimodality in Motion”). In personal conversations with Heilker, I learned more about his son and his scholarly contributions in the realm of autism rhetorics, including a video narrative submission, “The Eli Way,” explaining his son’s literacy process on the Digital Archive of Literacy Narratives (also see his essay “Autism, Rhetoric, and Whiteness”).

Other works I consider noteworthy within the umbrella of autism rhetorics explore historical and modern-day accounts of how people with autism are treated by society. First, Mitzi Waltz’s *Autism: A Social and Medical History* explores the cross-sections between the social and medical rhetorics surrounding autism, including the cultural fixation on finding cures for autism as a modern-day form of eugenics (143). Anne McGuire, a Canadian professor and scholar wrote the 2016 book *War on Autism: On the Cultural Logic of Normative Violence*, which discusses the history and sociocultural significance of autism *advocacy*, rather than of autism itself. She argues how autism is interpreted as a “thing” society wants to get rid of (11), a metaphor that is similar to Barton, Street and Graff’s metaphors of literacy as a “thing.” Just as literacy is culturally associated with power, McGuire seems to posit autism as a malleable phenomenon that is controlled by others with more power. Kristin Bumiller also addresses McGuire’s notion of normative violence, writing, “Autistics are ostracized when they are perceived as threatening by

those who misunderstand the condition” (979). Additionally, Shannon Walters explores the cultural impacts in the daily lives of people on the spectrum, including the workplace, writing how “people with autism have been invited and encouraged to take on the role of technical communicator” (*Autistic Ethos at Work* 7).

Autism is regarded in mainstream society as a neurodevelopmental disorder, while the Disability Studies community might define it as a socially constructed mental disability. In *Rhetorical Touch*, Walters also notes how “people with autism, frequently diagnosed as possessing ‘deficits’ in social interaction and communication are stereotyped as ‘asocial’ or ‘alone in their own worlds,’ present particular challenges to the limits of traditional rhetorical models of identification” (112). I personally find it difficult to walk the fine line of addressing some of the neuroatypical traits that Price describes without coming across as describing the deficits Walters points to.<sup>4</sup>

## 2.4 Autism in Rhetorics of Health and Medicine

Given the prevalence of medical diagnoses in the discussions surrounding autism rhetorics, it is worth noting some of the scholarship published within an emerging subfield called Rhetorics of Health and Medicine (see Scott, Segal, and Keranen), particularly the field of “neurorhetorics.” Of this subfield, Jordynn Jack writes that “neurorhetorics would question how discourses about the brain construct neurological difference, how to operationalize rhetorical inquiry into neuroscience in meaningful ways, and what those constructions imply for

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<sup>4</sup> For example, my article for *Praxis* “Inclusion for the ‘Isolated’: Writing Tutoring Strategies for Students with ASD” evolved through a delicate process of addressing the needs of autistic writers without singling them out. Indeed, much of these stereotypes are fueled by the medical community and related diagnostic tools, which Price and I discuss in our *Handbook of Violence in Education* chapter, too.

contemporary public discourse” (406). While some crossover in terms and theories may be noted, my criticism of Jordynn Jack and other scholars is that the rhetoric of autism is primarily socially constructed, with the science-based rhetorics following (also see Jordynn Jack and Gregory Appelbaum’s “This is Your Brain on Rhetoric”). While an interesting branch of rhetoric, I identify two major issues with neuro rhetorics: for one, there is an inherent dismissal of society’s eagerness for people to overcome disabilities (see Dolmage 121). Furthermore, neuro rhetoric studies lack the narratives and stories so prevalent within studies of composition and rhetoric, which perhaps also highlights the social constructivism common in Rhetorics of Health and Medicine.

Still, not all scholars in the field of mental health ascribe autism to social constructs, particularly those outside of the humanities. In her 2001 essay, “Disability, Impairment or Illness? The Relevance of the Social Model of Disability to the Study of Mental Disorder” as part of the collection *Rethinking the Sociology of Mental Health*, Julie Mulvany highlights some of the key disagreements between mental health disability theorists and mental health sociologists. She argues, “Although labeling theorists and members of the anti-psychiatry movement asked many important questions, their responses were often crude and unsophisticated. The blanket condemnation of psychiatric intervention and the determination to portray all mental disorders as social constructs, led their work into disrepute” (40). While Mulvany does give some credit to Disability theorists, her primary criticism is the supposed disregard for “impairments” she considers “severe” that would inherently not adhere to the umbrella of social constructs. She also argues that Disability theorists inherently perpetrate the perception of disability as victim, writing:

Many disability theorists are critical of the contribution medical sociologists can make to the study of chronic illness and disability. They argue that although research which examines the way people make sense of living with illness or impairment is important, it highlights the negative aspects of illness and neglects the structural context within which meanings are shaped. (49)

The problem here is that Mulvany, like other scholars who dismiss theories in Disability Studies, continue to adhere to ableist language and constructs. It is certainly a tricky balance between attempting to make room for voices within the disability community while also fighting against the ableist constructs that make it difficult for people with disabilities to be included in the first place, but it is a necessary one if we are to make progress towards an inclusive environment for all. The suggestion that inclusion is only designed for people with disabilities who are not labeled as “severe” is a dangerous notion.

## **2.5 Archival Research: Justification of Methods and Methodology**

Scholarship exploring the intersections between Literacy Studies and Disability Studies and Rhetoric and Composition has grown in recent years, but the intersections between Autism Rhetorics and Literacy Studies within an archival framework has yet to be explored. In fact, so much of this related scholarship falls within the realm of autism and writing studies, rhetoric and autism, and education-based scholarship in skills-based literacy. Disability studies is also an emerging interest in archival research methodologies, such as see in both the works of Jenell Johnson and Zosha Stuckey, as I discuss a bit more to follow. There is a need to go beyond autism and “skillsets” in education by researching how Autism Literacy came to fruition. I further explain how archival research can satisfy these gaps.

The scope of this work aims to define Autism Literacy from early advocacy efforts made by parents from the mid to late-20<sup>th</sup> century to reveal patterns and stories of an autism-rhetoric framework. To date, I have not found any scholarship that builds connections between autism and Literacy Studies within an archival framework—this is the very void I am seeking to fill. Instead, I first look to other scholars in archival research who have studied composition and underrepresented groups using archival methodologies. Thomas Masters describes his own experiences in archival research and *Freshman Composition*, in which he points to “the notions of *literacy* operative at that time” (161) from which he researched records dated between the 1940s and 1950s. Neal Lerner points to “the social forces that shape archival research” (195) that can also influence how documents are stored, as well as how they might be kept from the general public. Additionally, Hui Wu’s archival explorations of minority groups distinguishes between “writing women into history” and “writing rhetorical women into history” (130). Such a key difference here is evident in my discussion of documents within the Autism Society of Northwest Ohio’s (ASNO) collection of documents: rather than relaying stories about early autism advocates, it is crucial to explore their rhetorical agencies and how these shaped the evolution of Autism Literacy (also see Dolmage 68).

Two recent works within Disability Studies and mental health histories have demonstrated the growing interest in archival methods as a way to retrieve stories on behalf of those who historically have no voice. The first is Zosha Stuckey’s *A Rhetoric of Remnants*, in which she uses archival research to retrieve untold stories of individuals with mental disabilities. In her book, Stuckey investigates an “idiot” asylum established in Syracuse, New York in the 1850s, and explores the history of special education, showing how asylums were the early makings of this branch of public education. I also heed her arguments that “disability must gain a

positive signification so that we stop reading history normatively” and that “our challenge is to move beyond the notion of disability as deficit to arrive at people’s social historicity as agents even when they do not speak or write” (134).

The goal of all materials gathered from the Pitts Hames, Sloane, and ASNO collections is to uncover the stories of autism as they stand, rather than singling out autistic people. Stuckey also admits “particular prejudices” about her project, though she does her best “to be fair and accurate as possible” (7). Given my *ethos* as a parent of a child with autism, I take this point to heart as I carry on with my own archival research. Indeed, I have found some of the rhetoric repulsive and downright offensive at times—but I also keep the concept of *presentism* in mind and “listen” to what the documents tell me about the state of autism from where the author(s) sit, rather than passing judgment on parents and other advocates who perhaps did not know any better given the time and circumstances. As Glenn and Enoch argue in *Working in the Archives*, “the issue is not so much *why* we approach various groups of people or archival collections but *how* we work to understand and honor their perspective, their experience” (24).

The second recent work of note is Jenell Johnson’s *American Lobotomy: A Rhetorical History*, in which she describes the archival research proves as a way of telling stories of Americans affected by lobotomy. She writes, “Archival work is embodied work. Making contact with artifacts engages the senses in a way that making contact with digital images does not, or at least not yet” (175-176). Indeed, simply looking up the ASNO collection online would not provide the same sensations (also see Hesse, Sommers, and Yancey’s reflections in “Evocative Objects”). To that end, Johnson admits how much personal archival work can feel, expressing some of the same sentiments that Stuckey relayed during her own archival research of documents for the asylum. Johnson admits how she was “utterly unprepared for the particular emotional

impact it had on me” (176). I echo this admission, as I found myself working through strong emotions during my first project in the Pitts Hames collection. However, I learned early on that rather than disregarding these emotions, it is important to acknowledge them with the realization that my own feelings are not up for exploration, but rather explore what rhetorical effects from the archives are working together to make me feel this way.

It is also worth noting two Literacy Studies scholars who used archival methods in the latter 20<sup>th</sup> century. The first is Deborah Brandt, who remains a leading scholar in Literacy Studies. Her 2001 book *Literacy in American Lives* is based on archival methods to study how people use basic literacy skills. Her methodology includes a combination of interviews, ethnographies, and historiography. Shirley Brice Heath’s 1983 publication of *Ways with Words: Language, Life, and Work in Communities and Classrooms* is another example of ethnographic research methods, which details Heath’s observations of communities in the Piedmont area of the Carolinas in two towns: Roadville and Trackton. Unlike activist rhetoricians though, Heath does not stray from her role as the observer—instead of making suggestions for change, her primary role in the book is to relay the results of her observations to help her audience make meaning of them on her own, rather than advocating for any significant changes within the Roadville and Trackton communities. Such a methodology contrasts starkly with other scholars who rely heavily on autoethnography (see Yergeau’s “Clinically Significant Disturbance” and “Occupying Autism”). I value both of Brandt and Heath’s research methods, especially when it comes to not placing judgment. However, my own methodology influences me to talk about my positionality, and to talk about my research in narrative form without judgment—such strategies may help avoid presentism as I codify my findings while also avoiding criticism from others regarding my motives for this work.

Archival research is often stereotyped as “old” research. One could also assume that looking through boxes of materials is somehow “easier” compared to other research methods. This couldn’t be further from the truth. One issue is that archival research does not present itself any opportunities for a follow-up at the moment. I would love to ask Margie Pitts Hames questions about how she became interested in autism and disability rights for children, as well as where this work led to. The problem is that Hames died in the 1990s. All I have is what is left on paper, and I can codify the facts as best as I can from there. I cannot ask follow-up questions, nor can I make assumptions about her line of thinking at the time.

Yet this doesn’t mean the archives are without intimacy. Sure, they lack the depth of interpersonal communication, but we cannot neglect the tactile components of archival research. When I hold Hames’s papers concerning children with autism, I have to imagine how she might have felt at the time. Some of these feelings are transposed directly to my hands as I hold these same papers—this is just one of the ways we can build connections and create meaning through the archives. Any reputable researcher must keep his or her emotions in check as they conduct their work—or so we are taught. Archival research provides more quiet moments for reflection where it can be difficult to keep your guard up. I feel for the families who were taking a stand for their children in a society that tried to block them from school, as well as the individuals who were, and are still, ill-treated by society at large. Perhaps more important than sympathy and empathy though, is to make sure that these voices are heard—this is what makes archival research methods so important.

## **2.6 Overview of Archival Research Projects**

To answer my initial research questions on how Autism Literacy is acquired, used, and transmitted, I chose to focus on three archival projects. The first includes the Margie Pitts Hames

papers. Hames was a leading Civil Rights, Women's Rights, and Disability Rights attorney based in Atlanta in the 1970s and 1980s. While the breadth of the collection is quite large, I focused on two folders labeled simply as "Autism I" and "Autism II." In Chapter Two, I further explore how the Hames papers might prove as an example of early evidence of a growing interest in Autism Literacy in mainstream culture. I also discuss early evidence of parental advocacy.

The next archival project explores autism as a subject of interest via the entertainment industry as a way to appeal to families and religious organizations to learn more about this mental disability. I gained such insights through the Allan Sloane papers. Sloan was a writer for radio and television shows, whose own personal experiences led him to develop his passion for writing about "exceptional children." Sloane was widely praised for his works that garnered interest and many audience letters from across the country during the 1960s and 1970s.

With the rise of parental interest and advocacy, organizations such as the Autism Society of Northwest Ohio (ASNO) came to fruition. Stored in Toledo, Ohio, the ASNO archives provide insights into early forms of Autism Literacy for parents and other family members. Here, I also found evidence of Autism Literacy skills extending beyond participating families to expand out to the surrounding community at large.

## **2.7 Transition to Chapter Three: Autism Rhetorics in the Public Sphere**

Despite the wealth of scholarship in Literacy Studies, Disability Studies, and now Autism Rhetorics, no one has specifically researched the everyday experiences of reading and writing practices by autistic individuals. Autistics are often grouped as a disadvantaged community, but we also need to investigate the literacy practices that cause such groups to form and become oppressed. In their 2006 published study, Kliewer, Bilken, and Kasa-Hendrickson write: "We then examine in ethnographic and archival fashion how themes of literate disconnection have

continued over the decades to reverberate in the lives of people with disabilities and how certain labeled individuals and their advocacies have resisted the cultural imposition of subliteracy” (165). Indeed, archival and other primary research practices can provide us with the opportunity to look at the history of related literacy practices while also giving voice to oppressed groups, as demonstrated in both Johnson and Stuckey’s works. Stuckey has noted, “If ‘idiocy’ is a construct, then so is intelligence” (17). Therefore, to understand the everyday literacy practices of people with autism, we need to look beyond the supposed skills that make people smart. I turn to Kevin Mahoney, who raises the question: “In what *literacies* must a ‘citizen’ be skilled in order to be effective?” (Kahn and Lee 152). Interestingly, Siebers also had something to say about disability and literacy that could be relevant to Autism Literacy: “I believe that increased literacy identity and its defining experiences will transform critical and cultural theory yet again” (3). I would also add that our rhetorics assume that people with autism inherently desire to fit the normative literacy models of Western culture, which may also tie to my exploration of Autism Literacy.

### 3 EARLY AUTISM LITERACY AND PUBLIC KNOWLEDGE

**Overview:** In this chapter, I expand my definition of Autism Literacy through a discussion and identification of some of the overlooked intersections between Literacy Studies and Autism Rhetorics. In addition to the role of language as an influence on disability rhetorics, I further reflect on such connections and how they influenced the rise of Autism Literacy and public knowledge. I further define Autism Literacy as the ways we learn about and the practices we use to transmit information about autism, following a brief literature review on major scholarly works from the New Literacy Studies movement. Such concepts are further explored through archival research at the Margie Pitts Hames collection.

#### 3.1 Mainstream Autism Awareness and the Rise of Knowledge Acquisition

The ubiquity of autism is undeniable. The new century witnessed a rise in autism awareness and information, and it seemed that even if a person did not understand autism, they had at least heard about it. A phone survey conducted by the National Alliance for Autism Research estimated that 75 percent of Americans are aware of Autism, but less than half admitted having “knowledge” about the disability (2). Such statistics are telling when rhetoricians look at the role of language in mental disabilities like Autism in that exchanging and decoding terminologies does not necessarily translate to an in-depth understanding. While I posit Autism Literacy as gaining knowledge about this disability, it is also important to understand the continuous cycle of literacy practices, which do not equate to expertise. (And, as I will explain in subsequent chapters, there is also a grave concern about the prominence of expert groups such as Autism Speaks, which also happened to merge with the National Alliance for Autism Research in 2006.)

The gap between autism awareness and knowledge was evident in my own life. When I was pregnant with my son in 2009, a chiropractor warned me against vaccines because they could “cause autism.” I recall taking offense—not about the stark warning about “catching” autism, but rather the dire undertones of the recommendation. At the time, I admittedly did not know a lot about autism, but I definitely understood the negative social implications based on the language and contexts I previously heard. The rhetorical conversation at the time surrounded vaccinations and the whether or not shots “caused” autism. Depending on which side of the debate you stood, my decision to vaccinate my son would lead to contentment or despair. Yet each side had one thing in common: autism was regarded as a “bad” thing, no matter what the supposed cause.

Still, scholarly conversations about autism awareness didn’t really take off until the 1970s. The *Journal of Autism and Developmental Disorders* was established in 1971, but autism itself did not become its own category in mental health diagnoses until 1980. The 1990s saw increased awareness about autism through Jim Sinclair’s Neurodiversity Movement, though autism awareness did not become mainstream until about a decade later. I identify such an exchange of information during these movements as a form of Autism Literacy practices. But before delving further into these specific practices and how they were adopted by American society, it is important to first understand the scholarly definitions of literacy to further usurp the traditional definition as achievement, and instead delve into the processes that drive the exchange of autism-related information. In the previous chapter, I discussed the definitions of Autism at length. In the following sections, I briefly discuss the definitions of Literacy and the New Literacy movement to establish a better understanding of Autism Literacy as process, rather than as a tangible item to behold. Afterward, I discuss an archival research project that focuses on the

exchange of information pertaining to legal interests of Margie Pitts Hames, a late Georgia attorney, who dedicated a large part of her career to the disability rights movement.

### **3.2 A Brief Overview of Literacy Studies and Its Role in Autism Literacy**

In mainstream America, literacy means learning how to read and write, and argued as a necessary life skill that can determine your social and employment status. Within the scope of establishing Autism Literacy, I am not speaking of the traditional modes of learning how to read and write about autism, but rather *how* and *why* such forms of literacy occur in the context of autism. First, though, I discuss some of the main contributors to the field of Literacy Studies at the intersection of Rhetoric and Composition as a means to explore Autism Literacy processes and the contexts that drive the exchange of information, including the audiences and speakers (beholders of) autism information, as well as the methods and reasoning.

David Barton's *Literacy: An Introduction to the Ecology of Written Language* further defines literacy as a process, and one that can be empowering. It is also increasingly regarded as a right, rather than simply as a "thing" that is exclusive to certain demographics (12). As I noted in the introduction, I find Barton's metaphors of literacy "deficits" relevant to both the discussions of Disability Studies and Autism Literacy, which include "sickness," "handicap," "ignorance," "incapacity," "oppression," "deprivation," and "deviance" (13). Given Barton's explanation of "deficits" in literacy, we can see how literacy acquisition may vary among oppressed groups, such as those of lower social classes, as well as people with disabilities. Such arguments are echoed by James Paul Gee, who writes, "Traditionally, literacy is treated as a mental phenomenon. It is treated as 'the ability to read and write.' This places literacy in the individual person rather than in society. In turn, this viewpoint obscures the multiple ways in which literacy relates to the workings of power in society" (30). Indeed, being "illiterate," in

traditional terms, is widely regarded as a failure, and can cast doubts about an individual's ability to make a living for themselves and to contribute to society at large. Yet Gee emphasizes the societal component of literacy, and I also find his connections between traditional literacies and mental capacity on target, as primarily related to reading and writing. Autism Literacy becomes a multifaceted approach to the exchange of autism information between those who claim an expertise and those who know little or nothing about autism.

Pablo Freire's *Pedagogy of the Oppressed* investigates the social implications that literacy can have, beginning with a discussion of oppression and the oppressed, as well as the oppressors who either intentionally or unintentionally hold the oppressed at bay with mainstream ideals that ring of capitalism. He likens oppression to "dehumanization," which he argues can only be recognized through a "concern for humanization" (43). Yet overcoming oppression, according to Freire, is often wrongly marked by the desire to oppress the original oppressors, where the ideal is that "to be men is to be oppressors" (45). He goes on to note: "It is a rare peasant who, once 'promoted' overseer, does not become more of a tyrant towards his former comrades than the owner himself" (46). In other words, oppression is the mainstream ideology, and one that the oppressed strive to reach, and the oppressors strive to maintain, which also becomes a contradiction of oppression. Instead, in order to overcome oppression and find common ground and freedom for all humans, Freire advocates that the oppressed recognize that they are indeed being oppressed, rather than existing in denial. He recommends that the oppressed "continue in a state of submersion, impotent in the face of the oppressive reality" (52). Only when one can recognize they are being oppressed can they then discover ways to fight against it and discover methods of recreating the mainstream oppressive pedagogy used against them (69). At the same time, oppressors must also recognize the egotistical nature of this

pedagogy that “maintains and embodies oppression” (54). Ultimately, Freire argues that this mutual understanding will lead to freedom and humanization. If we were to apply the concept of Autism Literacy to Freire’s arguments though, I argue that this idea of mutual understanding is almost non-existent, due to the rise in advocacy groups and so-called experts who claim power to autism information.<sup>5</sup>

From a Literacy Studies perspective, we can argue that literacy practices advocated by a government and society at large also embody oppression. Recognizing the consequences of literacy could be one step for both the oppressed and oppressors to gauge the true values and intentions set forth by mass literacy efforts. The context of the oppressor and oppressed can also be applicable to the “abled” and the dis/abled, where both traditional modes of literacies and other forms of knowledge often widen the existing rifts between these two entities, rather than building connections. Autism Literacy may also create this push-and-pull between the oppressed and the oppressors, where Freire’s idea of mutual understanding cannot be achieved because the knowledge behind autism information is increasingly put in the hands of those who claim an authority or expertise. Concepts of reflection and action rather than only theory and only activism also relates to literacy, and it would be worth researching how oppressed peoples are not “liberated” through literacy alone.

Despite the definitions of literacy as a practice, when autism and literacy are mentioned together, the first connections generated may be the acquisition of literacy skills by people with autism who, according to our society, are stereotyped as possessing a deficiency. Moreover, Kliever explains that people who identify as being autistic are not equipped to possess traditional modes of literacy, where “according to definition and convention, the degenerate and

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<sup>5</sup> I discuss this further in Chapter 5, “The Rise of Autism Advocacy Groups”

the defective could not function as full and literate citizens of society” (168). Here again we see the traditional, mainstream definition applied to autism and its influence on what makes someone with a disability a valuable human being. According to Kliewer’s observations on societal expectations, people with autism are stereotyped as not being good readers and writers—but without these skills, they are doomed to being “non-contributing” members of society. We continue to see the terms “autism” and “literacy” used in traditional educational scholarship, where the emphasis lies in helping people with autism learn how to read and write up to society’s standards. With this project, I am instead positing the terms side by side in a Rhetoric and Composition framework to usurp this traditional definition of literacy, while also forming a new definition that focuses on the exchange and process behind autism information that relies on guidance from both Disability Studies and Literacy Studies for guidance.

The question is not whether people with autism can be literate—indeed, an abundance of evidence supports that they are. To distinguish, what I wish to discuss are the rhetorical implications of the practice of autism-related information exchanges rather than discuss whether people with autism can acquire and practice literacy (the short answer here is yes, of course people on the autism spectrum can read and write). In further exploring Autism Literacy, I identify with Barton’s definition of literacy as a process and practice. To further understand this more fluid definition, I acknowledge the important contributions made by other prominent Literacy Studies scholars within the intersections of Rhetoric and Composition. To date, Literacy Studies research continues to flourish, particularly by scholars who identify with the New Literacy Studies movement. Brian Street explains how New Literacy Studies, by definition, refers to “literacy as practice,” rather than a “set of skills” (1), and emphasizes an ideological approach to literacy, which acknowledges the variations between cultures and contexts (2).

Autism Literacy investigates how information is exchanged and used in an American society, an important difference to keep in mind. Worldwide practices and variations in literacy acquisition are beyond the scope of this work at hand.<sup>6</sup>

Historically, Literacy Studies, as an intersection with Rhetoric and Composition, investigates everyday experiences of reading and writing, as well as some of the theories of literacy as being “prone to perceptions of crisis and decline,” as noted by Harvey Graff in his introduction to the edited collection *Literacy and Historical Development* (2). Barton discusses many aspects of literacy that may be used as a framework for researching autism. For one, he notes that “literacies are not equally valued” (38) and indicates how a *perceived* literacy deficit (13) can undermine the practices of underrepresented groups such as people with autism. Rhea Estelle Lathan, in another historical work on Literacy in Rhetoric and Composition, contends that literacy historians have shown how access to literacy “is restricted by race, ethnicity, class, gender, religion, language, and geography” (xxiii) and that it “represents social status as well as identity ideology” (xxi). While I agree with Lathan’s argument about the restriction to access in literacy, I would also add disability to her list. Also, in further establishing the concept of Autism Literacy, I argue that all these restrictions, including disability, class, gender, race, and more, all contribute to a lack of access and dissemination in autism information.

Indeed, much of the interest of studying literacy in oppressed groups stems from Jack Goody and Ian Watt’s 1963 essay “The Consequences of Literacy” where they describe “alphabetic writing and popular literacy” as “new modes of social organization and transmission” (304). In fact, writing has made it possible to record history, as well as lead to the

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<sup>6</sup> Such future implications are further explored later in the Conclusion.

idea of “facts” versus “truths,” a concept that connects with Freire’s theory that mainstream education practices offer narratives full of supposed facts that do not actually represent reality. Despite this dichotomy, we can still conclude that the alphabet—the most significant consequence of literacy—is responsible for creating a literate society that is also (unfairly) deemed as worthier than the non-literate (305). Goody and Watt subsequently investigate the differences between literate and non-literate societies to prove that mainstream literacy acquisition does not necessarily make for a less “primitive” society—in fact, other consequences of literacy since the Industrial Revolution include greater social divides, isolation, confusion in meaning, and skepticism about information. Such focuses led to New Literacy Studies, where the movement contends that literacy is a practice that has neither good nor bad outcomes, but instead focuses on the factors that drive the practice instead.<sup>7</sup>

While New Literacy Studies looks at the ways in which people read and write, a challenge has emerged for scholars who rely on too much theory and not enough primary research in terms of their methodology. Deborah Brandt’s *Literacy in American Lives* is perhaps the epitome of primary research in Literacy Studies. Published in 2001, Brandt’s work encompasses literacy accounts of Americans born from 1895 to 1985. These accounts are derived through a combination of interview and ethnography, where each chapter presents a different aspect of reading and writing experiences. Such methods paint a more realistic representation of literacy experiences, rather than solely theoretical accounts. Her work also asserts Barton’s theory that literacy is not just experienced in school, but rather in everyday life.

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<sup>7</sup> Gee also discusses language acquisition as a sociocultural force behind literacy in *Social Linguistics and Literacy*.

Even Brandt's opening line in the introduction also highlights some of the issues and misconceptions Barton is concerned with: "Literacy is so much an expectation in this country that it has become more usual to ask why and how people fail to read and write than to ask why and how they succeed" (1). The latter approach is the basis of Brandt's research, where she investigates these experiences of "ordinary Americans" residing in Wisconsin. Additional scholars who use primary research in literacy studies include Shirley Brice Heath, Peter Mortenson, Sylvia Scribner, and Michael Cole. What is perhaps particularly interesting is Scribner and Cole's reference to the "cognitive consequences of writing" (125) they noted during a study of Cai children in West Africa, which they go on to describe as being embedded in "a different set of psychological functions from oral speech" (125). Such sentiments can even raise questions about the literacy practices of people with autism, which is why I regard these scholars in such high regard in terms of my own methodology.

Brian Street's explanation of New Literacy Studies refers to "literacy as a social practice," rather than a "set of skills" (1), which marks as further evidence of a departure from Graff's emphasis on literacy as history. However, as I explore here, the term "literacy" is as complex as its processes. Rather than choosing between a framework, I advocate for researching a combination of historical aspects *and* current social practices as a groundwork for collecting evidence of literacy within Autism Rhetorics.

### **3.3 Autism Literacy and Practices: An Overview**

Other scholars regard their roles in Literacy Studies as an opportunity for social empowerment. In considering my own positionality, I echo Rebecca Jones's position in Kahn and Lee's edited collection *Activism and Rhetoric: Theories and Contexts for Political Engagement* that "our work should, at least some of it, directly connect to social issues,

especially considering how many citizens matriculate through our classrooms” (186).

Considering the growing numbers of autism diagnoses and the perceived isolation that often follows, it is worth studying the history, theories, and practices that scholars have explored thus far to better understand the need for research within the intersections of Autism rhetorics and Literacy Studies.

While numerous studies investigate autism and literacy, cumulative analysis of the results of these studies remains few and far between. Lily Dyson, an education professor from the University of Victoria, has compiled the results and parameters of 21 studies from 1990 through 2013. The aim was to compare said data and then “generate a qualitative component” (1). Dyson’s overall purpose with her vast study of previous other studies is really to debunk the common misconception that autistic students are so cognitively impaired that they can never write at a proficient level. One of the most useful portions of her study is in the way she tallies the results on strengths and weaknesses within literacy. She identifies 22 strengths and 18 weaknesses, and researches how many studies have been done in these areas. So far, “word reading or identification” is the most commonly researched strength, while “Global discourse or reading comprehension” is the most commonly researched weakness among students with autism (Dyson 9-10). What is interesting, also, is how Dyson compiles these results—her method was primarily computer-based, where she searched the internet for a list of terms related to autism and literacy studies to investigate their prevalence.

In the end, Dyson contends that “future research may also explore other literacy skills that children with ASD may possess,” but cautions that this can become complicated because “literacy is viewed as an interactive process that encompasses listening, speaking, reading, and writing related to everyday life” (14). Such common definitions might automatically put ASD

students at a disadvantage; it might be useful to look at ways to instead define what it means to be literate with ASD, and how proficiency is measured without the emphasis on speaking and other challenging communicative skills.

### **3.4 Researching Autism Literacy and Public Knowledge in the Margie Pitts Hames Collection**

My first archival study of Autism Literacy took me to Emory University's Rose Library in Atlanta, Georgia, where I investigated a portion of the Margie Pitts Hames papers. I originally found this collection via the Archive Grid with key terms such as "disabled children" and "autism+children." At first, I was looking to find an archive that was accessible to me, as I reside in northern Georgia. However, the abstract from the Finding Aid further piqued my interest, as follows:

The personal and professional papers of Atlanta lawyer Margie Pitts Hames. Subjects covered include abortion rights, women's rights, school desegregation, employment discrimination, workers compensation, personal injury, social security claims, domestic relations, criminal defense, medical malpractice, defense, educational rights for gifted and disabled children, and general civil litigation. (1)

One phrase stood out to me the most: "educational rights for gifted and disabled children." Immediately I thought about some of the discussions this particular archive could entail. The scope of the archive states as: "The papers consist of subject files and legal case files. The subject files contain extensive research on legal issues linked to Margie Pitts Hames's major cases, information on her professional life, personal information, and material from her unsuccessful campaign for the Georgia Supreme Court Justice in 1982" (Finding Aid 2).

In total, the Finding Aid listed 13 boxes in Series One. For my research purposes, I focused on two folders in Box 4: Folder 11, titled “Autism: miscellaneous printed materials and court cases” and Folder 12, titled “Autism: notes and memoranda.” Series 2 in the Hames archive consists of 86 boxes that are not available to the public at this time because of privacy considerations related to the case files these contain. One of my early suspicions was that there could be a lot more information regarding Hames’s representation of disabled children and their families in Series 2; unfortunately, though, I would have to see what I could make out of the two Autism folders.

In referring back to the key phrase “educational rights for gifted and disabled children,” I thought back to some of my personal experiences with the public education system having a child on the autism spectrum. I personally have also fought against stereotypes about literacy in the traditional sense—while my son was strong in math, as is often noted in autistics, he was also just as strong in reading. I kept this in the back of my mind as I wondered what I might find regarding education and autism via the Hames papers. After looking through the Finding Aid, I had the following initial questions:

- What are the literacy histories of those on the autism spectrum? What archival materials are available (journals, notes, reports, etc.)?
- What was the extent of Hames’s work with autistic individuals? What was the extent of her advocacy for students, and how much did she advocate for autistic adults in the workplace?
- What was the rhetoric surrounding Hames’s cases? Was there rhetoric in any personal correspondence from Hames that suggested/reinforced any stereotypes?

- Do any of the files suggest any presumed rhetorical capacities on behalf of the individuals discussed in the court cases?
- What suggestions are made in terms of assumed strengths and weaknesses in autistic students? (For example, is it assumed that Hames's cases included defendants who were presumed to be greater at math than reading? Or that autism equated to intellectual difficulties more generally?)

Before going to the archive, I conducted some preliminary research to get a better sense of Hames's *ethos* in the realm of disabilities and found that she was most famous for overturning abortion restrictions in the state of Georgia. Hames is perhaps most famous for her litigation in the Doe v. Bolton case of 1973, in which she helped overturn a law that required advanced approvals from hospital committees for women who sought abortions. At the time, this case was compared to Roe v. Wade. Additionally, Hames advocated for Civil Rights and desegregation, as well as for the rights of disabled adults and students. To date though, I have not found any specific information or case overviews via secondary research. At this point, I was excited to see what I could find in terms of disability rights, especially in the Atlanta metro area, a place where I currently lived. The fact that the Finding Aid and all secondary information about Hames described "disability rights" seemed interesting in that the two folders I were interested in referred to autism specifically. I wondered if Hames was a bit more progressive in her profession as a lawyer in the 1970s, a time when autism was not widely known on a mainstream basis, and was instead grouped with the "other" group of disabilities.

I went to Emory University to look at the Hames collection in September 2016. As is often the case with archival research, I did not know exactly what these folders contained. When I opened up the box, I found the two folders of interest, which were simply labeled in pencil as

“Autistic I” and “Autistic II,” which was not as detailed as the initial finding aid. Since I knew that Margie Pitts Hames was a prominent Atlanta attorney, I expected to find that the “Autism I” and “Autism II” folders contained notes about her personal cases. At the time, I was thinking I might find a discussion on traditional modes of literacy and the discussion of the rights of autistic children. I ended up being correct in my assumptions—sort of. Also, since the scope of the archive included “extensive research on legal issues linked to Margie Pitts Hames’s major cases,” I assumed that I would find some notes related to autism-specific cases of Hames’s. However, this ended up not being the case—not only was the information not about Atlanta autism cases at all, but the folders were labeled differently in the box than in the Finding Aid. I assumed the contents were from Hames herself, but there is no way of knowing this for sure. Hames may have also had a secretary or an assistant who may have helped her keep her documents in order and made such notes.

Instead of finding court cases fought by Hames herself though, these folders contained copies of recent cases from other areas of the country (primarily in the Northeast region), which relayed broad experiences and situational contexts about literacy and children with disabilities. Additionally, most of the contained court cases did not identify the students as autistic, with the exception of one from the Rhode Island Society for Autistic Children. Such a dichotomy in the usage of terms goes back to the fact that her folders were labeled “Autistic” though most of the information did not contain any specific connections to autism. Hames evidently had an interest in working with autistic students, and she asked for some information from her friend Alan Abeson (Box 4, Folder 11). Since her personal court cases are sealed to the public we do not know how or when she used this information not clear how or when she used this information. I could not find any autism-specific court cases from Hames in the archive or through my

secondary research; the fact that many of the documents were left untouched seem to indicate that Hames encountered some dead-ends. Again, there are also 86 boxes in the Hames collection that are off-limits because of privacy issues. Hames may have possibly had client(s) who identified with autism whom she gathered the background information for. Without looking at the closed files, we cannot know this for sure.

Instead of focusing on specific Hames court cases then, I noticed an interesting pattern of the language being used to describe students on the autism spectrum. Despite the seeming lack of information, what was found in the collection of outside court cases spurred interest in the evolution of rhetorics surrounding autistic students (Box 4, Folder 11). For example, notable phrases about literacy and the children mentioned in the court cases include remarks made in the Pennsylvania Association for Retarded children case about Mark Moser on page 13, paragraph 41 (“He can read and write”), as well as Billy Reese, page 13 (“reads at a second-grade level”). My emotions came up when reading about both Mark Moser and Billy Reese. Their ages and experiences reminded me of my son, where I have constantly had to fight against him being stereotyped as someone who lacked interest or skills in traditional reading. In fact, at the time of my visit to the Rose Library at Emory, my son read at a second-grade level, just like Billy Reese.

Per my initial research questions, I wondered if I might find any stereotypical language contained in any of the file notes. However, none of the correspondence I found to or from Hames suggested any sort of stereotyping—each letter was very matter-of-fact. Some of the most telling information is from Abeson’s first letter to Hames in March 1973 in which he justifies (and almost apologizes for) not making photocopies of all of the court cases related to “handicapped children” (Box 4, Folder 11). Many of the children were addressed as having a “behavior problem” as the reasoning behind their denied access in public schools. Interestingly,

stereotypes were actually seen about non-disabled children. In the Pennsylvania Association for Retarded Children case, the plaintiffs argue that “normal” children might take education for granted, and that they might “develop skills willy-nilly and informally” (Box 4, Folder 11, Civil Action No. 71-42, page 23). Notably, the overall argument in this case, as well as other lawsuits in the Hames archive, is that children with autism were being denied public education due to so-called “behavior problems,” rather than for a disability. The Pennsylvania Association for Retarded Children argues on behalf of the plaintiffs that “each is a retarded child and would benefit from education” (3). For each of the plaintiffs (children), they use the label “Non-Education of” before each child’s name.

Another case included in Hames’s papers sent by Abeson was from the Eastern District of Michigan, Southern Division where the plaintiffs declare even more dire consequences about a lack of education: “Unless plaintiffs are afforded education as a right arising under and guaranteed by the Constitution of the United States, they face the almost certain prospect of permanent institutionalization, irreversible deterioration of spirit, and even death” (Box 4, Folder 11, Civil Action Number 33357, page 2). This statement is particularly notable in the discussion of Autism Literacy. For one, it is revealing of the high priority in which mainstream Americans likely regarded public education at the time. Second, the plaintiffs in this case are attempting to educate the court about what a lack of education might mean for children with disabilities: in this case, the plaintiffs argue that a lack of education increases the risk of being institutionalized, or even dying. Finally, the rhetorical strategy of fear is worth noting here, in terms of the threat of no public education being likened to a dire future outlook. Aristotle defined fear (*Phobos*) “as a sort of pain and agitation derived from the imagination of a future destructive or painful evil” (128). Experts today argue that public schooling is the most inclusive form of education for

students with disabilities, and the plaintiffs of the Michigan case are arguing that this lack of inclusivity can affect the way children are perceived by society. Yet these same experts are not necessarily concerned if such fears of institutionalization and death come true, but are instead using these concerns as rhetorical strategies on behalf of the plaintiffs that remain relevant today. Such perceived fears extend beyond the individuals with disabilities to society at large, especially in a day and age where asylums are no longer accepted as the “norm.”

Throughout my review of the Hames papers, I did in fact expect to find some stereotyping. I tried really hard to evoke *presentism*, the concept of researching historical documents knowing that its authors could not have known about present-day norms, but it was still difficult to ignore the era that the documents came from. I find the balance between these two things theories difficult. How can we go into an archive while being completely unbiased and present? This would entail not using a Finding Aid at all or completely going into an archive without any background knowledge whatsoever. Indeed, as Robert J. Connors writes, “until we have some knowledge of the situation a posteriori, our ability to understand the prior situation is hopelessly lacking” (50). Prejudice, as Connors points out, is not entirely unjustifiable, but rather a part of the archival research process. He argues, “In reality, data in historical studies are made up of at least three elements: the historian’s perceptions of the present, her assemblage of claims based on study of materials from the past, and an ongoing internal dialogue about cultural preconceptions and prejudices and the historian’s own” (50). Such arguments may be applied to my reading and reactions of “The Retarded” as outlined in the civil lawsuit filed by the Pennsylvania Association for Retarded Children. In 2018, the term “retarded” is not as acceptable as in previous decades, though I found it surprising that a seemingly prominent organization so blatantly called the children they served as such. Still, rather than disregarding

the related materials, I had to look beyond the “R-word” to see what the pages could instead tell me about the process of Autism Literacy at the time.

In the filing documents, the plaintiffs spend three pages on a section simply titled “The Retarded.” The plaintiffs first outline statistical information in the state of Pennsylvania before moving on to a discussion of the varying levels of severity in retardations. They then state, “Whatever the traditional label, retarded children of any intelligence quotient are capable of benefitting from education” (22). Indeed, the Pennsylvania Association for Retarded Children is not so much concerned with labeling, but instead argue for public education inclusion despite the labels. They go on to note that:

Among every 30 retarded persons, 29, if education is provided to them, are capable of moving toward self-sufficiency (25 of them, with education, would be able to achieve sufficient skills to enter the labor market and to secure employment in competitive jobs; 4, with education to secure employment in a sheltered or supervised setting), and one, if education is provided to hum, is capable of achieving some degree of self-care. (22)

This argument marks a remarkable shift from the statement in the Michigan case where the argument for education was self-empowerment, rather than self-efficiency. I am reminded of the very foundations of dis/ability where a large portion of ableist fear is based on the notion that persons with disabilities will not be able to contribute to society. The Pennsylvania Association for Retarded Children is instead arguing that yes, children with disabilities can contribute to society without being a burden—the key is to provide them with education first. Such arguments are reminiscent of Barton’s revelations that Western society largely believes that literacy can solve all problems. Notably, Hames’s own voice is missing in the copies of the lawsuits she kept

from her correspondence with Abeson. I noticed occasional check marks alongside the columns, but the writer and the purpose are not clear.

A year before my visit to the Hames collection, Zosha Stuckey's *A Rhetoric of Remnants: Idiots, Half-Wits, and Other State-Sponsored Inventions* went to press. I have since made numerous connections to her book in terms of methodology and the challenge of personal connections made with the research at hand. Stucky's own archival work looks at the role of the educational system's "need" for rehabilitating non-normative individuals, such as those with mental health disabilities. Her book provides a historical overview of the New York State Asylum for Idiots, which opened up in the mid-nineteenth century in Syracuse, New York. Stucky's overall conclusion is that disability is in fact language-based, which in turn lends itself to societal norms and expectations. This made me think back to some of the court cases Hames kept that contained language such as "handicapped" and "retarded," which further classified such labeled individuals as other. Stucky's own archival materials she researched included letters that detailed correspondence between pupils and their family members, as well as parents and educators at the asylum. Naturally, not all the letters were kept, and it was likely the case that the ones that were kept were those that painted the asylum in the best light possible. Yet, Stuckey reminds us that we do not need to perceive such gaps in information as detrimental, writing:

If we fail to collect remnants and thus bring presence to what is seemingly silent in the historical record of the asylum-school, we fail to do justice to historical erasures. My point in doing this work is that we do not have to *know* the exact experience in order to acknowledge its existence and power. Rather, we have to recognize that something happened—that remnants of experience exist—and that we will not necessarily be able to

precisely recreate experience from the language that remains. However, if we cannot easily access the points of view and evidence we desire, we still must at least try. (126)

The above statement resonates with me in terms of the gaps in my own research regarding the restricted access Hames's own personal court cases and also highlights the inherent point of Autism Literacy: language is the basis of the exchange of information that constitutes the actions behind it and will certainly not be dictated as such word for word in archival documents. I realized these connections early in my archival research on autism, which also helped steer me towards the need to unpack the term Autism Literacy. At this point, it was not the words themselves that mattered, but also the way they were used and how they were exchanged to create a picture of autistic individuals. For example, the "handicap" term transformed from a word used to describe someone with a disability to a phrase that contained meaning that our culture was made to understand that anyone associated with it would be presumed as someone less than human. I sought to look for other evidence of Autism Literacy that could provide further proof of such exchange of information about autistic individuals.

### **3.5 Key Takeaways from the Hames Collection**

While I did not find the type of information I had initially expected, such a situation seems par to the course of archival research. Even the archivists at Emory University seemed surprised that I was looking at the two folders on Autism and stated that most people looked into Pitts Hames's other works on abortion rights. It made me wonder if this is why Hames ended up (seemingly) focusing on the latter instead—unfortunately, I cannot make any solid conclusions without seeing the sealed files. Regardless, the few number of people who attempt to access Hames's work proves that this is an area needing to be researched and explained to the public. Below, I discuss some of the major outcomes from this research endeavor:

- **The Hames papers provided evidence of traditional literacy discussions.** Overall, this archive contained discussions about traditional literacy, as seen through statements from parents in the lawsuits that argue their children ought to be allowed to attend public schools since their children can read. However, I have come to view these documents in the context of Autism Literacy. It has long been acknowledged that children on the spectrum are indeed capable of traditional literacy skills—what the Hames papers provided instead was a direction in my research towards the ways we talk about autism.
- **Personal cases were slim.** It could be that the bulk of her own cases are in the “sealed” boxes. Stuckey ran into a similar issue in her own research due to the fact that the administration of the New York State Asylum for Idiots did not keep all the letters they received. Another possibility is that Hames may have taken an interest in children with disabilities (particularly autism) or maybe needed advice on how to proceed with a new case. Despite the lack of personal cases in this archive, the materials that *were* there prompted me to view Autism Literacy more abstractly—since literacy entails actions beyond traditional reading and writing, the actual collection of materials on the part of Hames was another way she was building her own literacy about autism.
- **Language is key to deducing attitudes and rhetorical contexts of Autism Literacy of the time.** The included cases serve as prime examples of Autism Literacy at the time. The defendants and judges were educated on what being “handicapped” or “retarded” meant, as well as the perceived consequences at the time. I imagine that if Hames were still alive and practicing disability rights law today, I suspect that she would also be advocating for inclusive language (again though, this is an assumption, as there were no personal notes in this archive that indicated Hames’s own attitudes about language use).

We cannot reasonably punish any of the people behind the writings in the archive; we ought to instead simply acknowledge the language of the time and focus on the driving factors behind them. For my purposes here, I also regard such language exchanges as a part of the history of Autism Literacy.

- **The papers show Autism Literacy in action.** In all, I did learn about Autism Literacy of the 1970s through this archive. However, I also got to see in real time how two individuals participated in the process of Autism Literacy: Abeson and Hames. Abeson was clearly the perceived “expert” in disability lawsuits, while Hames was on the receiving end of this form of literacy exchange. Aside from the collecting process of the materials themselves, Abeson’s letters were also evidence of Autism Literacy. What would of course solidify the “exchange” of information is if we were able to track down the original letters Hames presumably sent to Abeson. However, since most people do not keep copies of their own outgoing letters, we must assume that such correspondence first prompted Abeson’s own responses.
- **Refraining from personal attitudes was a challenge.** It was difficult not to establish a personal connection with the content at hand. As Connors notes though, “...along with the historian’s current perceptions and the inert archival material that can be worked with or discarded, there is one more source of data that the conscientious historian must keep in mind: his or her own prejudices. No person exists without prejudice” (53). Indeed, I resonated with some of the arguments parents made throughout the lawsuits about their children and how they were incorrectly perceived by the public school system. Some of the language differences, such as disability being referred to as “retarded” were also difficult to contend with. Instead of fully discarding my feelings in terms of maintaining

presentism in my research though, the Hames project was an opportunity for me to learn how to negotiate my personal attitudes while recognizing the time in which the archival materials were created.

### **3.6 Transition to Chapter Four: Early Parental Advocacy and Autism**

The Hames Papers shows just one collective example of language and autism rhetorics used as a means to create Autism Literacy. In the next chapter, I discuss my findings in another archive of Allan Sloane, a parent of a son with autism, and how he used technology as a form of Autism Literacy that contributed to the rise of autism advocacy and activism in the latter half of the twentieth century.

## 4 EARLY PARENTAL ADVOCACY AND ACTIVISM

**Overview:** In Chapter Two, I discussed my archival research findings within the Margie Pitts Hames Collection, which revealed early signs of a sociocultural shift in the 1970s relating to how parents of children with autism were starting to speak up for their children via the legal system. While such cases were not always made public, people started to take more notice of autism and become more literate about the disability. In this chapter, I explore how parental advocacy and activism further shaped Autism Literacy during the same decade. I also discuss another archival endeavor into the Allan Sloane Papers, revealing how Sloane's own advocacy impacted public literacies on autism.

### 4.1 Shifting Modes of Literacy

While the Digital Age notably impacted traditional literacy skills, the American culture witnessed another major shift thanks to radio and television. No longer was print the primary mode of information and literacy—radio and television programs paved the way for entertainment and news information, providing enjoyment as well as helping them learn more about each other. In their work on literacy in the Digital Age, Selfe and Hawisher write in “*Beyond Literate Lives*”:

...we began to develop an ongoing interest in characterizing how and why different people from different cultural and essential backgrounds, occupying various subject positions, and faced with different situations acquired and developed (or, for various reasons, failed to acquire and develop) digital literacies at a time in history when the United States and many other parts of the globe were becoming increasingly dependent on networked systems of digital communication technologies. (186)

As I will unpack later in this chapter, the correspondence throughout the Sloane Papers are written in traditional form, but they respond to a form of literacy presented digitally in film format. The responses from the viewers range from positive to negative, which is also reflective of the the rate of literacy in the emergence of disability rights. Compounding the rate of Autism Literacy is in fact dependent on emerging technologies, which disseminate information about autism reaching multiple regions across the country almost instantly, along with long-term impacts on autism discourse. As demonstrated through the Sloane archives, advocacy for people with autism eventually gave rise to autism awareness, sometimes with unintentional consequences. To better understand the connections between autism advocacy and literacy, though, I briefly explore what it means to be an advocate.

#### **4.2 Who is an “Advocate”?**

Historically, definitions associated with the term *advocacy* have evoked legal contexts. Today, we hear the term used quite loosely to mean that someone is fighting for someone else. *Merriam-Webster* broadly defines *advocacy* as “the act or process of supporting a cause or proposal” (1). When combined with disability terminology like autism, an “autism advocate” could then be defined as someone who supports autistic individuals. An “Autism Literacy” advocate can be surmised as an individual supporting the process and exchange of autism information to others, but not without consequence as McGuire states in her criticism of autism advocates, “the problem identified by advocacy is clear: inadequate supports for *parents and families living with autistic people*” (author emphasis), which is much different than advocating for people with autism themselves (5).

As noted in the Hames papers, the 1970s marked a time of rapid awareness about disabilities, where parents were taking action to fight for their children in the school system. It is

first vital to determine how these parents gained the Autism Literacy skills they needed *before* becoming advocates though. Adam Feinstein, an autism author and editor, published a historical overview of autism in 2010 titled *A History of Autism: Conversations with the Pioneers*, which uses a combination of secondary research and primary research via personal interviews.

Feinstein discusses the establishment of autism in both medical and social settings from the 1950s through the early 2000s, and we also learn that his work is inspired by his own son who is autistic. Feinstein identifies the 1950s as the time of autism awareness, where misconceptions about parents being “to blame” for autism in children were also rampant. In Chapter 4 of *A History of Autism*, Feinstein focuses on the 1960s, a decade in which “parents fight back” (76).

But before parents became more visible in the rhetorical spaces that occupied autism, the advocacy efforts were more subdued, compared to say, an on-screen awareness program, the establishment of an autism organization, or a protest. During the 1960s, there is evidence that Autism Literacy was gaining traction in spaces outside of clinical circles—for example, Feinstein highlights autobiographical novels written by parents of autistic children, such as Bernard Rimland’s *Infantile Autism*, published in 1964. Not only did Rimland’s book aim at “combating the psychogenic argument and showing that autism was biological in origin” (68), but Feinstein also credits the work as the first to spawn national autism rallies. Also, “parents around the US began writing to him” (99), which shows proof of exchanges of Autism Literacy where audiences are becoming more active in these transactions, rather than just accepting the information passed on to them by clinicians. On the flipside though, some authors took advantage of autism awareness and transformed autistic individuals as characters of science fiction. According to Feinstein, “Bizarre misconceptions remained intact, however. Philip K. Dick’s science fiction novel, *Martian Time-slip*, first published in 1964, features an autistic boy

who slips helplessly backwards and forwards in time” (82). As stated previously, my focus again in my archival projects is to gather and report evidence of Autism Literacy as written in history, and not to necessarily point out whether the exchanges of autism information are right and wrong—such an undertaking would be futile, as we know that much of the information was unfounded, or politically incorrect.

In this chapter, I unpack such terms a bit further and link them to the term Autism Literacy that I have discussed in previous chapters. I also argue that an individual can also become an Autism Literacy advocate unknowingly simply through the exchange of autism-related information. Allan Sloane was one such individual, as I discovered in studying an archive of his life’s work. I then focus on two of his made-for-television films, which feature male children with autism as the protagonists.

### **4.3 Researching Early Autism Parental Advocacy and Activism via the Allan Sloane Papers**

The Hames papers demonstrate an emerging mainstream interest within the public sphere to protect the rights of children with disabilities without shunning them from society. Coincidentally, around this same time mass institutionalization of people with mental disabilities was coming to an end, a far cry from just a century earlier, where Stucky notes an increase in asylum numbers “due to the growth of the eugenics movement, which created an air of fear around embodied differences” (88). Yet such fears did not end with the closing of institutions; on the contrary, Sloane’s films portray a confusion as to the new inclusion movement where ableist attitudes still run rampant. Through the Hames papers, we also see an early rise in parental advocacy, a newer form of Autism Literacy. Parents were no longer waiting to be told what to do with their children, whether this meant drugs or institutionalization. The

shift from hiding their children from society to a more inclusive environment was becoming more evident.

While I was researching at Emory University, an archivist gave me a lead to the University of Georgia for the Allan Sloane papers. Sloane was a veteran in World War II who came back to the States to begin his career as a writer for radio and television programs. He went on to write made-for-television films that explored family and cultural issues, often with religious undertones. According to the biographical note on the Finding Aid,

Allan Everett Sloane (pseudonym Ellison Carroll) was born in 1914 in New York City (NY). He was a writer for radio, television, and films. Although he began his career as a newspaperman in 1936, Allan Sloane became a writer for radio in 1943 (Man behind the gun), later moving to television and films. One area of subject matter for his writing was exceptional children. He once stated that he tried to draw the attention of his audience to the needs of children who were different, and often based the scripts on his own family. (1)

At first, I was not sure how an entertainment writer fit into my quest for rhetorical and literacy histories of autism until I found this statement in the Finding Aid for the collection: “One area of subject matter for his writing was exceptional children” (1). The “scope and content note” on the Finding Aid also including the keyword “autism” after one of Sloane’s works called *And James Was a Very Small Snail*. Another keyword noted by the archivist was “exceptional children,” which connected with another script titled *Sit Down, Shut Up, or Get Out* (1). The Sloane archive includes 33 boxes plus an additional series of movie reels. For my purposes of assessing the language and rhetorical contexts within Autism Literacy, I focused on the boxes and folder related to both *And James Was a Very Small Snail* and *Sit Down, Shut Up, or Get Out*.

Aside from original movie script drafts and edits, the folders in these boxes also contained fan mail, newspaper reviews, and other telling writings that demonstrate the rise in advocacy through upcoming modes of information technology (in this case, television) to help connect with an audience for the means of demonstrating Autism Literacy.

Based on this information alone, I had the following initial research questions:

- Who was Allan Sloane, and why was he interested in writing about “exceptional children?”
- What sort of “differences” does Sloane explore about children, per the biographical note in the Finding Aid?
- How did his own family play a role? How many of Sloane’s own children were considered “different” or “exceptional,” and how do these experiences affect Sloane’s *ethos* and positionality throughout his works?
- What do the movie scripts entail, and do the stories employ ableist language of the times (1960s-1970s)?

Due to the sheer volume of viewer responses, I was not able to analyze every one included in the Sloane archive. For full disclosure, I instead built connections with some of the most telling examples of Autism Literacy for the sake of the project at hand.

#### ***4.3.1 And James Was a Very Small Snail***

As I made the two-hour drive to the University of Georgia campus in Athens, Georgia, I thought about the first film title on the Finding Aid that I would be looking through in the Sloane papers: *And James Was a Very Small Snail*. Before getting to the archives, I conjectured the meaning of the “snail” in the title, a process of guessing that archivists ought not to do, but one I could not help refraining from as I meandered away from the mountains and through a more

desolate area of Highway 129 towards Athens. The title of the script itself is telling: not only do we know that James is the protagonist, but the connotations made by “very small snail” is indicative of someone who is slow, unworthy, and obsolete in the viewpoint of others. A snail in itself is already small, but Sloane emphasized the fact that the James character was even smaller than the average snail. Snails also stick their bodies inside their shells for security, and I was reminded of my son using his orange body sock whenever he needs sensory comfort. Snails are also easily crushed, I thought with a shudder, as I took myself back to my five-year-old self in California, when I once witnessed cruelty in a group of boys who crushed snails on a cool spring morning.

I stopped these thoughts before my arrival to the UGA campus so that I could focus on the materials I would soon sift through, ideally without bias. After arriving at the Hargrett Rare Book and Manuscript Library, I noticed how much cooler it felt in the room. I was immediately at ease and put the thoughts of the “snails” behind me. As I read through the series description and folder listings, I honed in on Box #10, which contained items related to *And James Was a Very Small Snail*, a made-for-television 1963 movie about a boy with autism. Folders four through six contained the first script draft, letters from fans and critics, as well as reviews published in magazines and newspapers (7). I found out that James himself is a young boy who is institutionalized, and purportedly exhibiting signs of autism, which explains the “snail” metaphor of feeling small and isolated. The first item in Box 10, Folder 4 included a short narrative about why Sloane wrote this script, claiming it is “probably the best example of my writing about children.”

As mentioned in the Finding Aid, Sloane himself had a special place in his heart for children, especially for children with disabilities. This compassion is based on his own

experiences, which we can tell through some of the language between the characters in the script. For example, a man named Dr. Apleton compares James to another boy, stating: “Joey. Wonderful kid, bright kid, normal kid” (Box 10, Folder 4, page 9). Sloane sets the scene in an interesting way, according to the “Set List” where an autistic boy named Peter likes writing on walls. (Box 10, Folder 4). I could not help but regard Peter as someone who was likely shunned for his lack of literacy skills, but when in fact he did indeed practice written literacy—it just so happens that he chose walls instead of the traditional method of paper.

While my original intention of looking through the papers related to *And James Was a Very Small Snail* was to read through the original script and notes, I ended up finding more telling information in the scope of Autism Literacy in Folder Five, which contained letters from viewers, as well as reviews. First, I found that Sloane was widely received by the Lutheran community. The First Lutheran Church, for example, describes how the movies captures “the growing problem of the emotionally disturbed child” (Box 10, Folder 5). Another related organization, the National Lutheran Council, says, “artistic child” instead of “autistic child,” which shows an honest typo made on an aged typewriter, but I also wondered about the attention to detail given by the organization if the topic was indeed so important to them.

Most of the reviews in Folder Five were overwhelmingly positive. For example, Campus Film Productions notes that Sloane “gave most of the viewing audience their first brief insight into the problems of the autistic child,” while a positive review letter to ABC (the network that played the movie) from Dr. Julius Kleiner describes how *And James Was a Very Small Snail* accurately portrays “the treatment given to a child suffering from autism, and the effects on his family.” Yet another review letter from the Federation of Jewish Philanthropies of New York stated, “I have rarely seen a show on mental illness handled so sensitively and truthfully.”

Despite such positivity, it is important to take a step back and acknowledge how such statements are commonplace in our culture, where society is fixated and more concerned about the rhetorical “burden” autistic people place on their families than they are about considering a person with autism as a full human being.

Based on the perceived burden of children with special needs, I was surprised to find only one negative review of the film by Harriet Hester from New York, who actually loved the movie but did not approve of all of the cast members (Box 10, Folder 5). At face value, I thought that the film must have really resonated with the audience if Sloane only received one negative review letter! However, I became a bit more realistic, thinking there might have been other negative reviews out there, but they did not end up in this one archive. Perhaps Sloane did not keep any other negative reviews, or maybe they ended up elsewhere to preserve his name, a puzzle that cannot be solved through this archive alone.

Another notable observation from the reviews and letters for *And James Was a Very Small Snail*, also in Folder Five, was the impacts that the film had on adults who either had children with autism or worked with students with autism. One postcard from Mrs. W.C. Miller, expresses her appreciation for the film and also states she has a son with “severe retardation.” Eveline Omwake, Department of Child Development at Yale, writes, “My senior students each work with a child who is deviant in some way or another, and several of them are autistic.” As with other sensitive social issues (such as the case of the #MeToo movement), once literacy circulates about them, a rhetorical space is created in which more people with information of expertise on a given subject feel compelled to share their insights.

Folder Six revealed some of the information related to Sloane’s family I was hoping to find, albeit narrow in scope. Clippings for *And James Was a Very Small Snail* contained one

newspaper review by Cecil Smith, who claims that the protagonist James in the film is Sloane's youngest son. I found no other information about Sloane's children in the rest of this box, though there was more information about his son Paul in correspondence related to the next film I will discuss.

#### **4.3.2 *Sit Down, Shut Up, or Get Out***

The Finding Aid indicated another film related to autism that I hoped would provide some evidence of Autism Literacy during the 1960s and 1970s. Boxes 16 through 18 contained correspondence for a 1971 film Sloane wrote called *Sit Down, Shut Up, or Get Out*, which was written for a religious television program called "Frontiers of Faith." Since the correspondence spans three full boxes versus the one box for *And James Was a Very Small Snail*, I was curious as to why the film gained so much more response from the public (though a part of this reason could be the later date, when there were likely more homes with televisions). In his narrative in Box 16, Sloane explains how he gained inspiration for the script from his youngest son Paul, who literally walked out of school after a teacher told him to "sit down, shut up, or get out" (Box 16, Folder 2). He goes on to note that "...there was something of Paul in every child I wrote about," which corroborates the information contained in the review for *And James Was a Very Small Snail* by Cecil Smith, as stated above.

One of the more poignant points pertaining to my research comes early in the script draft of *Sit Down, Shut Up, or Get Out*, where a boy named Chris Bright is sitting in the hallway and is criticized for being "lost in his book" (Box 16, Folder 2). I find such critique an oxymoron as well as a connection to my earlier point that STEM programs only seem to have become the focus for people with autism once our society found a seemingly "useful" occupation for them. Walters, in "Autistic *Ethos* at Work," expands on this notion, predicting real-world implications

as these children become adults, “The creation of jobs for people with autism is encouraging, but it is necessary to situate these positions in relation to broader perspectives about the role of ethos in technical communication and pervasive to stereotypes about autism” (7). Indeed, the idea that people with autism are not worthy of or are incapable of practicing literacy is one myth that we have created as a result of Autism Literacy information.

The bulk of the information pertaining to Autism Literacy was contained in multiple folders of correspondence letters from across the country, which were organized in alphabetical order either by Sloane or the original archivist. Unlike the overwhelmingly positive correspondence letters and reviews for *And James Was a Very Small Snail*, there was a mix of both negative and positive letters for *Sit Down, Shut Up, or Get Out*. Again, I surmise the reasoning could be that the latter film was broadcasted nearly a decade later, when televisions were more prominent in American households. The fact that the film came out right after the Civil Rights movement could have also played a role in the depth of the responses.

I would also consider the broadcasting of the film as a *literacy event*. Deborah Brandt and Katie Clinton define such an event as follows: “Generally, a literacy event is considered a social action going on around a piece of writing in which the writing matters to the way people interact. To this is added the more abstract concept of the literacy practice, usually treated as the socially regulated, recurrent, and patterned things people do with literacy as well as the cultural significance they ascribe to those things” (342). As demonstrated throughout the viewer response letters, *Sit Down, Shut Up, or Get Out* resonated with a group of people in such a way that they had a critical response (positive or negative), with some expressing individual interests at stake.

I found positive responses to *Sit Down, Shut Up, or Get Out* via letters directed to Sloane and his co-producers, the National Council of Churches, throughout the materials. One such

letter was written by Madalyne Allen and was directed primarily towards the Council (Box 16, Folder 3). Another letter from Mrs. James H. Claybrooke echoed Allen's pleasure with the Council's involvement, writing, "We were also pleased to see the organized church speaking out and doing it so well" (Box 16, Folder 5), which also indicates approval of the subject matter. Others still directly praised Sloane and found personal connections with Chris, the film's protagonist. Such is the case with Gwen Latham, a mother who says her gifted child excels in reading, but "the public school system has made it apparently clear to me that they will not acknowledge his reading ability" (Box 17, Folder 4). Such testimonies as Latham's share connections with case files in the Hames Archive that were filed by parents on behalf of special needs children in the 1970s, as discussed in Chapter Two.

Unlike the prominent praise for *And James Was a Very Small Snail* though, Boxes 16 through 18 of the Sloane Archive contained numerous negative critique letters for *Sit Down, Shut Up, or Get Out*. One letter from Ellen W. Field expresses her concerns over the timeliness of the film itself, asking, "When was this program written—1902?" She goes on to note, "It bears no resemblance to any real school I have attended or taught in... Why doesn't Allan Sloane put himself on the substitute list and try various schools for a year?" (Box 16, Folder 7). While Field does not elaborate on her rhetorical question, it is evident that the film, in her mind, brings issues to light that she is already aware of, therefore highlighting the fact that Autism Literacy is beginning to spread to some members of the American public at this time, but not others. Another more succinct letter from Roger DeLera emphasizes one word "Ridiculous," and then adds a P.S. that asks, "Was the author actually paid for that effort?" (Box 16, Folder 6). We do not know if DeLera agrees with Field, or if he is instead turned off by the film's exploration of disability. Yet another critique from Eligio Bullella claims that he didn't like the show and argues that "loners" end up being

killers, so there's no reason for him to feel sorry for Chris Bright (Box 16, Folder 4). Such stereotypes unfortunately remain true at the time of my writing this in 2018, where the perceived deviant is one who embodies so-called "red flags" such as being the loner that Bullella accuses the film's protagonist of being. Margaret Price and I have written on this very matter in *The Wiley Handbook on Violence in Education* in our chapter "Student Profiling and Negative Implications for Students with Disabilities":

While student profiling is often promoted with good intentions, it often feeds into the ableist agenda, through which students with mental disabilities are wrongly targeted. The "loner" for example, is sometimes perceived as having autism or another disability, while the "socially awkward" might be inaccurately perceived as having social anxiety. These profiles might identify students with mental illnesses to others, but mental illness and violence are not strongly linked. (110)

Interestingly, the archival materials also exhibited an underlying theme of wanting to take down the system of public education on the part of some of the viewers of the *Sit Down, Shut Up, or Get Out* film. I do not know if putting down public education was Sloane's original intent, though the show was co-produced with the National Council of Churches, which seemed to have a non-secular agenda. According to their website, the National Council of Churches, now known as the National Council of Churches of Christ in the USA, has a history of including different sects of Christianity to help fight against injustices based on "the irony of proclaiming Christ's gospel of love and salvation in a culture of acrimony and injustice" ("History"). Also, on page 89 in Sloane's film script, Chris's father is told by an educator to "get him out of the system before it chews him up." It seems like a lot of teachers commend the show, while administrators want to use the film for training purposes on autistic students. Still, not all viewers exhibited support for

teachers, as is the case of one letter from Sally Arnold, who puts most of the blame for problems in children on the teachers (Box 16, Folder 3). Roseoelt Acoff wrote in as a self-described and proud “high school dropout” (Box 16, Folder 3), further fueling the questioning of public education idealism. On the flipside, though, one writer, Mrs. Leo M. Berhtaume is not pleased with the idea of taking down the public education system, and instead accuses the film of advocating for anarchy (Box 16, Folder 4).

The three boxes also contained materials that used the word “gifted” throughout, though in different connotations. By definition, “gifted” means “having great natural ability,” or “revealing a special gift” (*Merriam-Webster*), while the National Association for Gifted Children offers the following definition:

Children are gifted when their ability is significantly above the norm for their age. Giftedness may manifest in one or more domains such as; intellectual, creative, artistic, leadership, or in a specific academic field such as language arts, mathematics, or science... It is important to note that not all gifted children look or act alike.... It is important that adults look hard to discover potential and support gifted children as they reach for their personal best. (“What is Giftedness?”)

As is evident with the above definitions of “gifted” in 2018, none are synonymous with disabilities as is suggested in mid 1960s through 1970s rhetoric. Yet when considering the term in the latter timeline, within the context of discussing a person with a disability, the term tends to be used in both positive and negative ways, as demonstrated via viewer letters. For one, the writing in this archive indicates a preference for using the phrase “gifted” instead of “disabled. For example, Anna and Ron Baggs claim to be parents of a “gifted” child, while Mrs. Dennis Gagnan identifies herself as a mother of a “gifted child” who has behavioral problems in school (Box 16,

Folder 8). Another letter was submitted by Frank Sacco, a self-identified “gifted student” (Box 18, Folder 1).

Given the context of these letters, “gifted” was widely understood to indicate disability. However, not all viewers used these terms interchangeably. Dr. and Mrs. H. Belkin complained, in their letter, that gifted children are punished just as much as disabled ones (Box 16, Folder 4). Another critique from Flora Brown asks, “If the boy was gifted why could he not learn to spell and write correctly?”, which clearly indicates her perception of the word “gifted” as the ableist notion of perfect intelligence (Box 16, Folder 4). Such juxtapositions clearly reveal the different connotations emerging with the term “gifted.” Stucky notes that “learning is corporeal and material regardless of whether the body is moving in ways normatively prescribed,” (91-92), a sentiment that is shared by other Disability Studies scholars, but is also in direct conflict with the letters to Sloane complaining about the rights of normative students who might somehow be negatively impacted by disabled students sharing the same educational spaces.

Aside from the different connotations used for the word “gifted” throughout the letters, I also noticed different terms used to describe autistic students of the time based on viewer perceptions. One letter from Vicki Cluff proclaims, “It’s so sad that there are so many exceptional children who are not being allowed to work up to their full potential” (Box 16, Folder 5), which highlights the upcoming word “exceptional” used for disabled children. Yet another letter outlines both terms from an organization called “The Association for the Gifted (a Division of the Council for Exceptional Children, Department of Special Ed, University of S. Alabama)” (Box 16, Folder 8). Such separation of the two terms used to describe disabled students is intriguing—when did “gifted” and “exceptional” become separate? When did Autism transform from between these two terms?

Mrs. Benjamin Corey uses more outdated terms in her complaint that, “It seems so much money and time is spent these days on the mentally handicapped, out of proportion to the effort that is spent on the mentally advantaged” (Box 16, Folder 5). Such statements emphasize the ableist rhetorics that Disability Studies scholars have long pointed out. As McGuire notes in *War on Autism*, “as an (undesired) autistic population gets bigger, the (desired) nonautistic population is compressed. As autism demands (costly, timely) resources, those valuable resources of the whole are diminished. As autism arrives late, the whole is held back” (141). Simply having an awareness of autistic students and their non-inclusive treatment is not the same as actively including students with autism and other disabilities in a normative setting, as is the public-school arena. Such statements as Corey’s reign true in today’s culture, where disability program budgets are among the first cut in order to save the resources needed for the able.

In testament to the rise in parental advocacy, I also saw letters from parents and individuals who identify their children or themselves as “handicapped,” such as a letter from Miriam Almeleh, who explains that she has a son who is “perceptually handicapped” (Box 16, Folder 3) and testimony from Patricia Hennessey, a mother, who explains how she removed the principal from her son’s school due to ableism (Box 17, Folder 1). Such an event presents evidence of an early sign of autism advocacy and activism that play roles in the development in Autism Literacy, a rise in which is further explored in Chapter 4.

One of the last pieces of correspondence in Box 18 was a copy of a letter from Allan Sloane’s son. Sloane typed a short note connected to his son’s letter with a paper clip that says, “This is (a copy of) the letter Paul wrote after he had been told to ‘sit down, shut up, or get out.’ You can readily see that the letter was used almost verbatim. As for the fan mail – it is good to know one’s efforts are appreciated” (Folder 1). Sloane’s explanation confirms that the film is

indeed based on his son's own experiences in school; unfortunately, since the letter at hand was a copy of a handwritten letter, it was difficult to make out some of Paul's original print. I was able to decipher some key phrases, though, including:<sup>8</sup>

Your notes are suggesting that I am a rude boy and out of whack. Well as to being out of whack I am, because I think differently but to being rude I feel that you are somewhat mistaken...Now I am a loner and should learn to participate but I loath being in a group because they have a tendency to crowd me out as I disagree on things in a way that seems offensive to them, so that I have gotten checks on self-discipline respect for others and in participation...Now I am being absolutely truthly...Also, the only way I can improve is to agree to everything and I am not like that because I have the nerve to tell a person that he is wrong. I think you have been short-sighted about me making it hard for myself. The fact that I am not the the equal of anyone I am inferior to some people and superior to some and here everything is like a jig saw puzzle and anything that doesn't fit like the untoucha of India. (Box 18 Folder 1)

Paul was writing in response to his teacher and that he is expressing his frustrations about being misunderstood or accused of intentionally rude behavior. The fact that the letter, and Paul's overall experience, inspired his father write the film script also demonstrates Sloane's intent to share the story to spread an awareness of the challenges that students with autism face, which also contributed to growing narrative of disabilities in public schools.

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<sup>8</sup> This note was transcribed verbatim, including duplicate words and misspellings.

#### 4.4 Key Takeaways from the Sloane Collection

When I first read about the Allan Sloane collection, I thought I might find more personal notes about the films and other scripts he wrote, but I ended up finding a lot more evidence about the breadth of Autism Literacy practiced during the 1960s and early 1970s through letters from the viewers. Overall, there was an evolving disability rhetoric that showed a clear split between viewers who empathized and those who simply disregarded mental disabilities entirely. A few other viewers were far more literate in disabilities, given the fact that they regarded Sloane's materials as outdated, while others found the same works revolutionary. Other key takeaways from the Sloane collection are as follows:

- **Early evidence suggests a resentment in the public education system concerning students with disabilities.** Some viewers felt that public education was not doing enough for children with autism and other disabilities, which were the same complaints echoed in the Hames collection. Others complained that public schools were inherently catering more to mentally disabled students than was fair to students who did not identify with a disability, which is an issue that remains prevalent in today's public schools concerning issues of inclusion. In the political eye, the issue all boils down to money, and whether it ought to be split evenly between all students, or whether some are more "deserving" based on their own abilities.
- **"Gifted" vs "Exceptionalism" vs "Handicapped."** A number of politically-correct terminology to describe people with disabilities started to emerge, and viewers who wrote response letters to Sloane's films used these terms as methods to reveal their own Autism Literacy skills while also putting them into practice to make critiques. Instead of students with any specific disabilities in the 1960s-1970s, the letters in the Sloane archive proved

an increase in other terms, but with differing connotations. For example, the term “gifted” seemed to connote “disability,” while today we often see “gifted programs” in public schools for children who exhibit extreme *abilities* beyond the “average” child.

- **Sloane gave room for parents to start speaking out about their children with autism.**

Both McGuire and Stuckey have described the inherent need to “hide” children with disabilities from the rest of society, a movement that shifted in the late 20<sup>th</sup> century. The viewer letters submitted to Sloane are evidence of this shift, as parents were not only speaking about their own children with disabilities more openly, but others were also discussing their own advocacy actions in public schools, too. In terms of Autism Literacy, such a shift in physical space for people with autism also lends itself to increased awareness among the public at large.

- **Students with autism were stereotyped as lacking traditional literacy skills.** Like the Hames papers, Sloane demonstrates via his scripts and the correspondence letters that the traditional literacy skills of autistic children are dismissed, despite the fact that students demonstrated the opposite. Such a stereotype links back to my discussion of “gifted” above, and how terms to describe individuals with disabilities evolve in their connotations. Sloane’s portrayal of autistic intelligence also mirrors that of the parents who sued public schools, as evidenced in the Hames archive.

- **Emergence of “quiet” activism.** Sloane was certainly an advocate for his own son, and he used his platform as a writer to further Autism Literacy and activism through his films. While we can perhaps consider Sloane a renegade of the times, one question Moss and Lyons-Robinson raise is, “Does taking on the role of protector make one a sponsor?” (“Making Literacy Work,” 146). In other words, there could be doubt to the extent of

Sloane's autism activism if he did not go beyond his subtle anti-ableist suggestions in his writing. Still, I do not believe that Sloane's role as the "quiet" activist ought to discount his efforts—the fact that his work resulted in so much response from his audience and the resulting discussions about autism and disability rights is revealing and noteworthy.

Sloane included a note of his own as a personal response to a positive review of *And James Was a Very Small Snail* submitted by one of his son Paul's therapists. Sloane writes, "It was heartening to learn that the program helped to teach other children. Her phrasing—'Paul taught me a great deal that I can now use in helping other people'—beautifully sums up what I have been trying to do all these years: help people" (Box 10, Folder Five). Indeed, whether disability rights advocates agree with the type of autism awareness Sloane projected or even his positionality, I think this statement certainly attests to his original intentions.

#### **4.5 Transition to Chapter Five: A Rise in Autism Advocacy Groups**

As the American public felt more empowered to speak about disabilities in the 1960s and 1970s, quiet advocacy for children began transitioning into more organized advocacy group efforts. In the next chapter, I will discuss this emergence and the long-term implication on Autism Literacy that we still see today. Additionally, I focus on a third archival research project in a collection of materials from the beginnings of a parental advocacy group called the Autism Society of Northwest Ohio (ASNO).

While I identified Sloane as a "quiet activist" in this chapter, the documents in the archive reveal that he was wearing multiple hats: writer, advocate *and* activist. Sloane, as with many parents of children with disabilities, advocated for his son. In my own experiences, I was told early on after my own son's autism diagnosis that I was "his biggest advocate." Indeed, like

Sloane, I advocate for my individual son's needs. At the same time, though, such actions of advocacy can transcend to activism, fulfilling the needs of a bigger picture. We can advocate for our children, but once we use our writing to explore larger societal changes, we become activists. The next archive I explore at the University of Toledo demonstrates such connections and transcendence between advocacy and activism a bit more explicitly.

## 5 EMERGENCE OF AUTISM ADVOCACY AND ACTIVIST GROUPS

**Overview:** Chapter Three explored the early shifts in parental advocacy, as demonstrated with Allan Sloane, a writer who used his platform as a means to share information about autism with his nationwide audience. While I also acknowledged the inherent controversies of advocates speaking for people with autism, it is important to understand the long-term impacts that such advocates have on Autism Literacy. Such individuals have also impacted the emergence of organized autism advocacy groups, which have further impacted Autism Literacy, for better or for worse. In this chapter, I discuss the early beginnings of one such group, called the Autism Society of Northwest Ohio, as well as the controversies of modern-day groups advocating *for* people with autism, rather than *with* people with autism.

### 5.1 Parental Autism Advocacy and First-hand Experiences

Parental advocate groups, such as Autism Speaks and Talk About Curing Autism, are often on the forefront of disseminating autism knowledge to the public. Such groups also have local chapters that are run by parents who often have first-hand experiences with autism, and who attempt to provide social support for other parents. Numerous Disability Studies scholars have rightly criticized such movements for their focus on the families, and not as much on the children, such as McGuire and her observation, “the problem identified by advocacy is clear: inadequate supports for *parents and families living with autistic people*<sup>9</sup>. What is made equally clear is the necessary response of advocacy: the ensuring of more services and better access for families” (5). However, this dissertation does not attempt to justify either side of that argument—what I am instead focused on is the exchange of Autism Literacy skills, as well as the increase of the dissemination of autism information in direct correlation to parental advocacy groups. What

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<sup>9</sup> Author emphasis.

drives such parents to become autism advocates is perhaps the same reason why I first became interested in Autism Literacy skills and information: my own personal experiences. Based on the hybrid methodology that has driven this project, including narrative and ethnographic observations, I feel it is important to share a part of my own story.

In 2012, my son (who was three years old at the time) was deemed as a special-needs student because of a speech delay. He would later be diagnosed with high-functioning autism *after* being placed in an “exceptional student education” (ESE) classroom. At the time, he was observant, would listen to others, but would not speak with anyone but his parents. He could count to 100, but he could not talk about books that were read to him. My son experienced huge successes in the ESE preschool program—so much so, that he was placed in a general education (“normal” or “traditional”) kindergarten classroom. At this point, he could read well above grade level, do some writing based off books, as well as answer some comprehension questions. This changed when my son was exposed to the Accelerated Reader (AR) program. At the time, he was an avid reader (and still is), and he would converse about the books he read. I was flabbergasted when his AR reports came home every day with “zeros.” Upon discussing the matter with his teacher, she stated that my son was struggling with reading, and that AR was proof of that. While it is a common reaction for a parent to get defensive about their child’s struggles, the “researcher” in me knew that something was not right.

I offered to come in and “volunteer” for AR in the class on Fridays. I had experience during my undergraduate years in volunteering for AR for quite some time—while the visual aspects of the program had certainly changed, the basic principles had not. My son took a quiz on one of his favorite books: *The Big Honey Hunt*, by Stan and Jan Berenstain. I felt that testing on a book I knew that he understood well could help identify the disconnect between the

comprehension and reading quizzes. It turns out that there was not so much of a disconnect about the material as there was with the format of the assessment. My son simply answered all the five questions as: A, B, C, D, and then A again. Upon my discovery, I asked him if this was the way he always answered his AR quizzes, which he confirmed. In helping some of the other students, I noticed that many were also confused about the format because they were not shown in advance what taking a reading assessment in this format (and on a computer) all entailed.

At the end of his kindergarten year, my son was given a math award—though his math scores were above-average, his scores were actually higher in reading, feeding into the assumption that he was better at math because children with autism are stereotyped as such. I found this experience as direct proof that that educators inadvertently classify autistic students, while also creating their literacy histories for them. My son was classified as deficient in reading but excellent in math because this is the Autism Literacy information widely accepted by society at large. Fast-forward to fourth grade now, my son is above-average in math, but far than deficient in reading, a combination that defies that autism supposedly looks like in real life.

These experiences ultimately inspired the project at hand. Again, I am not so much concerned with whether autism contributes to illiteracy (in fact, this has been proven otherwise through Kliwer's work and other research). What my experience does provide, however, is some context with autism and leads me to pose questions within the realms of disability and literacy studies to investigate the resulting rhetoric, as well as the struggles students face within writing acquisition and the sociocultural forces that oppress them. Furthermore, my experiences and early research have thus far led me to question the rhetorical methods used by those in power (such as *Autism Speaks*) to provide literacy about autism to the public.

Feinstein also speaks to the influence of parental narratives on Autism Literacy discourse<sup>10</sup>, as well as their impacts on the establishment of autism organizations in the United Kingdom and other developed countries. Part of the drive of parents to establish advocacy groups hinged on the persistent cultural blame placed on parents (particularly mothers, who were the primary in charge of childcare) based on the misconception that autism was environmentally and socially driven. As Buchanan notes, “motherhood, like gender, is culturally specific and historically variable” (15), which is important to keep in mind as I dissect the different roles that mothers play in shaping autism advocacy, rhetorics, and literacy. A few years after Bernard Rimland, a psychologist and parent of a child with autism, published *Infantile Autism*<sup>11</sup>, Bruno Bettelheim, another American psychologist<sup>12</sup>, penned *The Empty Fortress: Infantile Autism and the Birth of Self* in 1967 as a partial rebuke to Rimland’s claims of autism as being biological in origin. Yet the arguments presented Bettelheim were not just a clinically different from Rimlands—as Feinstein notes, *The Empty Fortress* had “worldwide repercussions” (54). Part of the misconceptions Bettelheim adopted stem from his own cruel past as a Holocaust survivor, after which “he came to believe that autistic children behaved like the inmates of the Nazi camps and their mothers were like the camp commandments” (Feinstein 55). Bettelheim used this metaphor and deflected it to the mother of an autistic child, where the mother’s parenting style was supposedly to blame for an autistic person’s symptoms. Of these stereotypical features, Frith describes as, “These features, autistic aloneness, desire for sameness, and islets of ability, are still considered to hold in all true cases, despite variation in detail and despite the existence of

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<sup>10</sup> See an explanation of parental narratives in traditional text and the further impacts of non-traditional text as evident in the Allan Sloane papers, as discussed in Chapter 4.

<sup>11</sup> See more in Chapter 4.

<sup>12</sup> Interestingly, Bettelheim was also originally from Austria, just like other early researchers in autism, such as Leo Kanner and Hans Asperger.

additional problems” (6). But while Frith and other clinicians identify autistic symptoms as problematic, Bettelheim takes this a step further by claiming that mothers cause such deviance in behaviors and personality, and that such children would be best served to be separated from their parents.<sup>13</sup>

Indeed, Bettelheim went on to create a special school in the U.S. called the Orthogenic school. Bettelheim created a school in the U.S. called the Orthogenic School. Feinstein notes, “The most controversial aspect of the school, of course, was Bettelheim’s insistence that he parents, and especially their mothers, were to blame for their child’s autism and therefore that the children should be separated from their parents” (59). Furthermore, “it was a disease, Bettelheim felt, which could be cured only by separating the child from his or her parent—a process for which critics devised a telling, if rather brutal neologism, *parentectomy*” (59). Such a separation in the rhetorical context of a “school” carries past implications of institutionalization, as earlier outlined by Stucky’s work, where parents were encouraged to place their “idiot” children in asylums as a means of hiding their children but also reinforcing the tenets of “good” parenting.

## **5.2 Researching Emerging Autism Advocacy Through the Archive of the Autism Society of Northwest Ohio**

As parents began to “fight back,” as Feinstein says, many parents did so by establishing autism advocacy organizations. These were established by parents, run by parents, and had a mission of helping other parents. Feinstein explains this phenomenon:

The years of being told that they were responsible for their child’s autism began to take a toll on parents around the world. Undaunted, however, they were determined to fight

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<sup>13</sup> Feinstein also notes that “many mothers themselves underwent psychoanalysis” as a result of the culture of parental shaming Bettelheim created in the 1960s (64).

back and, from the 1960s, they started forming their own associations for the first time to protect the interests of their children and spread awareness of a condition that was becoming a target for serious scientific research by lay mired in misconceptions. (76)

The first of these organizations were established in 1962 in London, as well as a U.S.-based version in New York in 1963 (Feinstein 84, 98). Interestingly, “when the initial moves began to form a national society for autism in London, there was instant opposition from those who felt that autism should be included under a general disability and not as a separate classification” (Feinstein 84). Such organizations have grown exponentially and have changed the course of Autism Literacy into a mainstream practice that ultimately focuses on the family unit as a whole, rather than just the rights of individuals with autism.

Despite some of the controversies surrounding autism advocacy groups, they ought not be discounted for their contribution to the process of Autism Literacy: for better or worse. To understand the current state of the rhetoric surrounding Autism Literacy, I took on additional archival research project that directly involves an early autism advocacy group called the Autism Society of Northwest Ohio (ASNO). After some preliminary research, I found that ASNO was among the first formal autism advocacy organizations started by parents (not a government agency), founded in 1968. Today, ASNO serves Northwestern Ohioans as a branch of the Autism Society of America. Based on a Finding Aid provided by the University of Toledo’s Canaday Center, I was interested in looking through files related to administration, advocacy, and in-house publications (primarily magazines). Furthermore, my initial hope was to conduct a historical investigation through archival research to help me identify the rhetorical situation surrounding literacy as positioned with autistic individuals and how the attitude evolved into the stereotype of illiteracy. As Cheryl Glenn and Jessica Enoch note, “Simply rethinking the starting

point of primary and archival research enriches the histories of rhetoric and composition with possibilities for new perspectives and voices” (*Working in the Archives* 15). Therefore, I hoped the ASNO Archive could help me further ascertain the historical foundations of Autism Literacy, a term used to describe what is written about autism and how certain audiences receive this information.

I have researched finding aids for ASNO, as well as their current website, which boasts the tagline of “improving the lives of all affected by autism.” Immediately after looking at their website, I am reminded of both Anne McGuire (*War on Autism*) and Melanie Yergeau’s arguments (see her essay “Occupying Autism”) that most autism advocacy is based on “helping” families and “fixing” people with autism.

To this end, some of preliminary research questions included:

- What is the history of the rhetoric surrounding reading and writing for students with autism? How is this rhetoric presented through ASNO?
- How does ASNO speak about literacy in those who are autistic? Are there any recommendations? Is literacy promoted, or is it withheld from this group?
- What is the resulting mainstream rhetoric when other parties speak on behalf of autistic individuals and literacy?
- How does the archive demonstrate autism literacy among parents? Who has agency in terms of parenting children with autism?
- What rhetorical strategies does ASNO use to persuade parents and caregivers about literacy and autism?
- What artifacts are included in the archive? What stories do they tell?
- What assumptions are made about literacy by ASNO?

The scope of this work aims to define autism literacy from early advocacy efforts made by parents from the mid to late 20<sup>th</sup> century to reveal patterns and stories of an autism rhetoric framework. Two recent works within Disability Studies and mental health have demonstrated the recent interest in archival methods to retrieve stories for those who historically had no voice. The first is Zosha Stuckey's *A Rhetoric of Remnants*, in which she uses archival research to retrieve untold stories of individuals with mental disabilities. In her book, Stuckey investigates an "idiot" asylum established in Syracuse in the 1850s, and explores the history of special education, showing how such asylums were the early makings of this branch of public education. I also keep her argument in mind that "disability must gain a positive signification so that we stop reading history normatively" (134) and that "our challenge is to move beyond the notion of disability as deficit to arrive at people's social historicity as agents even when they do not speak or write" (134). For the ASNO materials (and my overall dissertation research), I have tried to focus on uncovering the stories and information about autism as they stand in their time, rather than singling out autistic people. Stuckey also admits "particular prejudices" about her project, though she tries "to be as fair and accurate as possible" (7), a point I have tried to carefully keep in mind as I work through materials at ASNO. As Glenn and Enoch argue in *Working in the Archives*, "the issue is not so much *why* we approach various groups of people or archival collections but *how* we work to understand and honor their perspective, their experience" (24).

The second book of interest is Jenell Johnson's *American Lobotomy: A Rhetorical History*, in which she describes the archival research process as a way of telling the stories of Americans affected by lobotomy, writing: "Archival work is embodied work. Making contact with artifacts engages the senses in a way that making contact with digital images does not, or at least not yet" (175-176). Indeed, simply looking up ASNO online would not provide the same

sensations. To that end, Johnson admits how much more personal archival work can feel, and how she was “utterly unprepared for the particular emotional impact it had on me” (176). I have already experienced such emotions during some of my earlier archival research endeavors; but rather than disregard these emotions, I think it is important to acknowledge them with the realization that my feelings are not up for exploration here. I also value Brandt and Heath’s research methods in Literacy Studies as I move forward with my broader project (the dissertation), but my own methodology influences me to talk about my positionality, and to talk about my research in narrative form without judgment—such strategies may help avoid presentism as I codify my findings while also avoiding criticism of others regarding my motives for this work.

Both the Hames and Sloane archival materials raised different questions and provided me with the practice needed to effectively conduct research with the ASNO documents. The archive for ASNO is housed in the Ward M. Canady Center for Special Collections at the University of Toledo, and the materials date back to the 1970s (a few years after the ASNO was established in 1968). The Finding Aid is quite lengthy, detailing 191 folders, and there are six total series in the ASNO collection. Based on the Finding Aid, I am most interested in Series II, Advocacy Files, and Series III, Publications (7). In Series II, Box 1, I plan on requesting the following information from the librarians at the Canaday Center: Folder 60, Autism general fact sheet, n.d.; Folder 67, BGSU students study, 2004; Folder 70, Disability data report, 2005; Folder 80, Miscellaneous school information, 2000-2002; Folder 101, Securing special education services in northwest Ohio, 1992; Folder 106, Toledo Public Schools Coalition, 2003-2007; and Folder 107, University Hospitals—Cleveland neuro-psychological study, 2002. In a perfect world, I want to look at the entirety of Series III. However, due to time constraints, I believe the

following items ought to take priority: Folder 15, Choosing/customizing education curricula, 2002; Folder 16, Early intervention, n.d.; Folder 17, Educating Asperger's Syndrome in children, 1992-2002; Folder 27, "Tips for Teachers Working with ASD," 2003.

This notion of autism literacy is evident in some of the statements from ASNO, such as the following excerpt written in 1978: "Autism is a problem understanding messages from the senses, especially sight and hearing. When messages from eyes and ears reach the brain, they are not linked into an understandable picture of the outside world" (6). I find the last phrase—the notion that people with autism cannot understand the outside world—as one emblematic example of how society understands autism today. When I traveled to Toledo in October 2017, I anticipated I would find much more ableist statements from this parent-based autism advocacy organization—however, I had to put these criticisms aside in order to focus on my primary purpose of looking for information and patterns pertaining to autism advocacy as part of a movement in Autism Literacy overall.

The first notable materials in Box One were primarily visual, which featured children's pictures compiled out of puzzle pieces, as well as a puzzle piece icon that was reminiscent of the "missing piece" that has come to represent the national Autism Speaks organization. Folders 20-29 contained copies of the ASNO "Focus" newsletters, which became thinner over the years, possibly with the rise of digitalized materials made available online. One 2002 newsletter notes, "Without planned, positive experiences, these individuals often become increasingly victimized by their autism as they age," a key sentence in "Motivating" article, which inherently describes autism as a monster, a common rhetorical measure used throughout eugenics movements.

Autism is the monster that takes hold of the victims, which then in turn poses a threat to the rest

of the family as well as the outside community.<sup>14</sup> As McGuire notes, “autism awareness is, most often, normalcy’s awareness of autism’s abnormalcy; its deviance and therefore its danger” (68).

The ASNO Archive also included copies of fliers and emails that contain “red flags” associated with autism. The language used to describe some of these red flags is interesting, especially on the weird stick-figure flyer, such as: (note: italics are my own): *inappropriate* laughing or giggling; May *not want* cuddling; may *prefer* to be alone; *inappropriate* attachments to objects; *inappropriate* response or *no response* to sound; *difficulty in interacting with others*; acts as *deaf*; *standoffish manner* (Box One, Folder 60). McGuire dedicates an entire chapter of *War on Autism* that speaks to such red flags, titled, “Raising the Red Flags of Autism: Advocacy’s Call to Arms,” where she describes how these so-called signs of autism require that “the ‘good’ advocate must ‘take a stand’ *against* autism and, next, actively work in the development of nonautism (normalcy)” (68). Indeed, if we take some of the above red flags noted in the ASNO stick-figure flyer, one might question whether such signs are really problematic. An individual who does not want cuddling due to sensory differences poses no more of a danger to his or her community than one who “acts as deaf” or prefers individual activities over group ones. Pitting a child against this sort of a checklist inherently feeds into the preference of non-disability, a position of power. After all, “the belief that the healthy body/mond is reflective of a healthy society” (McGuire 34). Of posters on autism, McGuire writes:

“Watch,” the posters tell the potential advocate, but only if you embody normalcy. For it is normalcy, the posters point out, that is endowed with the power of the qualification to see. Abnormalcy is unseeing—deviance can and must only be seen—it does not possess

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<sup>14</sup> Mary Shelley’s “monster” in the acclaimed *Frankenstein* is quoted as saying, “All men hate the wretched. How then, must I be hated, who am miserable beyond all living things!”

the qualification to dwell within the limits of the space of the see-er. Autism is not qualified to see itself. (93)

The ASNO archive included other rhetorical methods of Autism Literacy outside of traditional written form, such as calls to group gatherings to further institute autism information and awareness. Such gatherings were organized via conferences, in which the ASNO archive retains informational flyers, including the 2-Day Conference for Asperger Syndrome: Strategies for Success, held November 15-16, 2002, and the Asperger's and High-Functioning Autism Fall Conferences (Box 2). These types of conferences are indeed days-long troves of autism information that can accommodate individuals who are at different levels of Autism Literacy, but the gatherings unfortunately also become places where businesses take advantage of families who feel like they need to "cure" their children of autism.<sup>15</sup> However, I admittedly did not see a list of "sponsors" or "vendors" that I have personally seen at modern-day autism conferences, so I cannot speculate as to how the 2002 conferences in Ohio were funded.

Aside from conference fliers, Box 2 also contained several handouts that may have been passed around to both members and non-members of ASNO in an effort to increase their autism literacy. However, much of the materials focus on the supports for family members contending and living with autistic children.<sup>16</sup> One such handout was called "Parent and Family Issues: Stress and Knowledge," written by Martin A. Kozloff and John S. Rice Watson from the Watson School of Education at the University of North Carolina Wilmington and published in October 1998. The greatest focus of this handout is an awareness of the "challenges" facing families of children with autism, as perceived by the authors, as well as their insistence that knowledge can

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<sup>15</sup> In the conclusion, I briefly discuss observations made at a 2018 Talk About Curing Autism annual conference.

<sup>16</sup> ASNO's parent organization, the Autism Society, has the motto, "Improving the lives of all affected by autism."

make a difference. Kozloff and Watson also identify five “undesirable changes in some families,” as follows:

1. There is increasing strain on family resources—time, energy, finances, coping skills.
2. Many families become vulnerable to individuals and groups (and there have been many over the years) making inflated claims for explanations and treatments for autism; to service providers, sitters, neighbors, and relatives who cannot be counted on for emotional support and hands-on assistance; and to the economic system, which may or may not enable a family to remain or relocate to communities offering needed services.
3. There is increased likelihood of conflict, anxiety, and depressed mood.
4. There is interference with work and career advancement.
5. As energy is depleted, there is the development of unproductive interactions with the child with autism as other members try to stop disruptive behavior in ways that reinforce the behavior. (Box 2, Folder 25)

The authors also raise the concern of families being taken advantage of financially, but I find their statement about a lack of emotional support troubling, given the fact that the majority of this list of undesirable effects of having a child with autism targets parents’ emotions. Statements, such as an increased likelihood of fatigue, anxiety, and lack of career advancements are anything but comforting. Furthermore, Kozloff and Watson have unfairly associated these “undesirable” effects with autistics, when in fact much of these “changes” could very well be experienced with children who adhere to the “normal” traits that society expects of them.

Aside from popular sources, the ASNO archive also included copies of expert or scholarly articles related to autism, all of which emphasize the important of taking action during young child development and the role of early intervention. Two example titles include “Advice

for Parents of Young Autistic Children” (2004) and “Fragile Success: Nine Autistic Children, Childhood to Adulthood” (1995) (Box 2, Folders 8-10). However, most of the educational materials consisted of popular literature, authored by a mix of experts with direct experience, such as parents, or those in the medical and educational fields. The archive included press releases for book titles, such as Mary Thompson’s picture book *Andy and His Yellow Frisbee* and a “book for caregivers” by former First Lady Rosalynn Carter and Susan K. Golant called *Helping Yourself Help Others*. Another example is Betty Manning’s *How to Be a Successful Advocate for Your ‘Special Needs’ Child or Anyone*, which was also written by a member of another Autism Society of America member based out of the organization’s North Virginia chapter (Box 2, Folder 13). Another book published by the National Society for Children and Adults with Autism: *How They Grow: A Handbook for Parents of Young Children with Autism* (published in 1981): Chapter 1, “So My Child is Different, What Does That Mean For My Life?”; Chapter 2, “Taking Charge”; Chapter 3, “Helping Myself”; and Chapter 4, “Getting Together,” which includes sections on how to become an advocate and to learn the laws pertaining to disability rights.

Chapter 3 was especially telling, and here are some of the phrases that stood out to me:

- “Unless one has lived with an autistic child, one cannot possibly know what it is like. Parents describe it in many ways: painful, time-consuming, disruptive, disappointing, traumatic, sad, but also deeply rewarding. If you have given an afflicted human being everything you have and make some progress, it is deeply rewarding...All parents want a normal healthy baby, and a serious, lifelong handicap is hard to accept—particularly if the baby looks normal and healthy as most autistic children do...Once the family has

dealt with its grief, it usually adjusts and learns to live with the realities of a severe handicap” (Section “Helping Yourself,” pgs. 31-32). (Box 2, Folder 20)

- “The commitments of time and energy demanded by an autistic child understandably impose severe strains on a family. Parents need to get away and spend time together. Brothers and sisters may have difficulty at first in understanding why their parents are forced to provide one child with so much attention. They may not like to bring their friends home because of their autistic sibling, or they may be angry at him for breaking or damaging their toys. There is a positive side to this, however. It is very good for normal children to learn that the less fortunate must be cared for and that the needs of other people can be more urgent than their own” (Section “An Around-the-Clock Job,” pgs. 33-34). (Box 2, Folder 20)

A copy of a chapter of a book: Chapter 7: “Disability Awareness,” September 6, 2006 describes the importance of advocacy:

Advocacy is essential to ensure that all children with Autism Spectrum Disorder have the opportunity to achieve their fullest potential. As important as professionals have been in furthering our knowledge of the needs of individuals with ASD, parents and family members have been critical in their role of informing professional (sic) and the larger community about the needs of their family members. As parents we must educate professionals, policy makers, and the larger community about all our children’s needs to help create school and communities where they can be successful” (pg. 1). (Box One, Folder 93).

I found that this definition tied into ASNO’s motto: The Autism Society of Northwest Ohio’s motto: “Providing support, education, and advocacy. “Another Chapter in the same book

outlines some of the feelings parents might have because they “grieve the loss of the ‘typical’ child that they expected to have.” Some of the feelings include: “shock or denial; anger; guilt; rejection; confusion; fear; confusion; fear; isolation; envy; relief” (pg. 1) (Box One, Folder 93).

### **5.3 Why Advocacy Groups Are Deemed Problematic**

Parental advocates certainly do what they think is best for their children. One of the issues with advocacy groups, though, is the theory of parents as experts—including autism diagnoses and treatments. Barton writes of traditional literacy being viewed, saying that “until recently it was a common view that parents should not be involved in their child’s education, and that helping a pre-school child with reading and writing was harmful” (162). This theory positions the teacher as the all-knowing power that is in control of a child’s reading and writing acquisition. However, this mode of thinking downplays the roles of reading and writing children learn outside of school, even at a young age. Barton concedes that the idea of “imposing literacy” is still an issue in “both developing countries and in industrialized countries” where acquisition is not based on “people’s own perceptions of their needs” (191). He recommends that “if teachers value marginalized literacies and literacy practices outside the educational domain, they will understand more about those children who reject school literacy” (207). Of course, today teachers encourage reading and writing at home to help prepare children for kindergarten, but to also help complement the skills they learn throughout school. Still, there continues to be a pushback by many parents who hold onto the old idea that literacy acquisition is solely the teacher’s responsibility. Barton’s concept of “imposing literacy” could very well be applied to autism advocacy groups and individuals. Of course, a lot of this depends on the information that is being exchanged, as well as through what means. An existing website of autism information may not necessarily be considered “imposing” if one were to go out of their way to find it.

However, as more advocacy groups become activists in the sociopolitical sphere, we see examples of imposing literacies through a context of assumption that parents who have children with autism want a cure and normalization.

We can also see connections between autism advocate groups as oppressors versus the rest of the “illiterate” public through Pablo Freire’s framework that he outlines in *Pedagogy of the Oppressed*. Freire moves on to discussion of education and how it further emphasizes oppression. This is largely based on a typical position in which the teacher is assumed as all-knowing and relays a narrative in which the student is expected to take in and memorize without questioning if the information is indeed reality. Freire argues that “education is suffering from narration sickness” (71), where “the students are the depositories and the teacher is the depositor” (72). The students are not taught real-world critical thinking skills that could act as both a quality source of education, as well as a means to overcome oppression. While Freire does concede that many teachers “unknowingly” contribute to the problem, he recommends that overcoming the depository-depositor relationship in education requires that teachers “be partners of the students in their relations with them” while also helping them “engage in critical thinking and the quest for mutual humanization” (75). This will help combat the oppressive results of the “banking concept of education” (77).

The mainstream concept of literacy as a necessity for success in industrialized societies bears similar markings of the “banking” theory Freire poses in education. Students are expected to learn sets of literacy skills, and at an idealized rate of speed. It is not common that students would even question *why* they need these skills, or why their own stories of literacy do not fit into society’s expectations of what being literate means. It would have been interesting if Freire delved into various aspects of education, such as reading and writing, by applying his depositor-

depository relationship. Barton refers to this application in *Literacy: An Introduction to the Ecology of Written Language*, where he writes that Paulo Freire's banking concept may be likened to "empty people" being "filled up with literacy" (Barton 12).

Freire moves forward with a discussion in dialogics, and how this can help transform the bank of education into an institutional mode of freedom. Freire says that oppression cannot be overcome unless the oppressors help liberate the oppressed right with them, rather than for them. He writes of the oppressors and depositors: "They forget that their fundamental objective is to fight alongside the people for the recovery of the people's stolen humanity; not to 'win the people over' to their side. Such a phrase does not belong in the vocabulary of revolutionary leaders, but in that of the oppressor. The revolutionary's role is to liberate, and be liberated, with the people—not to win them over" (95). Silence certainly exacerbates the problem, inasmuch as separatist liberation. Here, Freire advocates for a methodology in which the oppressed and oppressors "act as *co-investigators*" (106). Only then can reality be achieved.

In terms of literacy studies, we can gain some important lessons from Freire's observations and discussions in combatting long-held beliefs that literacy is based on single events. His point that "liberating actions upon an historical milieu must correspond not only to the generative themes but to the way in which these themes are perceived" (102). It is not enough to study historical facts about past social liberations, or literacy events. Instead, it is important to learn about the subsequent consequences and attitudes that such events are a part of as a continuous stream.

#### 5.4 Key Takeaways from the ASNO Archive

Based on my findings from the ASNO Archive, I have the following key takeaways:

- **Advocacy groups paved the way for mainstream Autism Literacy exchanges.** While autism was not necessarily a new concept, literacy about the disability were likely exchanged between medical professional and parent only. The rise of parental advocacy groups such as ASNO places the *ethos* of so-called autism “experts” on those with direct experience—the parents themselves. In this collection, the archival materials presented a trove of information related to Autism Literacy, including handouts on basic autism “facts” that ASNO felt was important for their audiences to know, as well resources.
- **Parental grief was an underlying theme throughout.** Aside from facts that ASNO wanted to share with others, the archive also contained materials that highlight parental grief about autism, which inherently proves the points made by McGuire and Yergeau about autism being perceived as something to be ashamed of. Furthermore, it seems that the idea of grief about having a child with autism was a state of mind that was expected. Such attitudes about autism remain relevant to this day, where the focus of a cure is advocated more than acceptance.
- **At the same time, the archival materials did not include discussions about a “cure” for autism.** As modern-day autism advocacy groups, such as Autism Speaks focus on finding cures for autism, there was not evidence of such a focus within ASNO. Again, the materials included information from the 1980s through the early 2000s, so it seems that autism awareness was more of a priority than trying to find a cure for the disability. Now that Autism Literacy has since become more widespread, the public obsession with “finding a cure” has taken the place of awareness and inclusion.

- **The ASNO materials assume that autistic parents are already advocates.**

Concurrently, we can see a push to transform parents into activists, too. Such a transference of power can unfortunately have its downsides, too, where parents who started out with good intentions in creating more inclusive spaces for their children sometimes inadvertently create more spaces of ableism with their wishes to effectively “erase” or “cure” autism. I am reminded of Lindal Buchanan’s descriptions of mothers as “God” or “Devil,” and I wonder if autistic parents could inherently be a little bit of both in such contexts. In *Rhetorics of Motherhood*, Buchanan writes that women are either placed in “Woman (Devil)” terms, or “Mother (God)” terms. She argues:

The mother, I maintain, operates as a god term within public discourse and connotes a myriad of positive associations, including children, love, protection, home, nourishment, altruism, morality, religion, self-sacrifice, strength, the reproductive body, the private sphere, and the nation. Meanwhile, its corresponding devil term, Woman, invokes negative attributes, such as childlessness, self-centeredness, work, materialism, hysteria, irrationality, the sensual/sexual body, and the public sphere. (8)

Could it be then, that the autism activist mothers we often criticize in Disability Studies are inherently *expected* to play such roles?

- **ASNO became involved with making public schools in the Toledo area more inclusive.** Throughout this archive, I found lists and letters to school board members in the greater Toledo area, made on behalf of parents fighting for more inclusive spaces in public schools. The push for public school inclusion reminded me of information I found

in both the Hames and Sloane archives, where a lack of resources for students with disabilities was highlighted as a problem in the 1960s and 1970s. Such efforts made for inclusion were drastically different than trends seen today, where more parents who have children with autism are looking for other alternatives, including private schooling, home-schooling, and specialized programs found outside of the public-school system.

As I left the University of Toledo's Canaday Center, I also mulled over the ASNO Archive's provenance. The Finding Aid clearly states that the materials were a gift from the Autism Society of Northwest Ohio, but does not say why, which is often the case in an archival finding aid. Thus far, the most logical explanation I can make based on the materials is that ASNO wanted to continue the process of Autism Literacy with their handouts, fliers, and meeting minutes, even if some of the information was outdated.

The ASNO archive also brings attention to the inherent problems associated with advocacy. Indeed, many parent-scholars write about their experiences in an effort to help their children while also attempting to make changes in society. I am reminded of Paul Heilker's work in autism rhetorics, which was partly inspired by his own son, as well as the mothers who contributed their own scholarly essays in Cynthia Lewiecki-Wilson and Jen Cellio's collection, *Disability and Mothering: Liminal Spaces of Embodied Knowledge*. Their work cannot be condemned as ableist. As McGuire herself admits, "Rather than rejecting the work of autism advocacy full-stop, I am instead writing an appeal to all who advocate (including myself). Advocacy—a mode of relating that is absolutely and unavoidably premised on uneven power relations—is never simple, certain, nor self-evident" (224). Rather than avoiding the process of advocacy entirely, it is important to keep such power relations in check, especially for those who advocate for children, who are already beholden to adults due to their age.

## **5.5 Summary of Archival Research/Transition to Conclusion Section**

Autism Literacy itself is not a new phenomenon; while there's been an influx of awareness since the digital era, people have been exchanging autism literacies for decades. The ASNO Archive included direct Autism Literacy practices between an author (in this case, ASNO), as well as a particular audience (both members and non-members of the organization). While this archival research project is that last one I am highlighting for this project, I certainly know that not all of my Autism Literacy questions have been satisfied, nor do I expect my research to end there. As with the Hames and Sloane collections, I regard the materials in the ASNO collection as an opportunity to learn new stories about the history of autism rhetorics and literacy, and how to fit all the stories together in a growing conversation about how Autism Literacy came to be. While a broader study of disabilities and literacy might also be of interest, such a large project goes beyond the scope of finding historical evidence of early autism literacy for my dissertation.

## 6 FUTURE IMPLICATIONS AND DIRECTIONS OF AUTISM LITERACY

In October 2017, I visited the online archives of the Georgia Department of Education's "Special Education" department and found something new: a red box telling me that the site was no longer being updated. While users are redirected to another webpage that outlines the basic definitions and signs of autism, the archives that held old meeting minutes and documents are no longer there. Such examples are important in assessing potential impacts of Autism Literacy acquisition for groups and individuals, whether such exchanges of information are intentional or unintentional. As funding and societal attitudes fluctuate, I suspect we will see more examples of withheld autism and disabilities information. The potential impacts on Autism Literacy remain to be seen, though the digital age has also brought about other modes of literacy, as well as opportunities for scholarly research.

Research surrounding the concept of Autism Literacy certainly doesn't end in the archives, nor does it end with this project more generally. As Connors notes, "When external and internal criticism have been brought forcibly to an end—and it is nearly always necessary to bring the research period to an end forcibly, since by its nature research is never 'done'..." (58). To that end, as my own project (the dissertation) is coming to a close, I also feel that it is necessary to lay out a framework for future projects and possible research methods. First, future research through surveys and interviews with parents, as well as autism "experts" and advocates could yield further answers to more in-depth questions about Autism Literacy, such as whether or not advocacy is congruent with eugenics. Digital research into Autism Literacy are also worth researching. Autism Literacy via the Web is in full swing, and it is important to see how major organizations update and relay this information as a contributor to public literacy. My hope is

that we will gain further perspective as to what the sociocultural visions are for the future of autism.

Nevertheless, I consider this dissertation to perhaps become a building block for exploring Autism Literacy at a national level and with other research methods. This leaves the door open for myself, and perhaps other scholars, to replicate my methods. A longitudinal research may be useful in exploring this topic on a national level for another project—perhaps this dissertation will build my *ethos* so I can secure funding for such a long-term effort. (Here I am reminded of Brandt’s ten-years’ worth of primary research in Wisconsin that led to her book *Literacy in American Lives*.) Connors writes, “What’s the lesson here? Not, certainly, that all received wisdom is wrong, but that all received wisdom is partial, incomplete. It must be examined again and again, not merely accepted. That, finally, is why there are, and why we need, multiple histories” (61). Indeed, Autism Literacy is a term I hope to coin, not just for the sake of a dissertation, but so that the concept can be researched over and over, in new contexts, and with other research methods in order to build a full historiography worth building upon for years to come.

Finally, this project serves as my own form of autism advocacy during a climate where populists are feeling emboldened to bully people with autism online, cut funding for important programs, and focus on an agenda imbued with eugenics. Even if autism information is removed from public archives in the future, as is the case with the Georgia Department of Education, I feel better knowing that my work is still out there as a buffer. I am also going to launch a website dedicated to Autism Literacy, as well as a possible course to further engage the public on the subject.<sup>17</sup>

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<sup>17</sup> See [www.autismliteracy.org](http://www.autismliteracy.org), which is currently under construction.

Before I delve in further to explore the possible future implications and directions of the project at hand, it is first important to recap how this current project has shaped and provided credence to Autism Literacy. Before embarking on this project, I wanted to know more about autism rhetorics and the forces that shape how people exchange information about this disability that is ever-growing as a “trendy” subject among a large fraction of the public who view autism as a threat to the desired state of normalcy. Like many others who venture into Disability Studies, this research area interested me based on my own experiences with invisible disabilities, as well as those of my son who was labeled as autistic at the age of four. In a world that often discredits personal experiences, I have felt it necessary to disclose some of what I have experienced with autism, not for my own satisfaction, but to provide my audience with an honest disclosure about my methodology. Such insights cannot be provided by a researcher without the types of personal experiences I offer. I have no further motives, with the exception of making the world a less ableist, and more empathetic place for my son and his peers to grow up in.

So, to answer my own research inquiries, I relied on a hybrid methodology that focused on narrative experiences, as well as primary research via archival materials. I started with the Margie Pitts Hames papers, which included personal notes and copies of case files the late Atlanta-based attorney likely used to provide a framework for her own arguments on behalf of clients with disabilities. The problem is that there are over eighty boxes of sealed files with personal information that is not yet available to the public, so I can only hypothesize on why Hames had these files, and how exactly she used the information. Still, beyond the context of the information at hand in this archive, I was able to identify evidence of Autism Literacy that existed between parents and schools, advocacy groups and courts, and even between Hames and her friend, Alan Abeson.

Based on the Autism Literacy information I had on hand, I wanted to learn more about the types of information exchanged about autism in the mid-20<sup>th</sup> century, as well as the contexts behind them. Such inquiries led me to the Allan Sloane papers, which contained notes, transcripts, stories, and public reviews on behalf of the late writers. The archive proved to offer a wealth of examples of Autism Literacy practices and exchanges, particularly in the case of the fain mail (as well as the critics) for Sloane's made-for-television movies about children with autism. I also learned that Sloane himself was a father of a son with autism, which further made me wonder about the complicated lines we walk between parents and advocates for our children, and how such lines can inadvertently detour and create negative consequences, such as the case of modern-day advocacy organizations that focus on erasing autism, rather than creating more inclusive spaces in a traditionally ableist society.

Thus, my research on Sloane as an individual advocating for autistics led me to an archive of papers from a current autism advocacy group: the Autism Society of Northwest Ohio. Much of the materials included informational reports, essays, and organizational advertisements created in 1990s and early 21<sup>st</sup> century. While the eugenics-like rhetorics were not surprising, it is worth noting the shift from inclusive spaces for children with autism argued for in both the Hames and Sloane collections, to the focus on alleviating pain and troubles families allegedly face when they have children with autism, as seen in the ASNO collection. Such attitudes remain, with the outright declaration of eliminating autism and "solving the puzzle."

There is no doubt that I regarded some of the rhetorics throughout the three archives as offensive, and sometimes even repulsive. Such emotional responses were even more challenging to control given my connections with having a son with autism, but I had to keep the concept of presentism in mind so that I could do my best to objectively "listen" to what the documents told

me about the attitudes and perceptions of autism from decades ago. In turn, I did not find it constructive to pass judgment on parents and other advocates who perhaps did not know any better given the time, circumstances, and expectations they faced. I did my best to define and interpret Autism Literacy based on such contexts in which the documents were written. From what we know about ableist rhetorics today, it is unfair to judge advocates from the late 1960s who may have just wanted to help their children, just as I might be judged for writing a dissertation that I hope will contribute to my scholarly community while also helping my son and the public at large in some way.

### **6.1 Proposed Future Directions for Autism Literacy Research**

The primary goal of this dissertation was to define and explore Autism Literacy, but I also argue for future discourse for further development. Below, I have identified five possible research opportunities that I hope will help extend the conversation surrounding Autism Literacy:

- **Detailed analyses on individual autism advocacy groups.** The Autism Society of Northwest Ohio is just one autism advocacy group existing in the United States, and it is also a local chapter of the broader national group called the Autism Society [of America]. A detailed rhetorical analysis of advocacy groups and their modern-day Autism Literacy practices may provide opportunities for better understanding the means of literacy exchanges, as well as their target audiences. Such a project would not aim to criticize or attack individual autism advocacy groups, but would instead be a stepping stone for building a future framework that other scholars could also perhaps use as means of conducting rhetorical analyses on advocacy groups of this kind to better understand their literacy practices.

- **Autism Literacy in specific regions.** The archival works I researched for my project include materials from a variety of regions. Per the Hames collection, while her own materials are from Atlanta, Georgia, some of the court case copies she held on to included those from Rhode Island, Pennsylvania, Michigan, and other areas in the Midwestern United States. The Autism Society of Northwest Ohio's materials were based from its headquarters in Toledo, Ohio. Perhaps the most far-reaching archive was that of Allan Sloane's papers, since the written correspondence from film viewers was nationwide. I envision future research opportunities that focus on regional aspects of Autism Literacy – such an undertaking could also trace patterns in agency and strategy.
- **Analyses on self-advocacy groups.** Just as parental advocacy groups were formed, according to Feinstein, as a response to Bruno Bettelheim's fierce criticism of parents for creating the "disease" of autism (59), self-advocacy groups were formed as a method of usurping the consequences traditional parent-run advocacy groups posed to disability discourse. The most notable is the Autism Self Advocacy Network, which goes by the inclusive slogan of "Nothing About Us Without Us," which is notably active in policy change and government affairs. According to their website, the overall mission of the Autism Self Advocacy Network is "to advance civil rights, support self-advocacy in all its forms, and improve public perceptions of autism." It is worth investigating the organization's own Autism Literacy practices and how they differ from that of a traditional autism advocacy group, beyond the difference in the need to "cure autism," which is often a rhetorical strategy advocated for by the latter type of group.
- **Rhetorics of autism cures.** Autism organizations have rightly taken heat for advocating for "cures" for autism, but the rhetorical premise still remains with the promotion of

“treatments” that aim to normalize autistics. The concept of Autism Literacy may be applied to the very vendors, businesses, and service providers who prey on families, promising that they can transform their children into the “normal” individuals that society demands them to be. Even Frith has her own reservations about this process, writing, “Rationality does not always prevail, and hope is powerful. Each new treatment success story feeds the hopes of parents who want nothing less than a complete cure” (Frith 31). The specific information used by such treatment advocates may be worth investigating in the broader context of Autism Literacy to help understand how this affects the understanding of autism as both a disability and an undesirable societal trait<sup>18</sup>. While still ableist in her use of language, Frith also notes the difference between autism and other disabilities, writing, “In other diseases a change in attitude has often occurred when a cause became known. Parents of children with Down syndrome now know that the cause is a particular chromosome abnormality, and are accepting of the lifelong nature of the condition. They are less likely to be preyed upon by charlatans who advertise cures” (Frith 76).

- **Intersections of feminism and advocacy rhetorics.** The intersections between feminisms and autism rights have been explored to some extent. For example, Kristin Bumiller wrote in 2008 how “some of its most notable proponents are female, and their writing focuses on a wide range of issues, including gender, sexuality, and mothering” (968). Now a decade later, we are seeing numerous other opportunities for an exploration of issues between the intersections of autism advocacy and feminism. On the flipside, we also see an anti-feminist rhetorics where mothers with children with autism are blamed

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<sup>18</sup> Brendan Borrell also discusses the financial implications that underscore the desperation of curing autism in his article for *Spectrum News* titled, “A ‘cure’ for autism at any cost,” September 2017.

for their “mistakes,” which is reminiscent of Bettelheim’s criticisms from the 1960s. Surprisingly, some women were satisfied with the fact that they could somehow be to blame for autism, though. Feinstein explains his findings in an interview with the Italian president of the Autism-Europe organization “that many Italian mothers were happy to embrace the notion that they could somehow be to blame for their child’s autism because it gave them hope that, by changing, they could improve the child’s condition, whereas in contrast, if it were a genetic or neurological disorder, there was far less hope” (64). We too often assume a parent’s positionality in relation to autism advocacy, particularly the mother’s, and this is an intersection that could be worth researching via focus groups, surveys, and interview in the future.

- **Literacy as applied to other disabilities.** Earlier in this project, I defined Autism Literacy as the methods, practice, and exchanges of information that are used to inform a particular audience about autism. Through my investigations into three separate archives, I found several of these methods to include traditional text, written letters, legal cases, personal notes, televisions scripts, handouts, and advertisements. However, these methods are certainly not an exhaustive list. Furthermore, I also encourage the use of this framework behind Autism Literacy to be used as a way to study other disabilities in this manner, not by means of singling out any particular disability, but in order to understand how information is gathered, argued, and shared.

In the final chapter of his work, *Pedagogy of the Oppressed*, Freire writes that “human activity consists of action and reflection: it is praxis it is transformation of the world...it is reflection and action” (125). A revolution in which the oppressed are liberated takes work from both sides and act “together in unshakable solidarity” (129). Without such

agreement, the oppressors reassert their roles, while the oppressed stay in their state, too. Freire admits that these notions sound naïve, but argues, “there is nothing, however, more real more concrete than people in the world and with the world, than humans with other humans—and some people against others, as oppressing and oppressed classes” (129). Cooperation and unity are crucial, according to Freire, in overcoming oppression and synthesizing freedom for all. I firmly believe that studying the literacies of disability can help change the power dynamics between the normative cultures that tend to write our literacies for us.

To that end, I am also proposing two new projects in the near future that will help build the conversations of Autism Literacy: Central State Hospital and Bittersweet Farms. Central State Hospital, located in the previous capital city of Milledgeville in Georgia, was a notorious asylum for the mentally ill. First opened in Milledgeville in 1842 as the “State Lunatic Asylum,” Central State Hospital was “Georgia’s first public psychiatric hospital,” according to the Georgia Department of Behavioral Health and Developmental Disabilities. Today, the hospital operates in a completely different campus and also with different intentions—rather than the asylum it once was, Central State now offers “psychiatric evaluation, treatment and recovery services for persons referred from various components of the state’s criminal justice and corrections systems, and staff-supervised residential homes” (1).

The original Central State Hospital, however, has a notorious reputation in the state of Georgia, much like other asylums of its kind do (see Stuckey). While the original campus once had a museum and public tours, these are now closed and available only as private tours, in which you have to call ahead and schedule. On top of my wish to visit the campus and conduct ethnographical research, I will also visit the Georgia Archives to access materials directly and

indirectly related to the hospital. Just among some of the records include those from the Governor's office, the Department of Education, and the Department of Family and Children Services, along with a slew of Public Health records related to admissions and management (Georgia Archives). Additionally, the Georgia Archives has recently released several digital documents and photos related to Central State Hospital that could aid my research.

Bittersweet Farms is a home in Northwest Ohio for adults with autism. During my archival research of the ASNO papers at the University of Toledo, I also looked through archival documents associated with Bittersweet Farms, which primarily consisted of personal journals from previous residents. Founded by Bettye Ruth Kay, a teacher of the first public school classes for autistic children in Toledo, Bittersweet Farms opened in 1983 in response to Kay's concern over the "long term care of her students." According to the Finding Aid from the Canaday Center, "At that time, the vast majority of autistics were placed in state institutions once they passed through the public school system. Many of these institutions were intended for either mentally retarded or mentally disturbed individuals, and did nothing to address the specific needs of the autistic" (3). Brooks Farms continues to serve autistic adults to this day, as I observed during a short visit to the home upon the completion of my archival research at the University of Toledo.

I chose not to use any of the archival information pertaining to Bittersweet Farms for the project at hand, partly because of a confidentiality agreement I signed that promises I will not use any of the names of those mentioned in the collection. While I could certainly analyze some of the journals anonymously, I have some reservations about doing so until I have gathered more secondary research about Bittersweet Farms and conducted interviews with employees first for context. Given the fact that the home is designed to serve the needs of autistic adults who might

otherwise be institutionalized, I do see grounds for further research but have not yet made connections between the residence and the concept of Autism Literacy as I have with the other three projects I have outlined via the Hames, Sloane, and ASNO collections. I plan on revisiting Bittersweet Farms in the future, both literally and figuratively, to see if I can build upon these connections to further propel our understanding of Autism Literacy. Until then, I have plans to visit Central State Hospital in Milledgeville, Georgia, as well as accessing newly released archival materials from the now-closed asylum.

## **6.2 Archival Research Implications**

In this dissertation, I completely outline the archival research process, which may be helpful for up-and-coming archival researchers, as well as instructors who are interested in using primary research methods in their own composition classrooms. From my experiences in teaching first-year writing courses, I find primary research projects to be of most interest to my students, but the thought of using their own research instead of relying on secondary information can be daunting at first. I argue that, as instructors, it is important for our students to reflect on the information they find in a narrative form so that they can more effectively build connections between themselves and the subject at hand, as well as within the information they uncover. My hope is that other archival researchers and instructors can perhaps use the three archival endeavors I have outlined as models for getting started. Throughout each of the archival research projects, I also maintained an honesty about managing my own emotional responses and prejudices. Such a composure is key to successful research in the archives—a prejudice about an archive or its original author(s) will set the researcher up for failure because they will not be able to postulate the contexts surrounding the materials.

As of 2018, there are few archival works researched and published at the intersection of Disability Studies. I hope my own project can add to such a growing need for more archival research in Disability Studies, and to perhaps inspire other Disability Studies scholars to explore these research methods. Additionally, the project at hand could influence other areas of archival research outside of Disability Studies, including activist rhetorics, historiography, and familial projects. As outlined in my own project, archival research methods are not clear-cut, and they require scholars to enter boxes and files with an open mind, and with the understanding that, more often than not, an archive is not at all what is initially anticipated, despite reading through the accompanying finding aid.

### **6.3 Pedagogical Implications**

Aside from research opportunities, the study of Autism Literacy also carries large pedagogical implications. I have thus created a course in Autism Literacy, which welcomes an interdisciplinary student body. The proposed course, aptly titled “Autism Literacy,” is an upper-level, interdisciplinary special topics course that asks students to critically interpret and engage in the rhetorical histories of autism, reading, and writing. Literacy Studies scholar Harvey Graff argues, “Literacy studies, an interdisciplinary studies, can be better understood with more attention to a longer chronological span of intellectual and sociocultural development and a broader, more dynamic focus on its place and play among a wide array of disciplines and locations” (210). To that end, my proposed course in Autism Literacy was written for a home within the English Department to appeal to students interested in Disability and/or Literacy Studies within a Rhetoric and Composition framework, but it is also suitable for students in other disciplines, such as special education, psychology, and writing instruction.

At the same time, this is not a course for clinical discussions about autism, but rather a social one based on rhetorical history. Disability Studies scholar Ella Browning has further argued for disabilities curricula in the composition classroom as it can potentially offer “opportunities for undergraduate composition students to consider, explore, and articulate nonnormative embodied experiences in meaningful ways, even within a standardized composition curriculum” (98). While my proposed course is written for an upper-level student body in mind, the foundations could very well be adapted by composition instructors for lower-level classes. Also, based on the definition of disability as a “product of social injustice” that Siebers outlines (3), this Autism Literacy explores intersections between the rise in autism and industrialization-backed literacy, two entities that remain prevalent in Western society today.

The course is broken down in seven major units:

- What is Autism Literacy?
- History of Literacy: A Sociocultural Phenomenon
- History of Autism
- Writing About Autism
- Autism and Writing Instruction
- New Media and Autism
- The Future of Autism Literacy

We start with learning about literacy, which is defined as everyday reading and writing *practices*, and not skillsets. Throughout the course, though, we will compare the rhetorics of skills-based literacy in autistic individuals and discuss who has rhetorical agency. We then turn to a rhetorical history of autism and disabilities discourse before we look at examples of written work about autism, including how the definitions of autism have evolved over time. Mitzi Waltz

writes how “the process of naming and defining a condition to attach specific meanings to it that can go beyond its actual impact on the affected person” (50), while Jenell Johnson notes that, “Definitions, as rhetoricians have argued for millennia, involve much more than correct or incorrect usage” (147). In her article “Clinically Significant Disturbance: On Theorists Who Theorize Theory of Mind,” Melanie Yergeau writes, “My argument here is that denying autistic selfhood and denying autistic corporeality and denying rhetoricity reifies systemic abuse and ableism” (15). Kliewer and Biklen bring up an end goal that I agree with (though they come from education studies). They write: “Definitions associated with severe intellectual disability often preclude the possibility of the person so labeled from effectively using symbolic tools for complex interaction... We must shed the use of the label all together” (12). Next, we discuss the creation of inclusive writing environments for *all* students without singling out students with autism or any other disability while also discussing the ableist expectations often put forth through remedial writing instruction. Examples include one of the intended supplemental readings required for the course, in which the authors assert, “The interventions provided for students with ASD historically have focused on reducing challenging behavior and improving communication, rather than treatments designed to enhance academic performance” and that “Reading is a complex skill that is influenced by cognitive processes, linguistic abilities, and relevant knowledge” (El Zein et al. 1303). Last, we will spend the last remaining weeks discussing how autism is represented in New Media and how it shapes current and future sociocultural perceptions of autism.

I chose to write Autism Literacy as a special topics course instead of a themed composition course because of my personal hesitations about teaching Disability Studies-themed first-year writing classes. Although Ella Browning has taught such a themed course in her

Composition II classes, she too admits how “although attention to disability is becoming more apparent in first-year composition curricula, too often disability is simply ‘tacked on’ to existing courses” (96). Indeed, I feel that such a specialized course as Autism Literacy will serve students better within a special topics curriculum to benefit students of multiple interests across disciplines. Furthermore, this is an upper-level course that requires basic knowledge of rhetorical concepts—while we may review such concepts throughout the semester, it is assumed that students will already have moderate to advanced understanding of such terms from general studies coursework, such as composition classes.

I would require six textbooks for the proposed Autism Literacy course. The first required text is David Barton’s *Literacy: An Introduction to the Ecology of Written Language*. Written in 2007, this is the most comprehensive text in literacy studies I have come across that also reflects the New Literacy movement. Barton also explores the various concepts, definitions, and misconceptions surrounding literacy, while also emphasizing linguistics as a large influence on literacy practices in everyday life (3-4). Throughout his chapters, Barton emphasizes the social contexts surrounding various reading and writing practices, rather than just the practices themselves (24-25), which is essential to our discussions of autism and literacy.

Two of the required textbooks, Mitzi Waltz’s *Autism: A Social and Medical History* and Anne McGuire’s *War on Autism: On the Cultural Logic of Normative Violence* provide context for our discussion of Autism Rhetorics. Waltz explores the evolution of autism in society, and discusses how the clinical definitions of autism have subsequently dominated sociocultural attitudes about autism. McGuire’s work, on the other hand, analyzes the rhetorics of autism *advocacy* and the dangers of trying to “fix” people with autism. We explore this work alongside Margaret Price’s *Mad at School: Rhetorics of Disability and Academic Life*, which primarily

discusses “activism and theory of disability studies to argue for changes to the ways that academic discourse is understood, taught, written, and evaluated” (7).

The final two required texts discuss writing pedagogy: Cynthia Lewiecki-Wilson and Brenda Jo Brueggeman’s edited collection *Disability and the Teaching of Writing: A Critical Sourcebook* and another edited collection specifically geared towards discussions of autistic students called *Autism Spectrum Disorders in the Composition Classroom*, by Val Gerstle and Lynda Walsh. Both discuss ways English instructors can make their classrooms more inclusive spaces, which I consider essential keepsakes for anyone wanting to teach writing to students with disabilities. At the same time, my intention is to encourage students to think about how they are acquiring and using their Autism Literacy skills throughout the process, too.

Disability Studies is a growing specialty within Rhetoric and Composition, and instructors are following suit by creating disability rhetoric courses. Such course designs not only fills a niche for instructors seeking to teach their interests and perhaps invest in the Scholarship of Teaching and Learning, but “disabilities studies encourages students to question normative social systems, making it an ideal theory to challenge the normal context of school writing,” according to Jay Dolmage (275). Elisabeth Miller also posits Disability Studies as an important aspects of writing studies because of “its commitment to articulating the interdependence of the social and the material aspects of lived experience” (36). Still, I contend that we need to go beyond discussing disability rhetorics in our composition classes. Aside from Browning’s first-year writing themed course, other notable Disability Studies scholars have written special topics courses, including Margaret Price and Melanie Yergeau. For example, Price wrote and taught a course called “Writing and Depression” (*Mad at School* 98), while Melanie Yergeau has taught a course called “Autism, Culture, and Representation” (Yergeau ENGL 416 syllabus). Both Price

and Yergeau use their *ethos* as grounding for their courses, as they are both open about their disabilities. I admit that I do not have autism, although I have another type of “invisible” disability. I do, however, have years of experience in working with and advocating for students with autism, including my own son. Aside from my personal interests in autism and literacy, I also see a professional stake in the subject: students who identify with the autism spectrum are enrolling in colleges at record numbers, yet many instructors do not know how to create inclusive classroom environments. What’s worse, others may stigmatize students based on their own literacies about autism.

Also, while disability-themed courses are traditionally taught within Disability Studies frameworks in Rhetoric and Composition, I have decided to write my course on Autism and Literacy as an interdisciplinary course for undergraduate students within or outside of the English department, which I hope will subsequently increase our understanding of the sociocultural aspects of Autism Literacy and how these attitudes differ across disciplines. Plus, I feel that we cannot make as much progress in Autism Rhetorics and Literacy Studies if we do not talk to others outside of our own discipline. I agree with Shannon Walters’s argument that “Resisting ways of thinking based on binaries or dichotomized oppositions, the disability community seeks to establish values that foster connection among its members and the nondisabled community” (*Rhetorical Touch*, 63-64). I take this a step further by arguing for more interdisciplinary special topics courses that address Disability Studies in the English Department.

My attitudes towards learning about disability also translate to an inclusive classroom space in this course, as well as every course I teach. As Wood et al. note, “Instead of rules or norms flowing from teachers to students, we see classrooms as spaces where teachers, along with

students, explore and discuss and write to audiences with the knowledge that disability is *us*” (Wood et al., 148). Therefore, while I consider attendance and participation a mandatory component of the course, I do not grade these items with the understanding that students can attend or participate in a course in various ways. As Price brings up in *Mad at School*, “What about a student on the autism spectrum who has difficulty apprehending the subtle cues that govern classroom participation, the difference between ‘showing engagement’ and ‘dominating conversation,’ the sorts of spontaneous performances that are considered ‘smart?’” (6). I believe that since this is a course about autism, I need to put these theories into practice in the classroom.

#### **6.4 Final Thoughts**

As I conclude this project, I know that there is much more work to be done to uncover the intricacies of Autism Literacy so that we can better understand, in academia and society, how this type of knowledge acquisition works and transcends between audiences and rhetorical situations. Such need is evidenced by the five future implications I have outlined, as well as the two research projects I have identified as work I will tackle in the near future. My hybrid methodology of narrative inquiries and archival research have just touched the surface of this subject. Through each of the three archival projects, I uncovered new information related to Autism Literacy, but also even more questions to consider. As I move forward beyond this dissertation, I aim to visit more archives and continue the Autism Literacy research process.

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