A Rhetorical Journey into Advocacy

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A Rhetorical Journey into Advocacy

by

Samuel Thomas Harvey

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Abstract

This thesis reveals how advocacy is rhetorically constructed by using several rhetorical tools such as Kenneth Burke’s terministic screens, Michel Foucault’s genealogy and archaeology, and Bruno Latour’s black box. It is told in an autistethnographic style where it is part narrative, part academic, and written by an autistic person. Advocacy is rhetorically constructed by beginning to define a label for yourself.
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INTRODUCTION/PROLOGUE

This part of each chapter will be the state of the thesis. I will discuss where my thesis had been and where it will go in this section. However, this introduction acts as a prologue, so my thesis was none existent prior to graduate school.

-----

I was hired as an emotional/behavioral disorders (EBD) special education teacher five days before new-teacher workshops began. When I asked my supervisor what school I would be teaching at, he told me they didn’t know yet. I went through the new teacher workshops waiting to find out where I would be teaching.

I found out where I was going to be on the Friday before school started: Walsh Elementary School. My blood ran cold; it was the worst school in the district behavior-wise. I had my work cut out for me, but I decided that I was going to be a good thing to happen to this school. I probably couldn’t turn the whole school around, but I could be there for my students even when everyone else abandoned them or set them up to fail.

Above all else, I was not going to put them into a physical hold. I was going to respect their boundaries no matter what.

-----

1. Definition of Terms

My definition of autism has evolved much through the research for my thesis. Prior to starting graduate school, I thought autism was a “disorder and disability” that caused “persistent deficits in social communication and social interaction across multiple contexts...[and] restricted, repetitive patterns of behavior, interests, or activities” (CDC paras. 2, 8).
However, once I started graduate school, I went to the opposite side of the spectrum (pun intended). Autism wasn’t a disorder, nor was it a disability. It was a different way of being, a culture, that must be recognized and accepted for the awesome thing it was. Chapter one includes a section of the paper I wrote and presented on at a conference when this was my opinion.

My definition of autism later came to reside in the middle. Autism is a disability, but it is not a disorder. I realized that in my haste to separate myself from the special education mentality of pathologizing and capital-O "Othering" disabled students, I viewed disability in a terrible light. At the time, I thought disability was a terrible thing, a shameful thing that dehumanized people all on its own.

Then, I learned about the social model of disability and the neurodiversity paradigm, (both of which are discussed in chapter 2). There are several models of disability, but for the purposes of this thesis, I will only focus on two: medical and social. The medical model says that the problem of disability lies within the person. The social model says that the problem of disability lies within society’s approach to a biological impairment (Oliver). The neurodiversity paradigm--which embraces the idea that different brains are just as part of human diversity as skin color, sexuality, and religion--stems from the social model of disability (Walker).

With a better understanding of these paradigms, I realized that, while I had used the term disability, I had actually been talking about disorder (a medical term that disregards the neurodiversity paradigm). Autism is not a disorder because it is a naturally occurring biological diversity, we don’t call African Americanism a disorder, nor should we call autism a disorder (See CHAPTER 3 for a further explanation of this idea).
My final definition is not yet fully defined because autism, an integral part of my identity, cannot be defined simply. I must continuously be critical of my own warrants (assumptions) and even then, I may not reach my warrant.

But I do know one thing: autism is a spectrum. But unfortunately, as the tumblr user alice-royal points out, people tend to think of binary ends when they hear the word spectrum. There is a line between two points; one end is severe autism, and the other end is mild autism.

However, alice-royal introduces the idea of the autism spectrum being similar to the color spectrum wheel. There are a nearly infinite amount of tasks humans are expected (or have) to do, so there is an infinite amount of spectrums of how autistic people do on a particular task. But here’s the other imperative thing to understand about autism, it is constantly and forever changing.

I might be able to word things very well one day, but the next, I might not be able to get any point I want to make across. The spectrum of how I am doing on tasks changes from day to do and even minute to minute. Right now, I am able to tell myself that I am hungry and should go eat, but in a few minutes, I might not be able to. So where I fall on the autism spectrum is a constantly changing thing from day to day, hour to hour, minute to minute and the binary line between severe and mild is arbitrary and dangerously simple.

-----

On the first day of school, I found out the district didn’t feel that I didn’t have enough experience to work at Walsh Elementary School, so they made the lead EBD teacher for the district watch over everything that I did. I will henceforth refer to her as “my shadow.”

She read every word I wrote, watched every interaction I had with both students and faculty, and criticized just about all of it. “If you do that, then they are going to walk all over
you.” The discipline had begun. It wasn’t me disciplining my students, but the school district disciplining me.

Two weeks in, I had a particularly rough day. It started with a conversation with my Shadow where she used an idiom that made no sense to me, so I asked, “What are you talking about?”

She sighed, shaking her head annoyed, “Well, it means...” She paused, looking at me as if for the first time, “Wait, are you autistic?”

Taken aback a bit, I replied, “Probably, but not officially, why?”

“A lot of stuff make sense now.”

After that conversation, one of my students bit me because I wouldn’t let him climb over the attack barricade, a gym mat that was put up against the doorframe of a side room where we would herd the violent students into and put the mat up so we would be safe when they would run up against it swearing, spitting, trying to kick and hit us. Using the barricade ensured that I didn’t have to put him into a physical hold, which was something I never wanted to do.

So the principal decided that he was going to be suspended because he had bitten me. He finally sat down, breathing hard from all the energy exerted. Sensing his mood had somewhat shifted, I told my shadow that I was going to go inside to sit next to and try and talk to him. As soon as I sat down, he bolted and I found out that my shadow decided that this was the time for a break in the next room.

The mat fell with a violent whoosh and he ran out the door. I ran after him, only to hear, “What the hell?” coming from my shadow. I didn’t have time to process it because I had to get him before he potentially hurt someone. I found him again in the classroom and tried to get him
out. The general education teacher just gave me a dirty look as if to say, “How dare you let this child back in here!”

I radioed my shadow because I didn’t know what to do. He was calmly in his classroom, not hurting anyone, but he had been suspended. I knew that removing him would cause a scene and he may get violent again. I heard back from my shadow, letting out a deep sigh of disappointment, “Just leave him there, then.”

I walked back to my classroom and entered just soon enough to hear my shadow talking to my co-worker, saying, “This job isn’t meant for everyone, I just don’t think he can handle this job and I hope he figures that out on his own.” I was crushed, to say the least. Does she think I can’t handle this job because she thinks I’m autistic. I wondered.

Then, a memory came to me of when my mom first told me that the school district wanted to hold me back in kindergarten because they “didn’t think I could handle 1st grade.” They decided that I was underdeveloped: emotionally, intellectually, and even physically. They pointed to my fingers, saying, “Just look at his hands, they’re pudgy, he isn’t developed enough to go to 1st grade.”

Reality grabbed ahold of me again when I found out that another of my students was not on the bus, so I had to go figure that out. I searched all of the places at the school where he might be, but couldn’t find him. At the moment that I really started getting stressed, I got a radio message from the school counselor, “Where’s the student who bit you? He needs to get on the bus.” I informed them that that student had been suspended, so he wouldn’t be riding the bus. “It doesn’t matter if he was suspended or not, he needs to get on the bus.”

I contacted the paraprofessional who was with him and let him know that he needed to put the student on the bus. I finally located the other student who wasn’t on the bus and found
out that he was riding the bus that he had ridden up until a few days earlier. I walked back to my classroom, feeling good about solving that.

I got in and my shadow was pacing, “What the hell!” She demanded.

Taken completely aback, I responded, “What’s going on?”

“That student was not supposed to get on the bus. We called his mother, who came by to pick him up while you were off doing whatever you were doing.”

“The school counselor told me to get him on the bus.”

“The school counselor didn’t know that he was suspended.”

“I told her that he was and she still told me to put him on the bus.”

“It doesn’t matter, he should not have gotten on that bus. You’re a teacher, you should know that!” With that, she stormed out.

I stood there, thinking again about my kindergarten teacher and school officials trying to hold me back. They didn’t think I could handle it, but my mom decided not to hold me back, I went to 1st grade with the help of a tutor and continued to go to that tutor until 5th grade. They didn’t think I could do it, but I did do it! Just like I would do it now.

However, a key element to my success in 1st grade was missing; I needed someone to support me. But I would not find that support there. In fact, I would find the opposite.

-----

2. Theoretical Methodology

In this section, I discuss the theoretical frameworks and how I use them in this thesis. I use the pentad and terministic screens to analyze how advocacy organizations represent and narrate autism. I use archaeology, genealogy, black box, and terministic screens to trace advocacy organizations back to their core idea.
2.1 Burke’s Pentad

According to Kenneth Burke, the motivation of human action can be found in nearly every discourse. This discussion on motivation usually falls into five categories (Blakesley 32-33), what Burke calls the pentad: act, scene, agent (actor), agency (the tool that the agent/actor uses to perform the act), and purpose (of the act).

Applying this framework to artifacts from several autism/autistic advocacy organizations reveals how these organizations tell the story of autism. Furthermore, it also reveals the motivation behind both the characters in the story of autism and the author telling the story.

-----

A week later, one of my favorite students (I know I wasn’t supposed to play favorites, but what can you do?) had a behavior that caused the school to go into containment—all doors were locked and teachers taught as they normally would.

I was there outside of his locked classroom as the principal and vice-principal put him into a physical hold. I asked him, as he was struggling to get out of the hold, “Do you want to get out of the hold?” If he responded, I was going to tell them to release him. Instead, he snarled at me, escaping their hold. He ran at the door, slamming into it with his shoulder.

The staff demanded that I put him into a physical hold because he was slamming against the door, but I refused because the door was solid and locked. He put his head on the door and began banging his head on the door, I walked up calmly to see another staff member giving him a back rub in an attempt to calm him down. Upon realizing he was crying, I asked, “Do you want her to continue with the back rub?”

He choked out, “No.” With that, the staff stopped rubbing his back and he stopped hitting the door. We stood there in silence for a few minutes before I asked him if we could
please go to the principal’s office. He hung his head low and said, “Okay.” As we were walking to the principal’s office, he said quietly, “I’m sorry I’m such a bad person.” I nearly broke down weeping right there.

Tears in my eyes, I stopped him, saying, with a voice cracking with emotion, “You are not a bad person, you are not your behaviors. You are an amazing guy who’s struggling, but that doesn’t make you bad.”

With that, he continued walking. The principal decided to suspend him for a week. That was understandable, but what happened next was neither understandable nor acceptable in any way.

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2.2 Burke’s Terministic Screens

Terministic screens theory states that an author’s word choice influences how the reader/audience thinks about that topic. They are a set of terms, phrases, or analogies that ensure the audience sees a topic from the author’s perspective. Terministic screens prevent the audience from seeing any other viewpoint. “Even if any given terminology is a reflection of reality, by its very nature as a terminology it must be a selection of reality; and to this extent it must function also as a deflection of reality” (emphasis in original, Burke 1341).

In this thesis, I use a cluster analysis, revealing the writer’s “verbal tics.” In relation to autism, this may include the use of terms associated with the medical model of disability. Blakesley gives the example of Burke’s cluster analysis on Adolf Hitler’s Mein Kampf, “Hitler habitually characterized Jews as devils and the masses as feminine, combining religious and sexual imagery to horrific effect” (104). When I first started researching for this thesis, I
wondered what writing tics I would find in articles on autism? Would the tics be similar in every
writer or would they be idiosyncratic—individual to each author?

-----

TRIGGER WARNING (TW): physical restraint, abuse

My favorite student came back the next week to a teacher who told me she did not want
him in her classroom. I told her that we couldn’t take him out of her classroom because that was
where he belonged. He was assigned to her classroom and she was his teacher. I assured her
that I would be there as soon as I could if anything did go wrong.

About ten minutes into the school-day, I got a call asking me to come to her classroom
because he was having a behavior. I got to class to find him sitting in his desk, quiet and calm.

He saw me and shook his head angrily. I went to the teacher, confused, and asked,
“What’s going on? You said he was having a behavior.”

“He is having a behavior,” she replied sharply, looking at him annoyed, “He’s refusing to
grab a clipboard.”

“Huh?” I asked uncomprehending

“Well, during math time in my classroom, my students have to have a clipboard, and he
has refused to grab a clipboard.” I heard her linguistically separate the student from his
classroom.

The student heard this and spoke up, yelling, “I tried to grab a clipboard, but she
wouldn’t let me use the one I chose.”

She replied, lips pursed, “Well, that wasn’t his assigned clipboard.”

My mind was reeling at the utter stupidity of this demand. Use a clipboard, no, not that
clipboard, I don’t want you in my class, so I’m gonna get you out by any means necessary!
“Let’s just let him use the clipboard he had chosen.”

“But that is not his clipboard, that is another students.”

“Is the student here today?”

“No.”

“So why can’t he use the student-who-is-not-here-today’s clipboard?”

“Because it is not his. And if he cannot follow the rules, then he has no right to be in this classroom.”

Just as I was about to respond, my shadow came in and asked what was going on. The teacher replied with what was going on and my shadow said, “He needs to grab his own.” She turned to the student and said, “You need to grab your own clipboard.”

“No, I’m not going to grab a clipboard because she won’t let me take one.”

It was at this point that my shadow decided to use a technique that behavior managers call the broken record technique, where you keep repeating yourself and your direction over and over until they finally comply. There is one flaw to this technique, if a student responds in kind, you have a circular loop where you keep repeating the same thing to each other over and over again and it becomes a battle of wills—a power struggle.

And in this case, my student responded in kind. The conversation went something like this:

Shadow: You need to grab your own clipboard.

Student: No, I’m not going to grab a clipboard because she won’t let me take one.

Shadow: You need to grab your own clipboard.

Student: No, I’m not going to grab a clipboard because she won’t let me take one.

Shadow: You need to grab your own clipboard.
Student: No, I’m not going to grab a clipboard because she won’t let me take one.

Shadow: You need to grab your own clipboard.

Student: No, I’m not going to grab a clipboard because she won’t let me take one.

It went on like this for about five minutes before he finally yelled in her face, “Fuck you!” The class became deadly silent.

My shadow replied, “You are coming with me to the principal’s office now.”

“Fine,” he said smugly and walked out.

The thought going through my head at that time was, This is not worth fighting over. Just let him choose whatever damn clipboard he wants.

I am a slow walker, so by the time I got to the principal’s office, they had been there for a few minutes. As I approached, I could hear him swearing and yelling at the top of his lungs. I rushed in to find five staff standing opposite of him in front of the telephone. “Just let me fucking call my mom, you assholes!” He demanded.

I was about to tell the people to disperse and let him call when my shadow responded, “No, you cannot call your mom. You need to calm down and talk to us first.”

He pushed passed the people blocking the phone and started picking up the receiver when my shadow bent over and unplugged the phone. I thought to myself, Why did she just do that? Asking to call his mom is a very logical idea because his teacher just set him up to fail. And so did we, and by we, I mean me, because we put him in with a teacher who didn’t want him in there.

He rushed over to another phone to try and call his mom just as a police officer came in and told him to calm down. He walked straight passed the officer and picked up the phone and
began dialing before my shadow unplugged that one too. He started yelling even louder and people started getting in his way and he started pushing through them.

Next, he walked into the principal’s office where she was having a meeting with someone and grabbed her phone to call his mom. And again, my shadow unplugged the phone. I said, “Just let him call his mom.”

“Don’t question me.” My shadow said vehemonously. “You don’t have the kind of experience I do. You don’t know what his motivation is here.”

“Neither do you.” I said quietly.

It was at this time that the police officer began trying again to calm down my student, who was way beyond the point of calming down—and with good reason. We had blocked every attempt to contact someone who was not trying to set him up to fail. The police officer tried to put his hand on my student, only to have my student push it off.

The police officer turned to us and said, “He just put his hands on me, did you all see that.” He then tried to put my student in a one-person hold, but my student was too strong for that, so the police officer then turned to me and said, “You grab him, we’ll put him into a two-person hold.”

And to my utter horror and shame, I complied. My one goal was to never put a student into a physical hold, one goal. One goal that was quickly dashed to smithereens. I am not ashamed because I failed my one goal, I am ashamed because I put a student who had been set up to fail into a physical hold for being understandably angry.

I did that. And at that moment, the discipline I had endured for six weeks began to take hold. I was becoming less of me and more of...a teacher.

END TW.
2.3 Foucault’s Archaeology and Genealogy

In their article “Towards a Foucauldian Methodology in the Study of Autism: Issues of Archaeology, Genealogy, and Subjectification,” Eva Vakirtzi and Phil Bayliss discuss Foucault’s concepts of genealogy and archaeology.

They define genealogy as looking back and attempting to determine what ideologies lead to the current idea: this image of autism as something that needs to be fixed. I look at the ideological precursors of Autism Speaks in order to determine how they have the authority to do what they do.

However, genealogy “cannot say many things about the causes of the transition from one way of thinking to another” (371). Foucault’s archaeology comes into play here by analyzing how we reached this ideological point.

2.4 Latour’s Black Box

In his book “Science in Action,” Latour explains that the Black Box is a term that comes from computer science and engineering and it is used “whenever a piece of machinery or a set of commands is too complex. In its place they draw a little box about which they need to know nothing but its input and output” (2-3). That is, Black Boxes are processes we veil because they are too complicated, focusing only on their inputs and outputs.

Latour's Black Box resembles Foucault’s archaeology because both focus only on the input and the output. The core idea of Autism Speaks can be critically analyzed using these theoretical frameworks. Therefore, this thesis breaks open these boxes to reveal how Autism Speaks has the authority to advocate for autistic people. But how?
Latour discusses how Black Boxes can be used “to lead the reader somewhere else downstream” (23). This is identical to the purpose of terministic screens. Black boxes, then, can be opened by analyzing what terministic screen was applied to the input to create output.

Black boxes are a reflection of reality because, as Latour puts it, "No more has to be said about it [the Black Box]." Therefore, it also deflects reality—just as terministic screens are. This means that black boxes can be analyzed via the same methods rhetoricians use to analyze terministic screens.

-----

I was transferred to Adonis High School two days after that incident. I hated what I had done, I hated everything about it, I hated myself for doing it. But I had new students to work with now and they hated me because their previous teacher had been transferred six weeks into the school year.

Throughout the rest of the time that I worked there, they continued to discipline me. It started small with things like, “Make sure all of your students are sitting when the bell rings.” My students, who were not used to sitting down at the bell, aggressively resisted this rule, but, eventually, got used to it.

But the disciplining continued. “You cannot be patient with your students or else they will walk all over you.” And gradually, the part of myself that I loved the most, my patience, was whittled away. The most disturbing thing, I began to realize, was they were not doing it to me. The district didn’t tie me down and whittle away the bits of me that weren’t teacher-ish, they disciplined me so that I did it to myself. But their final disciplinary lesson would prove to be too much.

-----
3. What to Expect

This thesis determines how advocacy is rhetorically constructed by documenting the journey I have gone through to get to my thesis as it currently is. Chapter 1 discusses my first semester in graduate school and how I was beginning to discover my thesis even then.

Chapter 2 discusses the first major topic shift in my thesis research, which occurred in my second semester of graduate school. Chapter 3 discusses the transition into the second major topic shift. Chapter 4 will begin to uncover where my thesis is now by rhetorically analyzing Autism Speaks.

Through these chapters, I will answer four questions: first, broadly speaking, how is advocacy rhetorically constructed? Second, what is pseudo-advocacy, what does it look like, and what are its consequences? Third, how does Autism Speaks establish itself as an authority qualified to advocate for autistic people? Finally, what rhetorical moves do people identified as “in need of help” use to advocate for themselves?

Throughout the paper, I use several discursive practices that I have observed in the Autistic Community, specifically, the use of the abbreviation A$ for Autism Speaks. In an attempt to remain professional in the academic parts, I use AS or Autism Speaks. However, in the narrative parts, I use the terms A$ or Autism $peaks.

Another discursive practice I use is for accessibility purposes, and they are trigger warnings. I put them in places where there could be some triggering language or events that happen (e.g., the story of how I put a student into a hold earlier in this chapter). The purpose of these trigger warnings are so if a person doesn’t feel up to reading something that may trigger a panic attack or anxiety, they can pass over it for the time being and come back to it when they are ready.
The district told me that I should act like a particular teacher whose pedagogy was to break her student’s will so as to scare them into compliance. She would go up to students and point out that they were failing a class in front of all of their peers. She would tell students they couldn't be a veterinarian because they were in a special education math class and math was required for being a veterinarian. They feared and hated her, but they did what she said.

“She brings results,” My supervisors told me. “Be more like her.”

They even made her my mentor. She tried to make me treat my student as less than. Saying things like, “These students will walk all over you,” “One of the parents of your students came up to me and said that her child is going to walk all over you,” “Sometimes, I just don’t understand you,” “Another of your student’s parents came up to me and told me, ‘how am I supposed to take this guy seriously?’,” and the dreadful vagueness of, "Might want to rethink how you do things.”

When I refused to treat my students as less than, she made my life miserable. She made sure that I had all of the paperwork-heavy cases bogging me down, making it nearly impossible to both teach and do all the paperwork required. No matter how hard I tried, my students continued to have behaviors and fail classes.

In the end, I decided I couldn’t handle the toxic environment of the public school district anymore. If they wanted me to be more like this teacher and rob these students of their dignity and agency, then I had no desire to teach in a public school. So I left, but the discipline I had gone through left its mark. I left a completely different person than when I entered, I had no patience, no hope, no identity.
I found myself in complete shambles, barely holding on to the last vestige of hope that I would be able to find out who I really am. I knew that I loved writing, so I applied to a writing and rhetoric program with no idea of what rhetoric was. I also had no idea of the deep impact rhetoric would have on my life and the journey I was just now embarking on: a journey of self-discovery, a journey to find out who I was now that I wasn’t a teacher anymore, a journey into advocacy.
Works Cited: Introduction/Prologue


Chapter 1: IDENTITY FORMATION

I spent the summer between finishing teaching and starting graduate school in a state of mental anguish. No matter how hard I tried, I couldn’t get the anxiety my job had produced out of my mind. On top of that, there was the knowledge that I had no identity. Teacher had been my identity for the past two years, and for the four years prior to that, a teacher in training. Who was I now?

I would be present in the now, but then suddenly, I would return to utter helplessness I felt while teaching.

What plagued my mind to the point of perseveration (every waking thought, every thought before going to sleep, and dreaming about it) was, I want to have an identity, I want to be me again. I sought answers, but found nothing.

Then, I began to distract myself with another worrying idea: what was rhetoric? I had never heard of rhetoric before and I was about to start a master’s program in it. What if I couldn’t do this program? What if I was doomed to a list of failures that added up to a meaningless life?

1 What is Rhetoric?

I took an Introduction to Rhetoric class my first semester. I read one theoretical article each week from a rhetorician and they all made my head spin. None more so than the third week when the professor gave us a cheeky smile and said, “Have fun with next week’s reading.” I found out that it was written by Michel Foucault.

It took me a whole week to read and “understand” six pages of Foucault’s writing. After three days of trying to understand what he was trying to say, I knew I had made a huge mistake; I
wanted to give up and quit the master’s program right then and there. Foucault wrote his ideas down and then took out anything that could help me understand what he was trying to say. I had no idea what he was saying or what his article had to do with rhetoric. And what even was rhetoric?

It wasn’t until the night before class that I understood a piece of what he was saying and how that piece related to rhetoric. He wrote about power and agency (the ability to make decisions). You could replace the word power with the word rhetoric. So, rhetoric leads to power and agency. But how does it do this?

A week later, I learned that rhetoric leads to power and agency through language. I read “Terministic Screens” where Burke says that the language we use offers the audience a lens with which to view something, a lens that cuts out any other perspectives.

So, the dictionary definition of rhetoric is “Language that is intended to influence people and that may not be honest or reasonable...[and] the art or skill of speaking or writing formally and effectively especially as a way to persuade or influence people” (“Rhetoric”). I learned throughout the rest of the course that the dictionary is only part of the definition. There’s more: there’s the implied meaning behind a word.

The basic implied meaning of rhetoric is getting your point across to convince others. If you begin to delve deeper into the theory of rhetoric, you get Barry Brummett saying that rhetoric creates language and language creates meaning, so rhetoric creates meaning. You get Michel Foucault saying that power is shifted through language and that we can give up our agency if someone uses the right kind of rhetoric.

But still, the question remains: what is rhetoric?
“What did you think of the movie?” My mom asked me when I was 12 years old.

“Well, it pissed me off, to be honest.”

“What?” She exclaimed.

“But what I can’t figure out is why it made me so angry. That’s what I’m trying to figure out right now.”

“Who cares, it was a movie, Sam.”

“Yeah, it was a movie, but I care. I feel angry even though I didn’t feel that way before. There was something in that movie that made me that way and I want to figure out what it was.”

I thought for a bit, and finally said, “Well, I think what pissed me off the most was when the other reindeer wouldn’t include Rudolph at all. First, it made me sad, then it made me angry.”

“It’s a Christmas movie and it ended happily.”

“Does it though? I mean the song is usually sung twice.”

“What are you even talking about?” She asked me, utterly confused.

“So, the song begins with the reindeer not including Rudolph, he saves Christmas and everyone likes and includes him. But oftentimes, the song is sung again, so even though he saves Christmas, the reindeer forget and decide to not include him again, but he saves it again, and everyone likes and includes him again. That is not a happy ending.”

She stared at me, not really knowing what to say until finally, she said, “You should just learn to enjoy movies rather than analyze them to death like you always do.”

“But that is how I enjoy movies, though. It also helps me understand what’s going on around me.”

“What do you mean?”
“Well, I don’t really know what is going on at school sometimes. I’m just kind of at a loss, so I just don’t say anything.”

“Okay, well, if you need to and want to analyze them like that, then whatever floats your boat.

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About halfway through the semester, we were required to rhetorically analyze a public service announcement as a class.

**TW: PSA on texting and driving, death of various characters including a baby**

In the class analysis, we watched a Public Service Announcement on not texting and driving. The video is shot in the style of reality TV, which adds to the realism of it. It starts with three teenage girls driving in a car with the driver texting on her friend’s phone.

She starts weaving into oncoming traffic and crashes into another car. You only hear the sounds of the accident (i.e. sound of crunching metal on metal, screeching tires, head slamming against dashboard and window, etc.). As soon as the action stops from that accident, another car t-bones the girls’ car and more sounds are heard (i.e. passenger’s neck snapping, glass breaking, more screeching tires, etc.)

The texting driver wakes up in her car to find she is the only one who survived the accident and screams as the camera pans out to reveal a sign saying, “TREDEGAR welcomes careful drivers.” Emergency responders come. There is a young child who constantly begs her parents to wake up followed by a close-up shot of a baby in its baby-seat, eyes forever open and unmoving with the sounds of the little girl asking, “Why won’t mommy and daddy wake up?”
Minor-keyed, sad music, begins quietly and slowly crescendos throughout the rest of the commercial ending with the emergency responders putting the texting driver onto a helicopter for medical attention (Funnyvideoso7).

There was so much to analyze in that one commercial that we spent nearly two and a half hours talking about it. Obviously, the creators wanted to communicate the message “don’t text and drive.” They get this message across in a variety of ways. The music at the end is a key piece.

I pointed out in class that the actual car crash takes less than a minute, the remaining three minutes are dedicated to the after-effects of the crash. The sign that says “TREDEGAR welcomes careful drivers” is something that people may not register consciously, but it adds further to the message the filmmakers were trying to get across.

Having only the texting driver survive is an equally powerful decision. If the driver had died, then we wouldn’t have seen the remorse over her friends’ deaths. Even though she doesn’t say anything, the audience gives thoughts to her character, thoughts of remorse based on her body language.

It really tugs at your heartstrings, almost ripping them out and feeding them to a pack of starving lions.

**END TW.**

I pointed all of this out throughout the night we discussed the video and finally asked what was on my mind, “So this is a rhetorical analysis?” I asked, surprised.

The professor nodded and I was left in shock. *I’ve been doing this all my life,* I thought, *with movies and human behavior since as long as I can remember.*
A week later, I found out that I had to write a twenty page paper in another class on digital humanities and rhetoric. I freaked out because the last time I had written a twenty page paper was an accident my freshman year of college (The paper only had to be five pages and I wrote twenty, whoops!). *How am I going to write a twenty-page paper on something I’ve only just learned about.*

Then I had an idea connecting my undergraduate special education degree (something I knew a lot about) with digital humanities: the hidden curriculum of the internet. The hidden curriculum is the set of “skills that we are not taught directly yet are assumed to know” (Myles and Simpson 279).

I was only able to find one source on the hidden curriculum and the internet. Little did I know, that little article would be key to the identities of both my paper and myself.

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My psyche was still in a bad place, at least once every day, I would feel the helplessness I had felt those two years teaching. Those two years where I cut off the parts of me that were “unteacher-like.” The parts of me that made me who I was. Who was I if not a teacher?

At one point, we had a class discussion on public education.

“Honestly, the public education system demands that its teachers be innovative, but then focus solely on the ‘no’ part of innovation.”

“Interesting,” the professor said, “Tell me more.”

“Well, I went into a special education class and I had what I think is a pretty good idea. I set up the class as a role-playing game, so every assignment was a quest and extra credit was a side-quest that was optional. My administrators looked at that and told me that I was doing my students and my fellow teachers a disservice because my students ‘weren’t actually learning
anything’ and were just having ‘fun for the sake of fun,’ which made my fellow teachers look bad.”

A fellow student came up to me after class and asked me why I had been so angry. I hadn’t realized that I had been angry, but looking back at what I had said, I completely understood why they thought I was angry. Honestly, I was angry. I had spent six years being disciplined into destroying myself in order to “be a teacher.”

I started picking up the pieces of my identity. And as I was picking up these pieces, I began to notice patterns converging on one thing. Trying to make me “interact better with my colleagues, students, and parents” by putting me through role-playing social situations. They defined this “better interaction” as looking people directly into their eyeballs; shaking hands properly; being okay with being touched; saying “fine” or “good” when people ask me how I was (I usually respond with how I actually am, which is almost always “tired”); sending flowery and emotional e-mails that took into account the other person’s perceptions of how I am saying something, rather than just straight to the point like I was doing; and sitting with my colleagues rather than away from them.

All of these “appropriately interacting with others” fit the diagnostic criteria for something my shadow at Wallace Elementary had asked me about two years prior: autism. Did I have autism? I wondered to myself, I looked at the new DSM-V and found that I fit that criteria. So, was I? I put it aside in my mind and turned my attention towards my homework.

And I looked at Autism Speaks’ website and read some things, but something didn’t feel right as I read some of the things on their site, so I just exited. I didn’t come back to this feeling for an entire year (If you want to read about it, skip to chapter 4).

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2. One Topic to Rule them All

It began with the readings of the Great Articles. One was given on the hidden curriculum of the internet, smartest and most logical of all topics. One was given for a weekly reading, the ones students rarely read. But they were all of them deceived, for another Article was made. In the mind of Samuel Harvey, his brain began to make connections between these two separate readings. One topic to rule them all, one topic to find them; one topic to bring them all and in thesis bind them (rhetorically, of course).

Okay, now that I have a customary paragraph combining Lord of the Rings and my thesis, let me explain what I’m talking about. The week after I found out about the twenty page paper, we were assigned to read “Engaging Urban Youth in Meaningful Dialogue on Identity through Digital Storytelling.” In the chapter, the author seeks to understand the identity of urban youth through digital storytelling.

When I was first assigned to read it, I thought that the author was going to look at what their identity was through digital storytelling. However, on the second page, they reveal how they were going to go about identity when they quote Sfard and Prusak saying, “We did not say that identities were finding their expression in stories—we said they were stories” (qtd. in Nixon 42).

I had never thought about writing product as identity. That meant that even though I didn’t know my identity, my writing was part of it. So, I became very cognizant of everything that I wrote because it was an integral part of my identity.

But then a thought crept in, is having autism part of my identity? If it is, then I don’t want to be disabled because disabled is shameful. And autism is a disability, right? But what if it’s not?
The second article I read was the one search result for the hidden curriculum of the internet: “Autistic Culture Online: Virtual Communication and Cultural Expression on the Spectrum.” In it, Joyce Davidson reveals that autistic people have come together on the internet to begin developing an Autistic Culture. She then asked many autistic people what they thought.

Both the Nixon chapter and Davidson article look at a group’s writing to determine their identity. Nixon looked at the digital stories urban youth made as examples of their identities, Davidson looked at the online discussions of autistic people as examples of the identity of an autistic culture.

And so, my topic shifted from the hidden curriculum of the internet to autistic identity.

3. Identity Formation in Autistic People

However, upon searching for sources on identity, I came upon the book The Social Construction of Reality by Peter L. Berger and Thomas Luckman. They say that knowledge is formed, confirmed, and maintained through social interactions and communications (194). Not only is knowledge formed this way, but so is identity (84).

I had to stop there because one thing I knew about autism is that it is “a condition or disorder that begins in childhood and that causes problems in forming relationships and in communicating with other people” (emphasis added “Autism”).

So, the Social Construction of Reality theory states that identity is developed through social interactions and communicating with other people, but the definition of autism is a “problem…in communicating with other people.” How, then, if autistic people struggle with social interaction is their identity developed?

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Around this time, Saint Cloud State University’s English department offered a series of workshops on conference presentations. I went to them thinking I was going to present sometime in my second year, so it was good to know. However, part of the workshops was writing a proposal. The two professors who led the workshops were also in charge of putting on the Great Plains Alliance for Computers and Writing (GPACW) for 2014.

The deadline passed and I didn’t submit a proposal, but then it was extended for another week. And, out of sheer temporary insanity, I submitted a proposal. I thought: *There is no way that this proposal is going to be accepted, this is just a chance to practice what I learned about writing proposals.* This thought process proved to be faulty because a week later, I was accepted to present at GPACW 2014.

I believe my thought process at that point included a bunch of swear words that would not be appropriate in this thesis. But be rest assured that there were many references to stupid, fat hobbitses.

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3.1 Identity and Discourse

How do autistic people form their identity? The first part of this answer can be found in Roz Ivanič’s book *Writing and Identity: The Discoursal Construction of Identity in Academic Writing*. According to Ivanič, identity reveals and develops itself through discourse. Discourse is defined in two different ways: “Verbal interchange of ideas; especially: conversation” (“Discourse” 2). This is the definition many think of when they hear the word discourse.

Discourse, as Ivanič uses it, is a “representation through language” (17). Identity, then, develops and reveals itself through multiple types of languages or discourses. Two of these discourses are verbal and body language. What is appropriate in both of these discourses is
determined by non-autistic people. It is natural for non-autistic people to participate in spoken and body language deemed “appropriate” for verbal and nonverbal language, but many of these things are not natural for autistic people.

The third language that Ivanič discusses is key to identity development: written language. Ivanič chooses to use another definition of discourse: “Connected speech or writing” ("Discourse" 3b). Written language is the key to identity development because “[neurotypical] conversations have a very fast-paced rhythm of little exchanges back and forth…[and the internet] slow[s]…down the fast-paced rhythm of…[these] exchanges” (Davidson 796).

The internet is almost solely written language and also allows for “slow[ing]…down the fast-paced rhythm of NT [neurotypical] exchanges” (Davidson 796). The internet is “just one channel of communication to worry about!!!!” (Jones and Meldal 39) instead of the other two that autistic people struggle with. Due to the asynchronicity of the Internet, autistic people are given the chance to communicate at their own pace instead of the normal pace found in face-to-face conversations. The chance to communicate through written language invites autistic people to begin the process of forming and crafting their identity.

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The day of the presentation was upon me and I was scared shitless. I knew what I was going to say, I knew that what I was going to say was not pointless, but I was still scared shitless. The night before, I only got about four hours of sleep and I was presenting first.

I decided to use quotes from actually autistic people who were quoted in several of the studies I had read. And I was going to use PowerPoint to show them to the audience. The main idea behind the presentation was how autism is a culture. At that time, however, the presentation also claimed that because autism is not bad, it is not a disability. Looking back, I realize that I
was mistaken. Autism is a disability, but I have since challenged the warrants (assumptions) that I held. Upon challenging them, I saw that the main warrant in my presentation was that disability is a bad thing. More on how disability is not a bad thing in chapter 4.

Looking at the points that I made in that presentation, there was an extra piece that I have only recently noticed: I talk about the social model of disability without even knowing it.

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3. Social Model of Disability

The social model of disability was first named by Mike Oliver in 1990. He begins by discussing individual models of disability which says that the problem of disability lies within the individual and is caused by impairments. He goes on to challenge the individual model by proposing that disability is a socially and culturally manufactured entity.

It’s not the impairments that cause the disability, but society’s refusal to accept disabled people’s different way of doing things. He goes on to discuss why using a medical approach to disability is inappropriate. If disability is, in fact, a socially manufactured entity, then we are medically treating someone for trying to “resist social regulation ... [in order] to maintain [their] personal integrity” (Buck 253 emphasis in original).

Oliver claims the fields of medicine and rehabilitation are founded on the privileging of one “normal” way to be. Therefore, any attempt to “cure” a person of a disability could be viewed as an attempt to “exterminate” their difference or abnormality (Henderson et al. 516). The social model of disability “rests on the distinction between disability, which is socially created, and impairment, which is referred to as a physical attribute of the body” (Corker and French 2).
Dimitris Anastasiou and James M. Kauffman explain what they believe are the five tenets of the social model of disability:

1. There is a sharp distinction between impairment and disability …
2. Impairment refers to physical/bodily dysfunction, whereas disability refers to social organization …
3. Disability is not a product of bodily pathology, but of specific social and economic structures …
4. Disabled people are an oppressed social group …
5. Disability is not a matter of personal tragedy. (442-443)

Connections can be made between this distinction and things like gender/sex and race/skin color. Gender and race are socially constructed whereas sex and skin color are biological in nature.

3.1 Deconstructing Disability

In my presentation, I set out to deconstruct disability because I thought it was a terrible thing. Autism was not a terrible thing, so autism was clearly not a disability. But again, most of this argument fits within social model of disability.

I quoted Simon Baron-Cohen, a scientist who, at the time of the presentation, I thought was a good person to quote. However, in chapter 2, I will discuss how Baron-Cohen is not as good of a person to quote as I had previously thought.

Simon Baron-Cohen (Sacha Baron-Cohen’s cousin), a world-renowned expert in the field of autism, challenges the view that autism is a disability, “Looking at the neurobiology...of autism, there is not much evidence for dysfunction, but a lot of evidence that people on the autistic spectrum are simply different” (Baron-Cohen).
Those who argue that autism is a deficit are looking at autism through the lens of pathology/medical model. However, let’s look at what a disability is according to the dictionary and the Americans with Disabilities Act (ADA).

The dictionary defines disability as “the condition of being unable to do things in the normal way” (“Disability” 2). There’s that word again! “Normal” comes up constantly in research on autism. The ADA, a civil rights law that borrows the language and definitions of several other laws, defines disability in two ways: “A physical or mental impairment that substantially limits one or more major life activities of such individual…a record of such an impairment” (“42 U.S. Code § 12102 - Definition of disability”). This definition aligns with the dictionary definition. However, the second way of defining disability contradicts the former definition:

Being regarded as having such an impairment…An individual meets the requirement of “being regarded as having such an impairment” if the individual establishes that he or she has been subjected to an action prohibited under this chapter because of an actual or perceived physical or mental impairment whether or not the impairment limits or is perceived to limit a major life activity. (“42 U.S. Code § 12102 - Definition of disability”)

This means that the government protects you as having a disability when someone else thinks you have a disability. You do not have to have an impairment that substantially limits at least one major life activity, you just have to be presumed disabled. This third definition fits with the social model of disability, the idea that disability is a socially constructed entity.

These definitions call to mind Louis Althusser’s ideas on interpellation, “[A]ll ideology hails or interpellates concrete individuals as concrete subjects” (173 emphasis in original).
Interpellating means to turn someone into a subject; in the case of disability, people are interpellating (or perceiving as termed in the ADA) a capital-O Other as having a disability and the government views that capital-O Other as having a disability. The ADA does not cause this; it protects those who are interpellated as disabled or “having a disability.” I used the ADA as an artifact to show that even the government in the form of the ADA recognizes that disability is a socially constructed entity.

Disability, therefore, is the subject and people are being made subjects to the term “disabled.” Interpellation can be considered an active version of interpreting. It is when something, be it a person or society, forces an interpretation onto your identity, such as the interpretation that you are disabled.

So, now we come full circle: is autism a disability? The definition of disability has been deconstructed, or torn apart and inconsistencies found, by looking at the government definition of disability. It is possible to label any person, whether or not they have an impairment that “substantially limits one or more major life activities” (“42 U.S. Code § 12102 - Definition of disability”), with a disability.

In the words of Davidson, “People on the autistic spectrum do, indeed, have a culture – one separate from the ‘normal’ world they must live in” (800). Autism is not just a disability—it is a culture.

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I had gastrointestinal problems the morning of the presentation. I always do when I am really nervous, or when I drink coffee too fast. And, in my nervousness, I drank an entire cup of coffee within a few seconds.
But luckily, these problems held off until after I was done presenting, and then it was a scene similar to Mount Vesuvius unleashing its contents onto Pompeii (with Pompeii being…well, I think you get the picture). One of the conference organizers and workshop leaders was at my presentation. I used every hour available making the best presentation possible, I knew I had my topic down. But the idea of one of the conference organizers attending my presentation remained terrifying.

I finished my presentation without any problems, I didn’t stumble on words, the technology worked, everything went pretty well. And then it came time for questions and the conference organizer told me, “My son has aspergers and I have got to say…”

This was one of those moments where time stands still from sheer terror. *What if he says I am full of bullshit!*

“You are right. I read an article a few years ago called ‘Autism and Rhetoric’ and they bring up much of what you just brought up in this presentation. So, I think you are spot on and I think I could see a thesis coming out of this.”

My jaw nearly hit the floor. A thesis from this? I had had a lot of fun when doing this research, but I had planned on this presentation and paper being a one and done thing. So, I wondered if I could actually expand on it enough to make it into a thesis.

Another comment someone asked was, “What interested you in this topic?”

Part of me wanted to answer with what I thought was the truth, “Because I’m autistic.” But I thought I couldn’t say that until I was officially diagnosed. So, instead, I said, “I was a special education teacher for the last two years and I saw that autism is not something bad, it’s just something that is. And that’s the message that I hope you walk away from this presentation with: autism isn’t bad.”
4. Disability as Interpellation or Disability as Culture (or Both)?

But is autism a disability? I showed in the last section that disability is tantamount to an interpellation where one gives up their agency and takes on the identity of a label given to them. But there is also a disability culture: a group of disabled people who have come together and embraced being disabled.

By embracing the label of disabled, aren’t they giving in to that interpellation? Aren’t they giving up their agency? And if they have given up their agency, how can they advocate for themselves?

The rest of this thesis explores this question. And the first small morsel of the answer can be found in Stuart Hall’s ideas on interpellation. Hall agrees with Althusser that interpellation is where one gives up their agency, but he disagrees with how that is done. Althusser says that it is a moment, but Hall says that it is actually a process.

So, if interpellation is a process, if the act of giving up my agency is a process, then it stands to reason that, at some point, in some way, I can interrupt that process. But how? To begin to answer, I delved deeper into research on identity formation.

Identity is possible in autistic people despite the fact that a major theory of identity development says that it is developed through social interactions. It is possible through discourse and social interactions on the internet, a place where autistic people have congregated and created an Autistic Culture.

This was what I took away at the time. But something was on the horizon, something I could not have foreseen.
At lunch after my presentation, someone came to our table and handed out bookmarks saying that the national Computers and Writing conference was extending their Call for Proposals for three more days.

I put the bookmark in my backpack and didn’t give it any more thought until that night when I got home. I sat in my chair in my apartment wondering if I should submit something. *What would I even submit? I don’t have anything.* Then, a thought hit me, *Submit the paper you presented today, but present on what you learn between now and then.*

In another temporary bout of insanity, I wrote the proposal for the national Computers and Writing Conference thinking the same as when I submitted the proposal for GPACW. *This is a national conference, there is no way I’m going to get in. But it’s worth a shot.* And just like GPACW, my proposal was accepted and I would be presenting at a *national* conference. And again, just like GPACW, my thoughts were full of comments on stupid, fat hobbitses in the Gollum/Smeagull voice.

Little did I know how life-changing that conference would be. It held the key to what I so desperately desired: a community, a culture, an identity.
Works Cited: Chapter 1


Chapter 2: THEORY OF MIND

Mr. Thesis Chair, members of my committee, my fellow humans, I write this introduction to the chapter to discuss the State of the Thesis circa Spring 2015. As you may have read in chapter 1, I began researching identity and my thesis was going to determine the connection between identity and rhetoric.

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I struggled with the realization that I might be autistic. I didn’t struggle with it because I didn’t want it, I struggled with it because what if I wasn’t autistic? This word that explained so much of my life that I had never been able to make sense of before, what if it wasn’t so?

On top of that, there were (and are) some major parts of autism that I don’t have. I had a theory of mind and strong empathy. Theory of mind is the ability to 1) know that other people have their own thoughts and emotions and 2) be able to accurately guess what those thoughts and emotions are. I could usually guess what other people’s thoughts and emotions were—I just didn’t know how to “appropriately” handle them.

I thought at the time that I couldn’t consider myself autistic or even call myself autistic because I wasn’t officially diagnosed. Therefore, I was on the outskirts looking in on a culture I desperately wanted to be a part of.

I didn’t think I was part of the autistic culture because I wasn’t diagnosed. Nor did I think I was part of the neurotypical culture because no matter how hard I tried, I couldn’t pass as neurotypical without returning to the anxiety I had in the two years of teaching.
I had nightmares almost every night. Nightmares that I would live my life always on the margins, never fitting in anywhere—an eternal social vagrant. Dreams where I was autistic, but people refused to believe it because I didn’t have a diagnosis and I believed their doubts.

I had dreams where I said I was autistic and everyone looked at me with seething scorn, but someone else would come in just as autistic as I was and they would fawn over them and recognize their autism.

But I couldn’t be autistic, neither in dreams nor reality, because I had a theory of mind. And I had learned in my undergraduate degree that autistic people lack theory of mind.

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1. Autism, Rhetoric, and Identity

My now thesis advisor asked me the pointed question, and rightly so, “What do psychological theories of identity have to do with rhetoric?” Honestly, I couldn’t give any answer because I couldn’t really find any. My research wasn’t really going anywhere that related to rhetoric.

He recommended that I read “Autism and Rhetoric,” an article by Paul Heilker and Melanie Yergeau. Heilker and Yergeau state that autism is a form of rhetoric and that autistic people use their own form and style of rhetoric. This unique rhetoric impacts the ways they interact with others, interact with the world, use language, etc.

This a concept made sense because I had been told by teachers and professors that I think about things in a completely different way. I loved the article so much that I wanted to do more
reading of their articles. What I found terrified me because much of Yergeau’s work related to
the things I was thinking about and wanting to research.

I e-mailed my Introduction to Rhetoric professor asking what I should do and she replied
with advice that changed everything: “Walk towards her, read her stuff, recognize that there will
be overlap, but there are going to be some places she doesn’t go that you may want to go into.
Don’t run away from your topic, look at her stuff and find your own niche.”

I read “Clinically Significant Disturbance,” where she discusses how theory of mind
disembodies autistic people because it is theory of mind, not theory of whole-body. The theory
further maintains the idea that autism and the autistic person are two separate things, leading to
statements like “That’s just your autism talking.”

“Clinically Significant Disturbance” would significantly impact something that I was
about to read and shape the course of things to come for my thesis.

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A few days after I found out that I would be presenting at the national Computers and
Writing Conference, I was perusing Melanie Yergeau’s website, where I found her articles, and I
found out she was going to the national Computers and Writing Conference as well.

I became more terrified than I had been previously about presenting at this conference
because I was only a lowly 1st year graduate student presenting at a national conference where
the person whose every article I was reading would be. I was excited to see her present, but
terrified of the possibility of meeting her. I don’t know if you have figured it out yet, but I have significant social anxiety.

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1.1 Researching Psychological Theories on Identity

I looked deeper and found that every theory on identity that I looked at pointed back to one name: Erik Erikson. Curious, I looked him up and found that he had created a theory called the “Psychosocial theory.” It basically says that the mind and psyche of a person is developed through social interactions. Not only that, but so is identity formation. This identity formation plays an imperative part in the development of the psyche and if the person “fails” to form the “correct” identity, then there are long-lasting psychological problems.

I looked deeper into Erickson’s theory and came upon a quote that deeply disturbed me:

in psychological terms, identity formation employs a process of simultaneous reflection and observation, a process taking place on all levels of mental functioning, by which the individual judges himself in the light of what he perceives to be the way in which others judge him in comparison to themselves

(Erikson, Chapter 3)

This quote disturbed me because I learned as an undergraduate that autistic people lack a theory of mind. Theory of mind is the ability to know that other people have their own thoughts and emotions and then, by extension, the ability to know what those thoughts and emotions are.
According to Erikson’s theory, you need to know what other people are thinking about you before you can develop an identity.

So I had to ask again: how is identity formed in autistic people? I searched for the answer, but couldn’t find any because this was a deal breaker. Every theory on identity revolved around Erickson’s original theory, so every single one required theory of mind for identity formation. And thus, the first dehumanizing enthymeme appeared in my research. An enthymeme is “an argument in which one premise is not explicitly stated” (“Enthymeme”). In this case, the enthymeme is:

1. You need to know what other people are thinking to develop an identity (Erikson)
2. You need to have a theory of mind to know what other people are thinking (Baron-Cohen, Frith, and Leslie)
3. Autistic people do not have a theory of mind (Baron-Cohen, Frith, and Leslie)
4. Therefore, Autistics cannot develop an identity because they do not have a theory of mind.

Now, it’s important that I point out that number 4 is not explicitly stated, that’s what makes it an enthymeme. It’s a line of logic that leaves something so the reader/audience has to participate and add it in. After I couldn’t find a workaround for how autistic people develop an identity because of theory of mind, I began focusing on theory of mind and found even more disturbing things: scientifically, enthymemically, and rhetorically.

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After reading Erickson, I was disturbed. It means that if I was autistic, then, according to Erickson and most psychological theories of identity, I couldn’t have an identity. I was back
where I was last semester. So, I used the same tool I had used the previous semester, deconstruction, to determine what was really going on with Theory of Mind.

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2. Theory of Mind

The first step towards deconstruction is understanding the meaning behind something. I have gathered several of the major articles from the first 17 years of the existence of the term “Theory of Mind.”

2.1 1978

The term “Theory of Mind” was first coined in David Premack and Guy Woodruff’s 1978 study entitled “Does the Chimpanzee have a ‘Theory of Mind.’” In this study, they tested a chimpanzee named Sarah with several tests they recognized at the publishing date did not actually test her theory of mind.

Daniel Dennet wrote an article entitled “Beliefs on Beliefs,” published in a section called “Commentary/Cognition and Consciousness in Nonhuman Species [emphasis added].” Dennett criticizes Premack and Woodruff’s tests because they take place in an unnatural environment. If the chimpanzee were to have a theory of mind, there was no way to find out if the unnatural environment taught the chimpanzee to pass the tests or if the chimpanzee had an innate theory of mind.

He then discusses what a natural theory of mind test would look like. He created what became the “acid test” for theory of mind: the Sally-Ann test. A person the child knows comes
in, places a marble in their basket, and leaves the room. Someone else comes in and moves the marble from the basket into their box. The person who the child knows comes back in and the child is asked, “Where will they look for her marble?”

2.2 1983

Wimmer and Perner took Dennett’s concept in 1982, but ignored his message about the problems of testing theory of mind in an unnatural environment on human children. A concept that was originally developed to look at Chimpanzees, an animal, was then being applied to humans. They found that the children under 4 could not pass the theory of mind test, but children over 4 did. From this, they concluded that children under the age of 4 did not have a theory of mind and children above did.

2.3 1985

1985 will live in infamy. That year, Simon Baron-Cohen, Uta Frith, and Alan M. Leslie conducted the same study as Wimmer and Perner but with autistic children. The title of that article is “Does the Chimpanzee have a ‘Theory of Mind.’” Wait, that’s not right. Sorry! It’s titled “Does the Autistic Child have a ‘Theory of Mind.’” Yeah, that’s right, they took out chimpanzee and replaced it with autistic child because they are pretty much the same (Please read that with heavy sarcasm).

They compared autistic children with matched neurotypical children (matched for IQ and verbal ability) and Down Syndrome children. The purpose of the Down Syndrome children was to ensure that a developmental delay did not explain the autistic children’s results. The
neurotypical children and Down Syndrome children passed the test, but the autistic children (save a few) could not. They concluded that autistic people lack a theory of mind.

2.4 1987

2.4.1 Alan M. Leslie

In 1987, Alan M. Leslie published an article that articulated the theoretical framework that was used in Baron-Cohen, Frith, and Leslie’s 1985 study. He claims that humans have an innate mechanism allowing them to “decouple” language from reality. An example he gives is that of a toddler who is able to pick up a banana and say, “This is my phone” and begin to talk on it. However, that toddler is just pretending that it is a phone, as evidenced by not trying to talk on bananas as they grow older. Leslie claims pretend play is a prerequisite to theory of mind.

He then points out the “fact” that autistic children cannot pretend play, therefore autistic children don’t have a theory of mind. However, in 1994, Jarold, Smith, and Boucher tested autistic children’s ability to comprehend pretend play. They found that there was no significant difference between autistic children correctly answering questions about pretend play and those of their non-disabled peers.

Therefore, Leslie’s premise that autistic children cannot pretend play is false, many just choose not to. There is difference between an inability to do something and a choice to not do something, which Leslie seems to ignore by assuming inability rather than agency (choice).

Leslie’s discussion on the decoupler theory sets theory of mind apart from other theories. He claims there is a decoupler separating language from reality. Now, as soon as you bring
language into the mix, you bring in rhetoric. Remember what Brummett said? Rhetoric creates language and language creates meaning. Now, is there a connection between meaning and reality?

Here’s where it’s gonna get highly theoretical (I can barely comprehend it, honestly). I’m bringing in the big guns in the form of Friedrich Nietzsche. Nietzsche claims that there is an objective capital-R Reality, but we rarely experience it. The reason we only rarely experience capital-R Reality is because as soon as our senses observe capital-R Reality, it becomes lower-case-r reality. Capital-R Reality exists, but we cannot experience it because we are subjective and our senses are subjective.

Capital-R Reality is objective, but lower-case-r reality is not. As soon as our senses begin to observe the capital-R Reality, it is subjected to our thoughts and biases. As soon as we think about something we observed, we begin to assign meaning to capital-R Reality, turning it into lower-case-r reality.

The fact that you are reading this (possibly on an iPad, computer monitor, TV, or something else) is capital-R Reality: you are reading this on something. However, as soon as you think about it, you subject it to your senses (you may be color blind, you may have synesthesia and see each of these words as a different color or hear a note as you read each word, the point is, you are subjecting the capital-R Reality and turning it into lower-case-r reality).

So, we know that capital-R Reality exists, but we cannot experience it; what we experience is the subjective lower-case-r reality formed by senses and language. Therefore,
language cannot change capital-R Reality because we can’t even access capital-R Reality to experience it. However, language does change lower-case-r reality.

Therefore, to say that language has no impact on reality, nor on passing theory of mind tests is hugely flawed. It is, in essence, saying that theory of mind is arhetorical: theory of mind exists outside the boundaries of rhetoric. If language is rhetorical (because rhetoric creates language), then anything that uses language uses rhetoric.

Science uses language to describe and discuss the results. Therefore, science is rhetorical because it uses language to write up its interpretations of the results. Theory of mind researchers claim theory of mind is scientific, yet Leslie’s decoupler theory claims theory of mind is arhetorical. Now, for a rhetorical question: theory of mind cannot be both scientific and arhetorical, so what is it? Before I can answer, I need to finish the history of theory of mind literature.

2.4.2 Beatrice de Gelder’s criticism of 1985 study

In 1987, Beatrice de Gelder presented the first critical argument of Baron-Cohen, Frith, and Leslie’s 1985 study. In it, she points out three main flaws as she saw them. The first was that, if you take into account the “fact” that autistic children cannot pretend play (Which, remember, is not true, they often choose not to), the testing situation is flawed. It is flawed because they are putting autistic children, who cannot pretend play, into a situation that expects pretend play in order to test their theory of mind. Sally and Ann are puppets, so to ascribe them
beliefs and thoughts is to pretend play. Therefore, if they failed, there was no way to know it wasn’t due to the pretend play situation.

The second point she brings up is very important to rhetoricians: the false belief test (that tests theory of mind) is embedded in language. She points out that “autistic children have impaired discourse abilities. Most typically, autistic children have problems with topic maintenance and with the illocutionary force of utterances, for example with understanding questions” (287). Therefore, if the pretend play didn’t set the autistic child up to fail, then the use of language would.

The last point she makes is that “without a theory of mind one cannot participate in a conversation” (288). More specifically, she points out:

To assume that the autistic children have understood the question means that one is presupposing that the autistic children do have a theory of mind which enables them to attribute beliefs, intentions, etc. to the experimenter asking a question” (288).

However after saying this, she says, “their theory of mind is less complex than that of normal children” (288). So, maybe autistic children do have a theory of mind because they can answer a question, but it’s not as complex and strong as everyone else’s.

Her criticism, while having many good points, uses terms and phrases that maintain the individual, or medical, models of disability. However, if the goal is to approach theory of mind from a critical standpoint, approaching theory of mind from the same perspective that the
original authors used isn’t going to work. This brings to mind the Audre Lorde’s quote of “The Master’s tools will never dismantle the Master’s house.” In this case, the Master’s tool is the language of the medical model of disability.

De Gelder probably did not set out to take down theory of mind or poke holes into it, she was just pointing out some errors she saw in the 1985 autistic theory of mind study.

2.4.3 Alan M. Leslie and Uta Frith response to de Gelder

Leslie and Frith responded with a co-written article in the same issue of Cognition as de Gelder called “Metarepresentation and Autism: How not to Lose One’s Marbles.” It is deeply disturbing that they approach theory of mind, a theory that has massive implications, with such trite humor. They point out three problems with her criticism. They first noted she had limited understanding of Leslie’s 1987 decoupler theory.

The second problem they had was with de Gelder’s understanding of autism. They point out that autism is distinctive because the “behavioral signs of autism form a triad (Wing & Gould, 1979) consisting of characteristic social incompetence, impairments of verbal and non-verbal communication, and, a lack of pretend play” (292). This triad of behavioral signs is not found in non-autistic developmentally delayed children like children with Down’s Syndrome.

They say that Leslie’s decoupler theory, or metarepresentational deficit theory, if correct, explains why autistic people have this triad whereas non-autistic developmentally delayed children do not. However, the 1985 study, while using this theory, was not set up to test this theory. His 1987 article demonstrated a common theme in a “wide range of arguments and
evidence” (292) out there to create the metarepresentational theory. In other words, the theoretical framework that the 1985 study used had not been studied before.

The third problem they had with de Gelder’s argument revolved around her criticism of their false-belief tests. de Gelder criticized the study for using a pretend play situation to test the theory of mind. Leslie and Frith comment that “we have had these worries ourselves and have repeated the experiments with real people instead of dolls—with identical results” (293).

They respond to her second criticism (how the false belief test is steeped in language and autistic people have impairments in the area of discourse) by pointing out that the autistic children were able to correctly answer two control questions.

If impairment of language comprehension is a problem for autistic children in these tasks, it seems to be strangely specific. It affects only language referring to mental states but not language referring to real states of affairs. We would also like to point out that we found the same specific failure in our second study, this time affecting language production (293).

So, according to Leslie and Frith, language impairments can only affect all language, not specific parts of it. That is curious because have you ever had a chinwag with someone? What about dipping chips in ketchup? What about abseiling? Hm, how about a barney, have you ever had a barney with a friend? Some may know what I am talking about here, but I’m guessing that many probably will not. These are all British English phrases and terms. A chinwag is a conversation, chips are fries, abseiling is descending a rope, a barney is a noisy quarrel.
The point that I am trying to make here is that, according to Leslie and Frith, you should know all of these. Why? Because language impairments only affect all language. But the biggest question is “Are you impaired if you don’t know these obvious terms?” Or is it possible that you just don’t know what they are because that is not your culture? So, if different cultures use different words to mean the same thing, then why isn’t it possible that only certain parts of language are different, misunderstood, or, if you desperately want to use the word, “impaired?”

Not only that, but if different cultures use different terms in the same language to mean the same thing, how will different neurotypes affect the use of language? Culture is usually an example of nurture and the brain is usually an example of nature. And we know autism is a result of brain differences. So, if the culture, an example of nurture, changes the way that language is used, then we would be remiss in saying that changes in the wiring and chemistry of the brain would not also affect language.

Now, I have to recognize that this was written in 1987, so we didn’t know as much as we know now about autistic neurology. Therefore, much of this is retrospective criticism, but it is imperative that we do criticize this because much of the argument supporting theory of mind uses these articles as proof of theory of mind. Any textbook on theory of mind has language that implies that theory of mind is true and no longer a theory.

2.5 1988
In 1988, Simon Baron-Cohen responded to de Gelder’s criticisms in the article entitled “Without a Theory of Mind one Cannot Participate in Conversation.” He focuses only on this quote from her criticism.

He uses an analogy to attempt to poke a hole in her argument that the autistic children in the study showed that they had a basic theory of mind by answering the control questions correctly. His analogy is this:

> When one switches on one’s computer and types the words “What is in disc-drive A?”, a correct response to this question is not taken as a sign that one’s computer has a theory of mind. If one then moves the contents of drive A to drive B and types the same words, again the computer’s correct response is no sign that it has a theory of mind. (83)

His argument for why autistic people do not have a theory of mind even though they were able to answer questions was that computers can do what the autistic children did, but computers don’t have a theory of mind so autistic children don’t have a theory of mind either. I really wish I was kidding here, but I’m not.

In his first study, he compares autistic people to chimpanzees by word replacement and now he’s comparing autistic people to computers. Now we have autistic people as either (possibly both) an animal or a computer. Hm, are they human? It would appear not if they are being compared to animals and computers. But more on that in a bit.

2.6 1995
Simon Baron-Cohen appears again on this list when he wrote his book “Mindblindness” in 1995. In Mindblindness, he postulates a theory on how theory of mind works. It involves four parts: intentionality detector (ID), eye direction detector (EDD), shared-attention mechanism (SAM), and theory of mind mechanism (ToMM).

The first part is the ID. ID is the innate ability in humans to understand people’s motivations. For example, Baron-Cohen gives the example of a man walking into a room, then walking around the room, then leaving the room. We assume this man probably walked into the room and completely forgot what he was doing in there, or he may have been looking for his keys. Baron-Cohen says many autistic people have this detector.

The second part is the EDD. EDD is the innate ability in humans to notice when people are looking at you (Baron-Cohen calls this dyadic representations). Baron-Cohen’s theory says ID and EDD are both needed to have a theory of mind. However, in cases of blindness, EDD is not important and the blind person can still have a theory of mind even though they do not have EDD (because they cannot see when someone is looking at them). Baron-Cohen says that many autistic people have this detector.

The SAM is the innate ability in humans to determine where the other person is looking and looking at it as well. Baron-Cohen calls this a triadic representation because you are looking at the person to begin with and seeing they are looking at something, then you follow their gaze to what they are looking at. This is the mechanism that stops autistic people from gaining a theory of mind according to Baron-Cohen. Baron-Cohen seems to think that because many
autistic people do not look other people in the eyeballs, they cannot follow where someone is looking (Remember the line between choosing not to do something and an inability to do something? Yeah, I guess crossing it runs in the theory of mind research family).

The final piece is the ToMM, ToMM is the innate ability in humans to know what other people are thinking as they are looking at something that someone else is looking at. Yeah, that’s how confusingly he describes it. So, you are looking at someone who is looking at something that someone else is looking at and you are able to know what the person you are looking at is thinking. Are you at least a little confused? Good! That is a rhetorical strategy many scientists use to make people automatically agree with what they are saying. The alternative, admitting you are confused, may make you look scientifically illiterate.

In chapter 8 of the book, Baron-Cohen says,

Some remarkable individuals with autism seem to overcome their mindblindness to some degree--certainly to the degree of being able to pass the trivial tests summarized in chapter 5 [(the test they conducted in 1985)]. But does the fact that they no longer fail these tests (they can understand, for example, that people have beliefs and desires) mean that they are now normal mindreaders? (139)

He goes on to say that they still do not have a theory of mind. So, in 1985, Baron-Cohen tests a bunch of autistic kids with a “trivial” test (the false-belief test) and after they are unable to pass it, he comes to the conclusion that they do not have a theory of mind. The neurotypical and
Down’s Syndrome children were able to pass the test, so he comes to the conclusion that they have a theory of mind because they can pass the test.

Then, ten years later, he writes a book talking about those autistic people who are able to pass this same theory of mind test (that determined that autistic people do not have a theory of mind and neurotypical and Down’s Syndrome people do have a theory of mind) and comes to the conclusion that they still don’t have a theory of mind. Huh? This brings us to the next section, the dangers of theory of mind.

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After reading over twenty articles and understanding the meaning behind theory of mind, I realized it had major problems. Prior to recognizing the problems, I was hesitant to even be assessed for autism. But if the only reason I had for not getting the diagnosis was because I had a theory of mind, that’s BS.

So I remember sitting on the phone listening to ringing and finally, someone answered and I set up my appointment to be assessed for autism 6 months out in August 2015. Even though I had set up the appointment, the nightmares continued.

Unseen voices in the dreams hissed, “You’re not autistic because there’s nothing wrong with you except you won’t change. You’re not autistic, you’re nothing!” But I wasn’t nothing, my research into theory of mind was going both steadily and intensely. I was reading almost an article a day, sometimes more.
Within the same week, I also decided to get my Autism Certificate at Saint Cloud State University over the summer. Little did I know how opposite these two decisions were at the time, but more on that in Chapter 3.

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3. The Dangers of Theory of Mind

Here are some “facts” about theory of mind:

- Alan M. Leslie commented that the decoupler is a mechanism found in *humans* that allows *humans* to separate language from reality. *Autistic people lack* this mechanism.
- Baron-Cohen claims that autistic people don’t have a theory of mind because *computers* don’t have a theory of mind and they can both answer questions.
- Baron-Cohen, Frith, and Leslie associate autistic children with chimpanzees by replacing the word *chimpanzee* with the word *autistic child*.
- Theory of mind is innate in *humans*.

All of these point to a disturbing enthymeme pointed out by Melanie Yergeau:

- To be human is to have theory of mind,
- to be autistic is to lack theory of mind, therefore,
- to be autistic is to be not human.

In other words, the line of logic put forth by theory of mind research leads to the unstated conclusion that autistic people are not human (Yergeau “Clinically Significant Disturbance”).

Another danger that evolves from this research is empathy. In Premack and Woodruff’s original 1978 study, they said that theory of mind and empathy are very closely linked.

However, very closely linked and the same are two very different things.

But in a news article published on Smithsonian, a study that looked at autistic children’s ability to read emotions in the body language of other people claimed to at empathy (Fessenden).
When theory of mind and empathy are the same, then autistic people “lack” both theory of mind and empathy. This leads to people thinking that because autistic people lack empathy, that means they can’t feel emotions either and proceed to dehumanize and mock them to their face. Yergeau’s article “Clinically Significant Disturbance” is full of examples of these types of experiences.

The final danger disrupts the idea of developing identity through writing that was discussed in chapter 1. Theory of mind is no longer found in just the field of psychology. The humanities, more specifically literature and composition, have begun to adopt it as a perspective for their fields. In her book entitled “Why we Read Fiction,” Lisa Zunshine claims theory of mind is used when we read literature.

Reading comprehension tests include questions like: “What was the author’s intent for this passage?” or “What was the character’s motivation as he was shaking with fear?” These are questions that ask the reader/test taker what the author or character are thinking.

In the field of composition, theory of mind appears when students are expected to “know their audience” before they write. If they tell too much or too little, they have lost the audience.

So, reading and writing requires theory of mind? That’s a big snag in my theory from Chapter 1 that the internet is key to identity formation in autistic people. If you need a theory of mind to understand and read things that other people say on the internet, then autistic people still can’t develop an identity.
This next section points out a new perspective: by looking beyond the history of the term theory of mind to the concept and process of theory of mind.

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As part of a class assignment, I presented my research on theory of mind at the Student Research Colloquium. I walked away thinking that it had gone okay, but was told that I “killed it.” This presenting stuff was terrifying before and exhilarating afterwards.

I now had a game-plan for my presentation at Computers and Writing, I was going to combine my presentations from GPACW and the Student Research Colloquium. I had a game plan and I continued to read about theory of mind.

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4. Onwards Towards the Deconstruction of Theory of Mind

4.1 History of the Concept

According to Obiols and Berrios, the concept of theory of mind dates back to the late 1800s to the work of James Mark Baldwin. Baldwin was a theoretical psychologist who created theories, but never tested them. In the late 1800s, psychology was just starting to get its foothold in the door of science. Prior to that, it was viewed as the philosophy of the mind. It wasn’t until Freud that psychology got a foothold in science.

JM Baldwin’s theories influenced a major player in the psychology scene that many people know of: Jean Piaget. Piaget was a developmental psychologist who followed the theories of the day in proposing childhood development happens in stages. He looks at several
common pieces in each stage. One of these pieces is perspective-taking. Sound familiar?

Perspective-taking and theory of mind are essentially the same thing.

The concept didn’t evolve much after Piaget until folk psychology began to emerge.

Folk psychology is defined as, “The ability to represent, conceptualize, and reason about mental states [in both oneself and others]” (Malle 1).

But what is the in-between in theory of mind? Theory of mind is defined as the ability to know that other people have their own thoughts and emotions and, by extension, knowing what those are.

There has to be something in between knowing other people have emotions and knowing what those emotions are. You can know that there is an answer to a mathematical problem, but there is something in between knowing that there is an answer and knowing what the answer is: you still have to work the problem out. Therefore, what is involved in working out what the other person is thinking or feeling?

In his article, Malle points to a possible, and I think very probable, answer to this question. “People deal with other minds by simulating, in their own minds, what is going on in the other person” (1-2). In other words, you work out what other people are thinking or feeling by asking yourself, “What would I do if I were in that situation?” and theorizing that the other person thinks the same way you do.

But theory of mind says that the first step is understanding that other people have their own thoughts and emotions. But simulation theory says that people think about the situation
someone else is in as if they were in that situation. In other words, they make the assumption that the other person thinks the same way they do. Any differences are assumed to be based on the situation, rather than differences between people.

To put this in context, the definition of theory of mind (knowing other people have their own thoughts and emotions) is contradictory to the process of theory of mind (assuming they think like you and determining what YOU would think in that situation). What if the person is from a different culture and thinks a different way than you? What if their brain is wired differently than yours, thereby making them think differently from you?

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A week before the Computers and Writing conference, I was asked if I wanted a mentor. I went through the rest of the day thinking about whether I wanted a mentor or not. I knew that I wouldn’t know anybody, but I wasn’t all that great around people. Who would I even ask to mentor me?

Then, an idea struck me, another awesomely insane idea. So, I sent back an e-mail, “Is it at all possible for Melanie Yergeau to be my mentor at the conference?”

I didn’t hear back for a few days, but I finally got a response, “I’m not sure, I have sent an e-mail to her seeing if she would be willing to be your mentor for the conference. I will let you know as soon as I hear back.”
The next twelve hours were excruciatingly slow, but I finally got the e-mail, “Yes.” I was not only about to have the chance to watch Melanie Yergeau present, but get to meet her as well. SQUEEEEEE!

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4.2 Different Brain Strokes for Different HUMAN Folks (that sort of rhymes)

After I presented on theory of mind at the 2015 Computers and Writing Conference, an audience member and now good friend, Alyssa Hillary, asked me, “Theory of Who’s Mind?” Sadly, and embarrassingly, it took me almost a month to figure out what she was actually asking. The following logical steps lead to the full extent of that question.

So, it is said in much of the literature that theory of mind is innate in humans. Yet autistic people don’t have it and that is widely known. But I ask: is it really innate in humans?

In Paul Heilker and Melanie Yergeau’s article “Autism and Rhetoric,” they point out that autism and rhetoric are closely linked. They both deal with how to communicate a message. Heilker and Yergeau claim autistic people use their own form of rhetoric. If they use their own form of rhetoric, then their use of language and pragmatics (or the use of communication) and the way they interact with both the world and other people would be different.

If autistic people use language differently, then they may have difficulty with the language aspects of the theory of mind tests. However, to prove this, I would have to show that passing the theory of mind test is based on language. To remind you, much of the literature on theory of mind claims that language has no impact on theory of mind.
However, “Hale and Tager Flusberg (2003) found that providing 3- to 4-year old children with training on sentence complements improved false belief performance as much as direct training on false belief tasks” (Miller 246-247). Sentence complements were defined as teaching them that two parts of a sentence don’t have to match truthfully. So, in the sentence “Tommy thinks that the world is flat,” it is true that Tommy thinks that, but it is also false that it is flat. Sentence complements help the child understand that mental state terms mean that what is coming up is true because it is connected to a mental state term. They found that teaching this to the kids was as effective as teaching the kids how to pass the false-belief test.

Lohman and Tomasello (2003) also found that sentence complement training resulted in better false belief performance. Furthermore, false belief improved following training with discourse about deceptive objects that did not include complements. In Lohmann and Tomasello’s study, the most improvement was found when training included both sentence complements (with either mental or communication verbs) and experience with deceptive objects. (Miller 147)

The deceptive objects test is another theory of mind test. It involves having an object that looks like something else and asking the kid “what is it” before they touch it, asking the kid “what it is” after they have touched it and then “what will Sally think that it is?” This study fits with what the previous study found: training on sentence complements and deceptive objects was the most effective. In other words, language matters in these tests.

Are you ready for the big guns on how language impacts theory of mind performance?
Shahaeian et al. [2011] recruited 135 Australian and Iranian children ages 3-6 years...These researchers found that, on average, both nationalities passed the same number of tasks, but for three types of tasks--FB [false belief], Diverse Beliefs, Knowledge Access--the two groups differed significantly on percent correct. (Fisch 2470)

That is, Australian and Iranian children have similar overall performance on theory of mind tests, but the Iranian children performed better on some tests while the Australian children did better on others. It could be argued that this is a language-based occurrence, or it could equally be argued that it is a culture-based occurrence (but most likely, it’s both). Either way, it suggests that perhaps theory of mind tests are flawed.

If we based whether the children have a theory of mind on how the 1985 study decided that autistic people don’t have a theory of mind, then those tests that the Iranian children passed, but the Australian children did not, prove that Australians do not have a theory of mind. And vice versa. Let’s say that both groups don’t have a theory of mind because they weren’t able to pass all of the theory of mind tests.

Peterson and Siegal [1995] examined 26 deaf children, ages 8-13 years, who grew up in homes where sign language was not used...Of the 12 children administered the standard FB [False Belief] task, only 2/12 (16%) passed...Consequently, Peterson and Siegal [1995] concluded that ToM deficits were not specific to autism. (Fisch 2473)
So, not only do autistic people lack theory of mind, but so too do Australians, Iranians, and Deaf people who have grown up in homes where sign language was not used.

This next study surprised me because I had no idea that I was going to find it. “Wahi and Johri [1994] assessed 42 Indian children, ages 3-8 years, from two distinctly different socioeconomic strata, using a FB [false belief] task...they also found that socioeconomic factors made for significant differences in percent correct” (Fisch 2470). Okay, so now we have autistic people, Australians, Iranians, Deaf people who have grown up in homes where sign language was not used, and people from lower socioeconomic statuses all lacking a theory of mind.

After seeing this, I looked at what other groups don’t have theory of mind. Here’s the list.

- Autism
- Epilepsy
- Schizophrenia
- ADHD
- Economically Disadvantaged
- Linguistically Diverse
- Culturally Diverse
- Alcoholics
- People who have had a stroke
- Deaf people who have grown up in homes that don’t speak ASL
- Frontal variant Frontotemporal dementia
- Alzheimers

I’m going to ask the question that I asked at the beginning of this section: Is theory of mind really innate in humans? My answer is that it is not. Theory of mind is used by dominant
groups as a tool of oppression meant to rob some people (including autistic people) of identity, agency, and personhood.

So, the answer to my friend’s question, “Theory of who’s mind?” is theory of the dominant mind. Theory of mind is only concerned with marginalized people understanding the minds of dominant and neurotypical people.

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The day before the conference, with the prospect of meeting Melanie Yergeau, I almost decided not to go because of my social anxiety. But, go I did, and I met her. I also met three other autistic people, all of whose presentations were amazing. We ate nearly every meal together and I finally felt like I had found a group where my social interactions fit in.

But I was constantly plagued by thoughts that they wouldn’t like me if I came out that I wasn’t officially diagnosed as autistic. I was like them, behaviorally and neurologically, but I wasn’t medically recognized as like them. So, as much as I felt like I fit in, I also felt like I couldn’t because I wasn’t diagnosed with autism yet.

But this thought process was about to change, everything was about to change in the coming months as I took the journey of self-acceptance and getting to know myself.
Works Cited: Chapter 2


Fessenden, Marissa. "Kids with Autism can Read Emotions through Body Language."


Fisch, Gene S. "Autism and Epistemology IV: Does Autism Need a Theory of Mind?"


Chapter 3: BRIDGING THEORY OF MIND AND ADVOCACY

For five months, I researched theory of mind. At the start of Summer 2015, I planned to give the history of theory of mind, and then deconstruct several watershed articles. Little did I know when I signed up to get my Autism Certificate over the summer, that plan would completely change.

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We began the first class as all classes do: with the always infuriating get to know you introductions. The professor asked us to say, “What our name is, what grades we teach, and what our autistic characteristic is.” As the only male-presenting person in the classroom, I was asked to go first. I said I have a very difficult time with social interactions. I knew that I could go on to say things like flapping my hands and verbally stimming (i.e. trilling, purring, chewbacca-ing, Golluming, etc.) when I’m excited.

But, if I say that, they would judge me. They might also ask me to prove it, which I didn’t want to do. I shouldn’t have to prove who I am to be who I am. So, I only said I have a very difficult time with social interactions.

Everyone else went and they said things like “I like having routines,” “I am hyperactive,” and “I have anxiety.” None of those things are actually just autistic. Neurotypicals enjoy routines just as much as the next autistic. Hyperactivity and anxiety are co-occurring conditions, but they are not autism.

Once we were all done introducing ourselves, the teacher said, “I guess we’re all autistic” and everyone laughed. Here were a group of teachers who were going to be teaching autistic students. And they were laughing that “we are all autistic.” To me, this seemed like a white
person saying, “I guess I’m black” because of some singular characteristic that they share with what they assume an African American would be. The laughter, therefore, is a laughter that says while they share a similarity with this subaltern group, they still fall under the dominant group and are protected. The laughter really said, “I have characteristics of autism, but thank god I’m not actually autistic.”

I recognize that probably not everyone in the classroom laughed, many may have laughed on the outside while cringing inside. This still created a very dangerous environment for this class and program.

If this had happened once (laughing after someone says, “we’re autistic”), I would have chalked it up to a mistake or a one-off occurrence. But it happened again. Someone would mess something up, then say, “Well, I’m autistic.” And everyone would laugh.

It still makes me sick to my stomach. This is a disturbing, if not disgusting, precedent for a career of working with autistic students in the PreK-12 system.

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1. Rhetorical Analysis of Autism Speaks’ Self-Advocacy Document

On their missions page, Autism Speaks declares that they seek to:

Change the future for all who struggle with an autism spectrum disorder.

We are dedicated to funding global biomedical research into the causes, prevention, treatments and a possible cure for autism. We strive to raise public awareness about autism and its effects on individuals, families, and society: and we work to bring hope to all who deal with the hardships of this disorder. We are committed to raising the funds necessary to support these goals.
Autism Speaks aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis [emphasis added]. It is our firm belief that, working together, we will find the missing pieces of the puzzle.

(Autism Speaks, para. 1-3)

In summary, Autism Speaks advocates for the cure of autism. They do this by claiming that autism is a struggle, hardship, and “urgent global health crisis” (para. 3). How, then, does this mission of eradicating autism reflect in self-advocacy documents?

1.1 Toolkit 1

The toolkit is a 10-page document called “Self-advocacy.” Due to the fact that it is called “self-advocacy” and Autism Speaks is an autism advocacy organization, I thought autistic people would be the audience.

However, passages like the following show otherwise:

“The most important place to start the transition process is with your child, who is now an adolescent with autism” (1).

“For most of your child’s life, you have probably been advocating for your child—making decision for him or her” (5).

“It is important that an adolescent with autism be told that he or she has autism” (11).

Based on the “you” is in these sentences, the intended audience is not autistic people, but their presumed non-autistic parents.

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I was two months away from the neuropsych test that would allow the neuropsychologist to diagnose me with autism if I had it. My dreams were plagued with nightmares of telling people I was autistic. The people I told would then demand I show them my paperwork. When I couldn’t, they treated me with seething disappointment that made me feel like shit.

Am I really autistic or is my brain just making all this up?

What if this thing that explains so much about who I am is taken away?

What if...

The “what if” questions went on and on; on and on my brain continued to perseverate on them. I was reading Alyssa Hillary’s post on self-diagnosis when I realized sie was saying self-diagnosis is valid. I had met Alyssa at the national Computers and Writing Conference in May, so I sent an e-mail asking about it, admitting I was not (yet) an officially diagnosed autistic person.

Sie responded “You can definitely say the words. How well that goes depends on what context you’re saying it in. ASAN and AWN and ANI have all gone with yes, but Autism Speaks doesn’t addresses it, but they also suck...Within Autistic-run communities, the answer is almost universally yes” (Hillary “Re: Self-Diagnosis”).

Then, sie said something that I can never thank sier enough for, something I didn’t even realize I needed to hear. “Welcome.” It took me a bit of time to realize sie was welcoming me to the autistic community. And just like that, all of the anxiety and nightmares stopped. I was officially part of the autistic community.

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1.2 Toolkit 2

Toolkit 2 is a 4 page document that looks like it is written for the audience of autistic people. One page is dedicated to what self-advocacy is and the other three are slides from a PowerPoint. However, if you look closer, you will see that the part on what self-advocacy is is taken directly out of the parent one. There’s a quote taking up half page where “you” again references the parent.

“Yet if we deny [sic] kids our children this very important aspect of identity, we limit their ability to become the successful adults we want them to be” (Autism Speaks 4). So, both self-advocacy toolkits are dedicated to the parents. Perhaps they are self-advocacy toolkits, but who would be the self-advocate?

Before I move on, I would like to reflect on one slide of the PowerPoint found in the second document. In slide 3, they give the following information on a young man with autism (person-first language here is due to a point on the second slide: “I have autism, but it does not define me”): name, age, birthdate, birthplace, gender, living family, and where he went to high school. All of this is true, if you search this information, you can find a video of him walking for his high school graduation.

Where is this young man’s right to privacy? If his parents decided that they were going to share it, he has no right to privacy because he didn’t make the decision, his parents did. This is the unfortunate reality of Autism Speaks: parents are the go-to people for (in quotation marks) “self-”advocacy.

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In the second week of class, the professor presented on a topic I knew a lot about: theory of mind. However, whereas I was trying to discredit it, she was using it to make the unproven
claim that in order to learn, you need to have a theory of mind. The reason behind this is because theory of mind is intricately connected with executive functioning because...unexplained reasons.

I looked at her sources and found Autism $peaks was among them. Autism $peaks is the self-proclaimed “world’s leading autism science and advocacy organization” (“About Us” para. 1). If they are an advocacy organization for autistic people, then why were they supporting a theory of that clearly 1) dehumanizes the very people they claim to advocate for and 2) has huge logical and rhetorical flaws.

That feeling I had from Fall 2014 began to surface again. But I was still on the theory of mind binge, so I believed that wasn’t going to change. Until it did with the next class’s conversations and assignments.

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2. Rhetorical Analysis of Autistic Self Advocacy Network’s (ASAN’s) Self-Advocacy Documents

ASAN’s mission statement is as follows:

Seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens [emphasis added]. (Autistic Self-Advocacy Network)

ASAN is advocating for the world to accept autism and cure, or eradicate, ableism, not autism. Ableism is the “discrimination or prejudice against individuals with disabilities” (Ableism) and is similar to racism and sexism, but in regards to disability rather than race or sex.

Autism Now, The Arc, and Autistic Self Advocacy Network (n.d.) published a self-advocacy curriculum that is 74 pages. The following quotes represent who the audience is:
“Keeping an eye out on the trends can help you advocate along with other autistic advocate” (p. 30). “So you may be curious to know what it looks like to run a meeting effectively? It does NOT mean having your advisors in charge. Let them be there to assist you only when needed” (p. 36). Autistic people are the audience.

The one flaw of this curriculum is that it doesn’t have any tips on self-advocating. It is more a guidebook on things that self-advocates may encounter.

However, after a bit of searching, I found another curriculum on ASAN’s website that did gave tips on advocating for access to home and community services. It is 139 pages and again, autistic people are the audience: “Self-determination is controlling your own future. It means you are the one in charge of your life” (Administration on Intellectual and Developmental Disabilities 12) and “Working with government programs can be very confusing, but Home & Community-Based Services can help you live the life you want to” (15).

ASAN has a total of 213 pages within just these two documents (there are many more that ASAN has published, but I just chose these two for this analysis). This is vastly juxtaposed with Autism $peaks’ 14 pages total. ASAN’s audience is the Autistic person, whereas Autism $peaks’ is the (non-autistic) autism parent.

3. Medication as an Autism Treatment?

On the first day of the second class, which focused on Applied Behavior Analysis (ABA) and effective treatments, I was assigned to write a paper on medication as a behavioral treatment for autism. After a bit of pre-research, I decided that I was going to focus on the medications that supposedly treat the core symptoms of autism: “repetitive and stereotyped patterns of behavior...language impairment and...impairment in social interaction” (“Risperidone is effective...” 1).
3.1 Research Units on Pediatric Psychopharmacology

In 1995, two governmental groups (the National Institute of Mental Health and the U.S. Food and Drug Administration) cosponsored a conference that brought researchers, patient advocates, and mental health professionals together. After the conference, a request was sent out asking for more research studies on the psychotropic drugs that were being prescribed to autistic children between the ages of zero and seventeen.

Prior to this, doctors prescribed drugs that had been tested and determined effective for adults to autistic children. However, nothing was known of their effects on children. This request is now known as the Research Units on Pediatric Psychopharmacology, or RUPPs (“Risperidone is effective for one of three core symptoms of autism”).

In the years that followed, many studies tested new drugs and old to determine their effect on autistic children. My immediate research question that comes up was “How many children with autism are prescribed medication to treat their autistic symptoms?”

3.1.2 Prevalence of Medication in Children with Autism

In 2014, Jane Schubart, Fabian Camacho, and Douglas Leslie studied this exact question. They gained access to “Medicaid Analytic eXtract (MAX) data from 41 states for 2000-2003...[which] provide person-level data and include information on Medicaid eligibility, service utilization, and payments” (632). The data set they studied included nearly 3 million children and adolescents. They broke psychotropic drugs into six categories: antidepressants, neuroleptics, anxiolytics, mood stabilizers, sedative/hypnotics, and stimulants.

The population of children with autism they studied was “13,390 in 2000...15,805 in 2001; 16,818 in 2002; and 19,243 in 2003” (632), which they pointed out to reveal an exigency (an importance) of their study. In 3 years, the prevalence of autism had risen by nearly 6000. For
the comparison group, they looked at people who did not have autism who were diagnosed with certain types of mental health disorders. They do not give the size of the comparison group.

They found that about 65% of children with autism received psychotropic medication, most commonly receiving antipsychotics. 30% of these children were prescribed psychotropic medications in more than one class. The control group had a smaller percentage (54.3%-57%) of patients receiving psychotropic medication. An average of 36.9% of children with autism were on antipsychotic drugs compared to 13.7% in the control group.

If 65% of children with autism are receiving psychotropic medications, what studies have been done to determine the efficacy of these medications in children with autism? Furthermore, how do they define efficacy and do the clinical benefits outweigh the side-effects?

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In my research, I found a page dedicated to medication on Autism $peaks’ website. They begin by commenting that combining medication with ABA is the most effective treatment for autism. This reminded me of a concept from an author who had made me want to quit graduate school 11 months prior. It was Michel Foucault’s concept of docile bodies.

In “Discipline and Punish,” Foucault discusses how groups in power desire people who don’t question or challenge the status quo, in other words, docile bodies. Was it possible, then, that medicating autistic people is just a form of turning them (us?) into docile bodies?

But, here was my point of confusion. Autism $peaks was again supporting something that felt wrong. If they were an advocacy organization, who were they really advocating for? Again, however, I turned back to Theory of Mind.

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3.2 Antipsychotics: Risperidone

Risperidone was approved by the Food and Drug Administration (FDA) for treatment in 2006. It was the “first drug to treat irritability associated with autism” (“FDA Approves”). According to McDougle et al. (2005), risperidone significantly decreases the behavioral disturbances of autism (defined as severe tantrums, aggression, and self-injurious behavior). The study cited here sets out to determine if risperidone has any effect on autism’s core symptoms.

They conducted an 8-week double blind, placebo-controlled trial of risperidone. During this time, they modified and administered 3 times (baseline, week 4, and week 8) several rating scales that related to the core symptoms of autism: the Ritvo-Freeman Real Life Rating Scale, the compulsion scale of the Children’s Yale-Brown Obsessive Compulsive Scale, and the Maladaptive Behavior Domain of Vineland Adaptive Behavior Scales.

They found that, compared with the placebo, risperidone significantly reduced the overall score on “subscales [on the Ritvo-Freeman Real Life Rating Scale] for sensory motor behaviors (subscale I), affectual reactions (subscale III), and sensory responses (subscale IV)” (1144). However, risperidone did not have a statistically significant effect on social relatedness or language. The Children’s Yale yielded similar results on the repetitive behaviors, which “went from 15.51...to 11.65” (1145). This is compared to the placebo group, which went from 15.18 to 14.21.

This was their conclusion:

The results of this analysis of secondary measures indicate that 8 weeks of treatment with risperidone is not significantly different from placebo for the qualitative impairment in social interaction and communication that characterize
autism, but repetitive and stereotyped patterns of behavior, interests, and activities did improve. (1147)

This study shows that while Risperidone is FDA approved to treat irritability, it also has treats repetitive behaviors, a core symptom of autism.

3.2.1 Rhetorical Analysis of the Study

But I have to challenge the warrants of this article. Efficacy is defined as treating the core symptoms of autism: repetitive behavior, social interaction, and language.

Why are we trying to medically fix these things? Would we try to medically fix an English language learner because they are not like us? No, we wouldn’t, and if we would try, there would most likely be an uproar. So why are we trying to medically fix autistic behaviors?


They are using the medical model of disability here as evidenced in their use of the words disorder, symptoms, impairments, and restricted. Disorder is solely in the medical model because it says that something is not ordered. Who gets to decide what is ordered and what is not ordered? The dominant groups, in this case, non-autistic people.

If a non-autistic person enjoys writing so much that writing is all they do, we would not say they have “restricted repetitive and stereotyped patterns of behavior, interests, and activities” (1142). We would say that they are a writer. Yet, if an autistic person does the same thing, it is
evidence that they do have “restricted repetitive and stereotyped patterns of behavior, interests, and activities” (1142). There is a double standard here!

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One of the things that I had read online was that Autistic people really don’t like ABA. I began my second class wondering why that was and found that they feel it “changes and gets rid of autistic behaviors.” I wondered how it did this and why society was okay with it.

On the second day, we watched a series of lectures by Gregory Hanley and I found out. The first was on how to do a functional behavior assessment as an applied behavior analyst and the second was how he implemented a functional behavior plan on three case examples. A functional behavior assessment is determining what the purpose of a behavior is.

This introduced me to three kids who were subjected to ABA where the goal was to “reach the goals of the parents.” These goals included make my kid play basketball with me; go to super walmart and buy things for the parents, but nothing for the kid; make the kid do math in the way he was taught, rather than the way he was doing it (which was correct); or play with the kid’s toys with the kid’s siblings while refusing to allow the kid to join in. These were their goals, all of them make me feel very uncomfortable.

What if the kid doesn’t like basketball, should we train him to like it or just suffer through it? Why bring the kid to the store at all, stores are boring (I can attest, I practically lived in one because we went there so much). If you want to bring him to a boring store that has nothing to do and not reward him afterwards with buying him something, don’t be surprised when he gets angry.

The kid was doing math correctly, but nobody understood his method. But he was getting the right answer, why are we trying to fix that? Finally, I don’t even know how to
respond to the playing with the kid’s toys without letting the kid play because there are so many things wrong with that.

This reminds me of something Amethyst Schaber says in her YouTube Video, “Ask an Autistic - What is ABA?”: when you put an autistic kid through hours and hours of therapy (40 hours per week) that drills into the kid’s head that they can’t say no to adults, you are setting a dangerous precedent.

But, when I first watched the video, I didn’t think anything was wrong with it until I began to realize that they were, indeed, attempting to remove autistic behaviors. When Bob loves to do math in his own way because of the process, but is told that he can’t do math in his own way, they are attempting to remove autistic behaviors, autistic thoughts, even.

According to this logic, the following people should not have existed in the way we know of them today: Albert Einstein, Leonardo DaVinci, Michaelangelo, Steve Jobs, and many others. I’m not retroactively diagnosing these people with autism, I’m simply saying that their radically different thought processes and ways of doing things (like math) have changed our world.

However, if it was left up to Applied Behavior Analysts, we wouldn’t have Steve Jobs, who had the troublesome behavior of being borderline verbally abusive to his staff when they didn’t give him what he wanted. He would have been forced to follow the status quo. Which again reminded me of Foucault and docile bodies. And that’s when I realized what the autistic people against ABA were really saying: ABA forces autistic people to act neurotypical even when that puts us (us? Am I one of them?) into a dangerous place mentally, emotionally, or physically.

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3.3 Medication + Therapy

A study was published in 2009 by Aman et al. that set out to determine if there was a statistically significant decrease in problem behaviors (temper tantrums, irritability, self-injurious behavior, etc.) when comparing medication alone with parent training of behavior management and medication. While there was no placebo in this study, there was a control group who just received the medication. If the child did not respond to the risperidone, the researchers switched them to aripiprazole.

They gave multiple modified assessments including: the Autism Diagnostic Interview-Revised, Home Situations Questionnaire (HSQ), Vineland Adaptive Behavior Scales, Clinical Global Impressions (both Severity and Improvement subtests), Aberrant Behavior Checklist, and Children’s Yale-Brown Obsessive-Compulsive Scale-PDD Version.

The parent training group “consisted of 11 core treatment sessions, three optional, and up to three booster (two via telephone, one in person) sessions (maximum of 17 sessions), each 60-90 minutes” (1145).

They found that scores on the HSQ declined 71% from 4.31 to 1.23 for the children who received both compared to a decline of 60% (4.16 to 1.36) for the control group.

Also of interest is that their weight increased during the study. For the medication alone, the average weight increased from 69.27 to 81.15. For the combined, average weight increased from 67.55 to 80.98.

Many adverse effects were listed during this trial. Approximately 80% of both groups developed rhinitis from the medication. Symptoms of this are similar to hay fever (allergies).

They concluded that Combined treatment of parent training and medication reduces behavior problems.
3.3.1 Problem Behaviors

The efficacy of this treatment was the reduction, or eradication, of problem behaviors (i.e. temper tantrums, irritability, self-injurious behavior, etc.). But what are these problem behaviors?

Behaviors, problematic or not, are a form of communication. As a child, I had temper tantrums and irritability, and they would usually start after something absolutely tiny would happen like my mom trying to make me eat vegetables or my dad saying something that angered me. I would be well-behaved for a long time, then suddenly, blow up and become so angry that I scared myself.

What I am trying to say is that it is very dangerous to medically stop these behaviors. I’m not talking about the side effects, I’m talking about the docile-body nature of it. As evidenced in these studies, medicine can be used to stop autistic people from communicating their needs through behavior.

Is it easier to shove some medicine down an autistic child’s gullet? Yes, but that doesn’t make it right. We are medically lobotomizing autistic people when we give them medication that will end their “problem behaviors.” Their behaviors are trying to communicate, “Something is wrong!” Yet, we too often just see them as inconveniences or not trying to communicate anything.

But their behavior could also be doing another thing, resisting. It could be resisting a sensory-overload environment (i.e. loud, fluorescent lights), it could be resisting the demands placed on them. If these problem behaviors are resistive, then we are erasing their voice when we medicate them.

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Outside of class and researching for the paper, I decided that I wanted to 1) know more about why autistic people were against ABA and 2) find out what rhetoric and logic my teacher would use when responding to it. Nothing could have prepared me for what I would find. It was beyond just getting rid of the autistic characteristics.

**TW: ABA aversives and abuse**

I watched a series of segments of Anderson Cooper 360 called “The ‘Sissy Boy’ Experiments.” It talked about a study that was done in 1970 by George Rekers and Ivar Lovaas that treated an effeminate boy named “Kraig.”

Their idea was to make the boy straight (in both behavior and sexually) before he could become gay, so they used aversives (beatings carried out at home) when he acted effeminate and rewards when he acted masculine. The idea was to shape the boy’s behaviors and thereby shape his mind. Make him act masculine and he won’t be gay.

Several years earlier, Lovaas also dealt with another kind of behavior therapy that was intent that “by forcing a change in a child's outward behavior he can effect an inward psychological change” (Grant para. 6). He called this kind of behavior therapy Applied Behavior Analysis.

Lovaas, the founder of ABA, co-wrote the article on gay conversion therapy that used the same techniques as ABA. What were some of these techniques? Be warned, what I’m about to cite is deeply disturbing, yet, it doesn’t portray the doers of ABA as cruel, it portrays the children as such.

In the Alan Grant’s 1965 article “Screams, Slaps, & Love,” he talks about four young autistic children who were “utterly withdrawn...whose minds are sealed against all human contact and whose uncontrolled madness had turned their homes into hells” (para. 1). It is a
picture essay, so I will explain the images (see Appendix 1 for images). In the first picture, you see a still of a man about to slap a child in the face (image 1).

The next picture sees the same man’s hand making contact with the young boy’s face (image 2) still screaming. We are then told that the child is 7 years old named Billy. The final still of this set is the child crying and the man still screaming (image 3).

If that wasn’t bad enough, the next four images and descriptions of them made me sick. The first shows a 9-year-old girl named Pam stimming with her tongue out. She is standing barefoot on a floor with metal strips going from one end of the room to the other (image 4). The next image finds her doubled over with her left foot raised, seemingly flapping her hands (image 5). The third image of this set sees her hugging the person in the room with her (image 6). The final image sees her seemingly screaming (image 7).

The story that goes with these is equally as disturbing—and disgusting. “The most drastic innovation in Lovaas’ technique is punishment...insantly, immutably dished out to break down the habits of madness. His rarely used last resort is the shock room” (para. 10). The shock room is a room with metal strips on the floor, those metal strips can send an electric shock into a barefoot person’s foot.

Two electrodes were put on Pamela’s back and her shoes were removed. When she began to stare at her hand, he would send a mild jolt of electricity through the floor into her barefeet. The words that follow show the mentality of the times, “With instinctive cunning, Pamela sought to mollify Lovaas with hugs” (para. 11). I don’t know about you, but I would be trying to be really cunning if I were put into that situation.

END TW.
So, I sent this information to professor and asked her, “How do we respond to people when they brings these things up.” Her answer would prove to be terrifying!

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3.4 Memantine

In their 2006 study, Erickson et al. conducted an experiment to look at the efficacy of memantine on the social impairment of autism (one of the three core symptoms). They point out that “some investigators have hypothesized that glutamatergic dysfunction may be important in the pathophysiology of autism...Glutamate is the primary excitatory neurotransmitter in the brain and plays a critical role in cortical functions, as well as neuronal development” (142). They used rating scales to determine the efficacy of memantine in the area of social impairment.

The population they studied was 13 patients diagnosed with autistic disorder, 3 with aspergers, and 2 with PDD-NOS for a total of 18 patients. 11 of these had a comorbid developmental delay. 13 of these 18 patients received other medications during the memantine trial.

11 (or 61%) of the 18 patients were deemed responders as determined by receiving a 1 or 2 on the improvement rating scale. Using the Aberrant Behavior Checklist that was available for 6 of the 18 patients, they were able to determine a significant improvement on the hyperactivity subscale from 23.17 at baseline to 16.33.

The adverse effects affected 7 of the 18 patients. They included “increased irritability (n=4), rash (n=1), vomiting (n=1), increased seizure frequency (n=1) and excessive sedation (n=1)” (145).
They concluded “some patients showed clinically significant improvement in social interaction and attention” (146). However, one of the main limitations of this study is that it was a retrospective study. Therefore, it may have had observational and assessment bias.

3.4.1 Bias

So, there was observational and assessment bias in this article, but there was also another type of bias. One based on brain structure? Neurotypical bias. There is a neurotypical bias in this article, and all of the articles on medicine that I have cited so far. This is evidenced in their medical-model terministic screens, in their decision to “fix” the core symptoms of autism so they can “normalize” autistic people.

I fell for the terministic screens. When I originally wrote a paper on medicine, I gave it an external ethos (credibility). I trusted that because it was scientific, it was trustworthy and credible. But again, the most important thing that I can do right now is challenge all of my warrants (assumptions) that I hold. Because I was raised in an ableist society, I was raised in a society that has ingrained neurotypical bias, and I was raised in a society where most people don’t even know that ableism or neurotypical bias exists.

And so, I must challenge my warrants and critically analyze them. Perhaps some are true, but more often than not, I have seen that they are incredibly flawed. And there is shame in that. There is a deep sense of shame that encourages me to stop. But that is the moment that every fiber of my being tells me to push on and continue, embrace the shame, be okay with it, and not be okay with putting a student in a physical hold, for claiming that autism is not a disability, for claiming that disability is a bad word, for believing that theory of mind was true.

Shame is not bad, it is an agent of change begging and encouraging us to do better next time!
She asked to wait to answer my question until the final class period. When that part of the class began, she asked me to explain what I had found. I explained all that I had found and when I stopped, she started shaking her head, disappointedly.

**TW: Ableist tirade supporting ABA and forcing autistic people to change**

She began what I can only call a diatribe for ABA. “First off, Ivar Lovaas never shocked anyone. Secondly, these supposedly autistic people, who by the way were probably diagnosed after they were 4 years old, which means they are almost guaranteed not actually autistic, are probably lying. Those who claim that ABA is akin to child abuse and causes PTSD are all also probably lying. Not only that, but there is no research out there that suggests that ABA causes PTSD.

“Thirdly, there is absolutely no connection between ABA and gay therapy, none whatsoever. And now to address the idea that ABA robs autistic people of their identity, well, that’s just bullshit. We need to change them because I don’t care if you have a diagnosis or not, behaving and complying is what you should do because, in the end, if you want to have a good life, you need to change your behaviors.

“I had a kid come into my clinic who was stimming all the time and had problem behaviors up the wazoo, and now, now he is indistinguishable from his peers. He doesn’t show any signs of autism and that, I think, is pretty damn cool.”

**END TW**

She gave the class a proud smile and many of the other teachers joined her by smiling and saying quietly, “That is cool!”

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3.4 Oxytocin

In 2003, Hollander et al. studied oxytocin’s efficacy on treating repetitive behaviors. Oxytocin is a naturally occurring hormone that is has been long known to play a role in milk ejection and uterine contraction during labor. However, recent theories and subsequent research suggest it also plays a role in developing neurotypical cognition.

They hypothesized that “infusion of synthetic oxytocin might modulate the severity of this repetitive behavior domain in patients with autism spectrum disorders” (194). They had 15 adult patients, 14 male and 1 female. 6 of them were diagnosed with autism and 9 with asperger’s syndrome. They determined that the control group would be individualized. That’s every time they came in for an infusion, they randomly given a placebo or oxytocin. By doing this, they could compare each individual to themselves as autistic people are a heterogeneous group. Every two weeks, they received an intravenous infusion of oxytocin or placebo over a four hour period.

They observed for repetitive behaviors during these four hours and found that 13 of the 15 patients (86.7%), when infused with oxytocin, showed a decrease in repetitive behaviors whereas it was only 6 patients (40%) did when infused with a placebo. For 1 patient who received the oxytocin, their repetitive behaviors increase and it didn’t do anything for the last patient. For 6 patients who received the placebo, repetitive behaviors increased and two were unchanged.

The adverse effects noted in the research were listed as mild and included “drowsiness, anxiety, depression, headaches, tingling, backaches, trembling, restlessness, stomach cramps and enuresis” (196).
They came to the conclusion that “administration of exogenous oxytocin decreased the core autistic repetitive behaviors measured” (196). Why are we trying to decrease repetitive behaviors? Are they problematic? No, they just aren’t “normal.” Therefore, therapy then decides to try to medically make autistic people act like neurotypicals, just like ABA.

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I sat there, speechless, with no idea how to respond to such disgusting ableism. Autistic people need to be changed? What the hell is wrong with her! Not only that, but there are clear ties between ABA and Gay Conversion Therapy.

Lovaas worked with the father of Gay Conversion Therapy on a study that “converted an effeminate kid” into being straight—that’s right, he was indistinguishable from his peers. So indistinguishable that he killed himself because of the hatred instilled in him towards himself during the Gay Conversion Therapy at the hands of Iverson and Lovaas’ study (SISSYBOY THING).

I made the decision that I would not remain silent in the next class, even if that meant that I would fail it. I couldn’t handle the stress of remaining silent when these teachers who were going to go out and teach with all of this absolute BS in mind!

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3.5 Thoughts on Medicating Autistic People

These are just some of the studies from the Research Units on Pediatric Psychopharmacology, a request put out after the NIMH and FDA asking for research on the medications doctors were prescribing autistic children.

The studies discussed previously have shown that some of the symptoms of autism can be treated, depending on the child. Risperidone and oxytocin can both possibly treat repetitive
behaviors. Memantine could possibly treat social withdrawal and inattention. However, should they be used?

There are some opinions that say that autism is a way of being in the world. If looked at from this terministic screen, autism could be viewed as a subculture much like the African American subculture. To use the African American subculture as an analogy, what if we were to pathologize their behaviors and say that they are wrong because they are not the norm (which is defined as of “acting white”)? Their way of interacting with others, their way of using language, their way of behaving, and their way of being shows a deficiency, an impairment, an inability of “being normal.”

Take this one step further, what if one of their only ways of communication is deemed “not normal,” “deviant,” or “problematic.” Due to this perspective, those who are “normal” (dominant) decide to medicate in order to get rid of this communication. Communication is tantrums, irritability, stereotypic behavior for autistic people.

What are they communicating? They are communicating resistance. It could be resistance from the demands being placed on them, it could be resistance from sensory-hell environments, it could be resistance from a parent who refuses to let them stim.

If we medicate one of the strongest forms of communication, resistance, because it is “not normal,” “deviant,” or “problematic,” what are we really doing? So: should we medicate them? Should you medicate them? Should you medicate us?

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In my search for more information on ABA, I found a page of Autism $peaks’ website, I found a page dedicated to ABA. On it, they say that they have funded and continue “to fund
research on developing and validating ABA techniques” (*What does Research Tell Us About ABA and Autism* para. 1).

Here, I had to pause my thesis research. After talking with my thesis supervisor, I decided to look at Theory of Mind as it relates to Autism Speaks. How the dehumanizing enthymeme in Theory of Mind actually helps Autism Speaks advocate not for the autistic person, but for the parent of the autistic person. Thus, the second major shift in my thesis occurred. But I had one class left, so I couldn’t quite work on that part of my thesis yet.

For the next class, I promised myself I was going to make a difference. I didn’t know how, but I knew I would. And that would begin by subverting the person-first language they demanded I use (e.g., person with autism, rather than autistic person) by using the phrase “autistic person with autism.”

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4. Primary Communication Characteristics of Students with ASD

Many people, including autism scholars, view autism as a disorder that negatively impacts social communication. However, I disagree with this idea because Pat Crissey (2011) defines communication as “the exchange of messages, thoughts, feelings, and information from one person to another” (location 31). Rhetoric is defined as how we communicate something (like a message, thought, feeling, emotion, etc.) to someone else. In other words, Crissey’s definition of communication matches the definition of rhetoric.

Rhetoricians believe that every rhetorical style is acceptable, even if it is different from the mainstream rhetoric. This is not only acceptable, it is expected and striven for. A different rhetorical style is simply a different way of exchanging ideas with another person. In other words, a different communication style is simply a different way of doing the exact same thing.
So, two questions come from this information: 1) when is communication impaired and when is it just different? And 2) why would autistic people have a different rhetorical style?

One of the communication characteristics of autism include an “impaired understanding and use of nonverbal communication” (Cassady, PPT slide 6). To answer the second question, you need to know that autistic people’s brains are wired differently. This different brain wiring impacts rhetorical styles and communication. The neurodiversity movement says that autism is simply a neurological difference. Therefore, if an autistic person with autism communicates in a different way (due to a neurological difference) than a person with neurotypicality, then both would struggle understanding each other’s ways communications.

For the person with neurotypicality, non-verbal communication is essential to communicating. However, after talking to several of my autistic friends (they prefer to be called autistic people. Therefore, I will respect their wishes), they agreed that non-verbal communication is not essential to communicating for autistic people with autism.

Some other communication characteristics include:

“impaired ability to understand and maintain reciprocal interactions[,] lack of using verbal or nonverbal means to bring, show, or point out things of interest[,] impaired ability to communicate for a variety of reasons[,] impaired ability to initiate and maintain a conversation[, and] ritualized use of language when interacting with others” (Cassady, PPT slide 6-7)

What if autism is not a disorder per se. What if these “impairments” are not actually impairments at all, but cultural misunderstandings (Heilker and Yergeau)? I think autistic people with autism have their own way of communicating and using language. In other words, they have a subculture. This is similar to African American’s using their own ways of communicating with
each other that includes how they use language, what words mean, the pragmatics they use, and the way they say words as well.

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The professor asked us to write a learning log on the first day about the three questions she had on the syllabus. True to what I had decided after the last fiasco with the ABA class, I was going to voice my disagreement. This was the first chance to do it.

Now, the professor asked us to use person-first language (person with [insert name of disability here]), so I decided to flip the script on its head. It was no longer neurotypical people, it was now people with neurotypicality; it was no longer normally or typically developing people, it was people who are developing in a normal or typical variety. Autistic people or people with autism became “Autistic People with autism.” My goal was to subvert the expectation, revealing the inherent stylistic flaw in person-first language. I made it as unmanageable as I could because I didn’t want to maintain the dominant discourse I had experienced that whole summer.

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5. Communication Characteristics’ Impact on Life

These communication characteristics impact social interaction, communication, behavior, and the student’s ability to benefit from incidental learning opportunities because there is a wide gap between autistic people with autism and their caregivers and service providers with (most likely) neurotypicality.

This gap means both groups have difficulty understanding each other, leading to negative relationships with their peers with neurotypicality. These negative relationships would be detrimental in the school setting where much is done in groups with peers.
This gap impacts behavior because the autistic person with autism is trying to communicate something, but the caregivers, service providers, and peers with neurotypicality are not understanding their communicative attempts. Therefore, behaviors could come about due to frustration or if the child finds out that a “problem behavior” is the only way to get what they want/need.

This gap also impacts the benefits of incidental learning because teachers may teach in the way that most people with neurotypicality learn and think rather than how the autistic person with autism learns and thinks because neurotypicality is dominant and expected.

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The professor was very impressed, and surprisingly, positively so, at what I had written. She asked me to present what I had written to the whole class on the last day. I only remembered at that point that my neuropsych appointment was scheduled for the last day of class as well. Luckily, though, it was right after class.

It was definitely an interesting twist of fate that I would be presenting on the last day when I wasn’t even allowed a rebuttal for the previous class. This would be my chance to challenge the teachers into thinking in a new paradigm. So, I prepared as best I could.

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6. Combination of Autistic Interests, Limited Social Understanding, and Anxiety’s Impact on Student’s Ability to Benefit from Incidental Learning Opportunities

The restricted range of interests impact the student’s ability to benefit from incidental learning opportunities because teachers may not use those interests, and student engagement is thus lost.
Autistic people with autism don’t have a limited social understanding. They understand their own natural social skills, but because that understanding is not “the neurotypical variety of social skills,” the dominant group decides autistic people with autism have limited social understanding. The teachers need to teach “the neurotypical variety of social skills” incrementally because most social rules require other skills or rules to master it.

A good comparison with this is if you were to go to study abroad in a country you didn’t know anything about. You wouldn't know the social practices of the country, but you do know your own skills. However, you may give a thumbs-up meaning good job to you, but a f-you to them.

Anxiety negatively impacts this ability because it may consume to the point where they are perseverating over something that was said or done or will happen that they cannot focus on learning the skill.

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The day of the presentation and test arrived and I was ready for both. I knew the presentation would take about an hour, which I had cleared with the professor. She wanted me to share my unique insight into autism before the class was over no matter how long it took.

After my presentation, several people came up to me and said things like “I’ve been teaching for a long time and I can’t look at autism in the same way again.” And with that, I left to take the test to determine if I was autistic or not.

When I got there, I was taken back for an interview. After the interview, I went through four hours of mentally grueling testing. Then, I missed the bus that went back to my apartment and got onto the next one, which didn’t get me home for 2 hours. Once I got home, lights were
too bright, sounds were too loud, I couldn’t speak, and I was boiling. In other words, I was having a shutdown. An autistic shutdown.

My results appointment was scheduled four weeks out. September 3 would decide if I had cleared the neurotypical’s gates for autistic people. But I was already inside the gate in the autistic people’s gates. The last words I thought before I went to bed were, “I’m autistic no matter what they say.”
Works Cited: Chapter 3


Hillary, Alyssa. “Re: Self-Diagnosis.” Message to author. 2 June 2015. Facebook E-mail.


Chapter 4: ADVOCACY

My fellow academics, this is where I introduce my thesis chapter 4, and my introduction to my Thesis Chapter 4 is as follows: this is chapter 4 of my thesis. How about that for a Perd Hapley-esque quote to begin a chapter with?

Anyways, my thesis included more than theory of mind, but still include theory of mind in it. Throughout the Fall semester, both my research and I grew together in perfect harmony. My immediate question was: what is advocacy. Within that question lies another: how is advocacy rhetorically constructed?

1. Advocacy - A Working Definition

In this section, I will look at several public service announcements (PSAs) using the pentad to determine the motivation behind the PSAs. The pentad examines the act, scene, agent (actor), agency (tool used by the agent), and purpose within a discursive artifact (the PSAs in this case).

1.1 AARP

AARP is as reputable in the world of elderly care as Autism $peaks is to the world of autism care. To analyze an artifact from AARP, then, will provide a way to compare the two organizations’ motivations as they advocate.

The PSA by AARP points out how the process of families taking care of each other comes full circle: eventually, the children take care of the parents. The following is the transcript:

Little Girl: I want to thank my mommy for loving me so much, for taking me out to the park, for reading me books...
Young Girl: ...For taking me to the doctor when I broke my foot in ballet rehearsal...

Teenage Woman: ...For leaving me alone when I wanted to be alone and...

Adult Woman: ...Now as a grown-up, I’m thankful for being able to take care of you, my dear mom, for having the chance to take you to the park, for reading those books we enjoy so much, for being able to take you to your therapies after you twisted your ankle. For understanding that sometimes you simply want to be alone.

Narrator: Roles change without us noticing and in your new role we help you help. Visit aarp.org/caregiving to get practical health and wellness tips to provide even better care for your loved one. Remember, visit aarp.org/caregiving.

AARP, we help you help.

We can find the motivation behind the story in this PSA by using Burke’s Pentad.

- **Act**: Helping out the parent
- **Scene**: Home and Community
- **Agent**: Caregiver (Adult Child)
- **Agency**: Resources available (provided by AARP and advocacy organizations like it)
- **Purpose**: To help people who need help

This PSA specifically focuses on the agent, purpose, and act. The adult child (agent) helps someone who needs help (purpose) by helping the elderly parent (act). Everyone, be they directly involved or not, is supported and empowered in this PSA. The elderly parent is supported by their adult child. The adult child is supported by the resources available. People in
society are supported by knowing resources are available when they need to take care of their parents.

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I sat there, bouncing my knees nervously. Waiting, so much waiting. Waiting for the neuropsych test, waiting for the grades to come in for the summer, waiting for bus to pick me up and take me to my neuropsych test, waiting to get in, and now, now, waiting to be called in to the results appointment.

“Sorry, we’re running a bit late.”

I nod in a way that I had seen in movies that somehow means, “I understand.”

Waiting, waiting, waiting. So much waiting. My mind repeats this on a loop over and over, an everlasting loop of echolalia calming me and encouraging me to slowly relax. My legs stop bouncing and I hear, “Sam, I’m ready for you.”

The neuropsychologist explains the results of the entire neuropsych test, waiting, waiting, waiting, waiting for him to finally get to the moment that I had been waiting almost 6 months for. “And I think, based on your test, that you may have a mild autism spectrum disorder, but you don’t have to worry, it’s mild.”

The wind blows out of me like when Poseidon got pissed off at the ancient Greeks of old. This was it, I was autistic. No, not was, am. I am autistic.

I felt so much relief, 6 months of stress from waiting fell off me. I was ecstatic to finally have a name for why I am the way I am, but there was also an unease. This unease kept me up at night, trying to figure out why I felt uneasy. Something felt very familiar about this unease. I set out to determine what this unease was and brought my thesis along for the ride.

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1.2 No Kid Hungry

The following is the transcript for the PSA run by No Kid Hungry, an advocacy organization that seeks to, yep, you guessed it, make sure there is no kid hungry in the United States.

Girl holds a sign reading, "I'm hungry."

Jeff Bridges: "Look around you, one in four kids faces hunger.

An African American boy holds a sign reading "I got my dinner from a gas station."

Bridges: It's not always easy to see the signs
A red-haired boy holds a notebook with the words "I haven't eaten today" written on it.

Bridges: But in this land of plenty, there are kids that don't know where they will get their next meal.

boy holds a sign saying, "Don't ignore the signs"

"Join share out strength at food network "

Jeff Bridges holds a cardboard sign that reads, "take the pledge."

Bridges: and take the pledge to end childhood hunger here in America by 2015

A boy holds a sign reading, "Why is this happening?"

Bridges: learn how at nokidhungry.org. their next meal could come from you.

● **Act:** Feed hungry children

● **Scene:** Online

● **Agent:** The audience, us

● **Agency:** No Kid Hungry
• **Purpose:** Help people who need help

This PSA also focuses on the agent, purpose, and act. We, the audience, (agents) help someone who needs help (purpose) by helping to feed hungry children (act). Everyone, be they directly involved or not, is supported and empowered in this PSA. The children are supported by the agent donating money and the advocacy organization giving them food. The agent is supported by having a place to donate money to. People in society are supported by knowing that resources are available for feeding hungry children in America.

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I went through the next several weeks on Cloud 9, if you will forgive me using an idiom that makes no sense what-so-ever...because I wasn’t living in a cloud, nor is there such a thing as a 9th cloud. *I am autistic*, my brain said over and over and over, pride welling in my heart. But all the time, I felt that unease, and it was growing.

The first part of my journey was to figure out where I had felt this unease before. It took me several weeks, during which, I was still planning on doing my thesis on theory of mind and Autism. I was working on my thesis one day when I realized where I had felt that unease.

When I was researching for my 2015’s GPAC...W presentation, I had felt the same unease reading a source from Autism $peaks. The same feeling had come up again when I found out in the Summer of 2015 that they claimed theory of mind was a fact, and supported medicating autism and applied behavior analysis (ABA).

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1.3 Synthesis

Both of the PSAs were different (obvious, right?). The agent was different each time as was the action, but the purpose always stayed the same: to help those who need help. That is one
part of the definition of advocacy I will be using when looking at several advocacy documents on autism.

There was another similarity that becomes the second part of my definition of advocacy, they supported everyone in society. They support the people who need help by being there for them, they support the people who are helping by being there for them, they support larger society who aren’t yet affected by providing information.

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I looked at Autism $peaks website and came away feeling uncomfortable. So, I began by doing something I had learned throughout my master’s classes: challenge my assumptions. So what were some of my assumption about Autism $peaks? The first and foremost assumption was that they are an advocacy organization. The question then became, “What is advocacy?”

The first part of the definition of advocacy is “helping people who need help” and the second part is supporting everyone involved. The three PSAs that I looked at do both of these things. But, the question was: what would I find when I look at Autism $peaks PSAs?

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2. Autism $peaks to Washington - A Call for Action

On November 11, 2013, Suzanne Wright, the co-founder of Autism Speaks, wrote an op-ed piece entitled “Autism Speaks to Washington - A Call for Action.” It was published the day before Autism Speaks held a national conversation demanding the government develop a national plan for the “autism crisis” (para. 1). In it, she rhetorically sets up an exigency for why there must be a national plan about autism. Here is an excerpt from the piece:

Each day across this country, those three million moms, dads and other care-takers I mentioned wake to the sounds of their son or daughter bounding
through the house. That is - if they aren’t already awake. Truth be told, many of them barely sleep—or when they do – they somehow sleep with one ear towards their child’s room—always waiting. Wondering what they will get into next. Will they try to escape? Hurt themselves? Strip off their clothes? Climb the furniture? Raid the refrigerator? Sometimes – the silence is worse.

These families are not living.


Working- most definitely - 24/7.

This is autism.

Life is lived moment-to-moment. In anticipation of the child’s next move. In despair. In fear of the future.

This is autism.

On the good days my daughter Katie and all the other moms out there – 70-million around the world – see the sun shine. They notice the brilliant colors of the autumn leaves. On bad days, they are depleted. Mentally. Physically. And especially emotionally.

Maybe they have been up all night caring for their teenage child who’s having a seizure.

Maybe they are up yet again changing the sheets because there’s been another bed wetting accident.

Maybe their child has been trying to bite them or themselves.

Maybe they can’t afford the trip to a doctor specializing in autism.

Maybe there is a waiting-list for ABA, speech and OT.
Maybe their insurance won’t pay.

Maybe they don’t have the money to pay a special lawyer to fight for school services.

This is autism. . . .

Close your eyes and think about an America where three million Americans [with autism] and counting largely cannot take care of themselves without help. Imagine three million of our own – unable to dress, or eat independently, unable to use the toilet, unable to cross the street, unable to judge danger or the temperature, unable to pick up the phone and call for help. (para. 11-25, 40)

2.1 Pentadic Analysis of Wright’s Article

Here’s the pentadic analysis of the story told in this piece.

- Act: Making life difficult for the parent (by breaking up marriages, making families go bankrupt, forcing parents to live in despair)
- Scene: Home
- Agent: Autism
- Agency: The Autistic
- Purpose: ?

This pentad doesn’t look anything like the pentad for the AARP PSA. That much is obvious, but a deeper analysis can explain where the biggest diversion is. The biggest diversion here is the purpose. The purpose in the other PSAs is to help those who need to be helped—part of the definition of advocacy. But what's the purpose here?
If we are only looking at the story here and what is written, there is no purpose here. Wright is focusing on the act and agent in her piece by blaming autism (the agent) for breaking up marriages, making families go bankrupt, and forcing parents to live in despair—in other words: autism seeks to destroy the family (the act).

To look at this explicitly from a narrative point of view, we have to ask ourselves, “Who’s the protagonist?” In the AARP PSA, it’s the caregiver and elderly parent. In Wright’s piece, it’s the parent/caregiver. Now, “Who’s the antagonist?” The AARP PSA doesn’t really paint anyone or anything as the antagonist. But Wright’s article demonizes autism by pointing out how it destroys families.

So, what is the purpose of autism’s actions here? None is given. In other words, as Michael Caine’s Alfred says in The Dark Knight when giving an analogy of the Joker, Autism can’t be “bought, bullied, reasoned, or negotiated with...[it] just wants to watch the world burn.” In this way, Autism, as Wright portrays it, does not care about the consequences of its actions—it just seeks to destroy the family.

The pentad for Wright’s piece lacks the first part of the definition of advocacy I’m using: helping people who need to be helped. Is everyone involved empowered and supported—the second part of the definition of advocacy?

We’ve been talking about autism so far, which leads to the question, “where is the autistic person in this story?” By neurological association and analogy, the autistic person becomes the tool that autism uses to destroy the family. For thirty-nine paragraphs, Wright talks about how Autism negatively affects the parents and for all thirty-nine of those paragraphs, the autistic is the tool that autism uses to cause these negative effects.
In the fortieth paragraph, she finally discusses how autism affects the Autistic: they are not able to do anything for themselves, even eat or cross the street. This is not empowering everyone involved; at best, this is only empowering the parents. At worst, this is empowering the parents by disenfranchising the autistic. Or perhaps, it is not empowering anyone. The autistic is demonized, autism is demonized, and the parents are portrayed as drained and not living.

If this piece does not advocate for the autistic person, then what is Wright’s motivation in writing this? Awareness Months play an important part in answering this question.

2.2 Awareness Months

Another rhetorical move that Autism Speaks uses is their use of the term “Awareness.” Many in the autistic community demand we move beyond awareness to acceptance. After hearing this, I wondered why and happened to glance at the calendar.

At the bottom, it said, “Breast Cancer Awareness Month.” I grabbed the calendar, rifled through it, and saw other awareness months: Domestic Abuse Awareness Month, Sexual Assault Awareness Month, Sudden Infant Death Syndrome Awareness Month, Heart Attack Awareness Month and many more. They were all associated with (1) death and/or (2) abuse. In other words, Awareness Months are associated with things that we want to get rid of or prevent. There are very few people out there who would think that we shouldn’t prevent death, abuse, and cancer whenever possible.

April read, “Autism Awareness Month.” Curious, I did a websearch and came up with hundreds of awareness month names. Nearly all of them were associated the criteria for Awareness Months. But autism was also thrown into the mix. Is autism associated with death or abuse? Nope!
However, looking back at Wright’s article, specifically the beginning and paragraph 40, we see her construction of autism to fit this definition of awareness months. If you cannot take care of yourself, if you have been kidnapped, or if you have a grave illness, now autism fits within the criteria for Awareness Months. Grave illness results in death, not being able to take care of yourself leaves you susceptible to abuse. Now that Wright has created an image of autism that fits the criteria, autism awareness month fits.

However, autistic self-advocates do their damndest to challenge this image. Autism awareness is not what we should be after; it is autism acceptance that we need. Autistic self-advocates have recognized this. Groups like the Autistic Self-Advocacy Network (ASAN) create Autism Acceptance campaigns, explicitly challenging Autism Awareness campaigns.

Should disabilities be associated with diseases, death, and abuse—should they be prevented? To answer this, we have to go back to Wright’s piece and analyze it using terministic screens.

2.3 Terministic Screen Analysis of “Autism Speaks to Washington - A Call for Action”

Terministic screens theory claims the author’s word choice influences how the reader/audience thinks about the topic. It is a set of terms, phrases, or analogies that ensure the audience takes/shares the author’s perspective. This prevents the audience from seeing any other viewpoint. “Even if any given terminology is a reflection of reality, by its very nature as a terminology it must be a selection of reality; and to this extent it must function also as a deflection of reality” (emphasis in original, Burke 1341).

Part of what I have done by revealing and challenging my warrants is also revealing and challenging the terministic screen that Autism Speaks uses: advocacy. By claiming that they are
an advocacy organization, they use a terministic screen that prevented me from looking at them from any other lens.

She begins by writing “This is the week America will fully wake up to the autism crisis” (para. 1), and goes on to give two analogies.

“If three million children in America one day went missing - what would we as a country do?

If three million children in America one morning fell gravely ill - what would we as a country do?” (para. 2-3).

Using these analogies implies autistic people are missing and gravely ill, which can be associated with abuse and death, respectively. Thus, in the first three paragraphs, Wright establishes how autism fits within awareness months: kidnapping is abusive and grave illness is death and disease. Autism now needs to be prevented in order to help someone who needs help.

However, in the narrative Wright weaves, who is this person who needs help? The immediate answer that could come to mind is: the Autistic needs help. But in the pentad, the Autistic is the tool that autism uses to destroy the family. This destruction of the family causes suffering, requiring much help. But again, who is most impacted?

She goes on to say that we, as a nation, would declare martial law. “We would call out the Army, Navy, Air Force and Marines. We’d call up every member of the National Guard. We’d use every piece of equipment ever made” (para. 4). So, just as we would for three million children who went missing and three million children who fell gravely ill, we should do this for autism.

This leads directly into her next point, “Yet we’ve for the most part lost touch with three million American children, and as a nation we’ve done nothing” (para. 6). It is at this point that
Wright puts her full views out there explicitly without the use of analogy. If three million children disappeared, we would have lost touch with them and Wright is saying that we have lost touch with autistic children. Therefore, Wright is saying that the analogy is not just an analogy, kidnapping and grave illness are equivalent to autism.

Next, Wright really begins to show how Autism Speaks influences, if not controls, the representation, narrative, identity and agency of autism and the autistic. Families split up, go broke, and struggle through their days and years! Autism causes this and more. It is curious that they do not talk about what it causes for the autistic person, only what it causes for their families.

She says this will not be the case anymore because the next day was the summit in Washington, D.C. to “demand a national response” (para. 8). She returns back to the idea of “Think about the families of our nation” in the next paragraph. “Don’t our families deserve it? America has always been about its great people” (para. 9). What is interesting to point out here is that Wright is appealing to her audience’s sense of national pride. “American children”, “Army, Navy, Air Force, and Marines...National Guard”, “as a nation we’ve done nothing” are all examples of her appeal to this national pride.

“Yet we seem to have forgotten our children - and our children are our future” (para. 10) is an example of her appeal to pathos. It also is a very rhetorically savvy move because she uses second-person language here. By using first-person plural language, she is able to get away with saying what she says. If she said, “Yet you seem to have forgotten your children - and your children are your future,” that would have been read as an attack.

She returns to families when she talks about how moms, dads, and care-takers barely sleep. When they do sleep, it is with an ear waiting for their child to do something next like “escape, hurt themselves, strip off their clothes, climb the furniture, and raid the refrigerator”
She ends the paragraph with another representation of autism “Sometimes – the silence is worse” (para. 11). Autistic people are silent according to this article.

She continues with her story of the families by saying that families with children with autism “are not living” (para. 12). It is wonderful to know that autism can make it so families are not living. So, I wonder, are they zombies? Or perhaps they are lichs? I guess what I’m actually asking is what type of undead are these parents? Because it is very important to know!

Wright continues that “they are existing. Breathing – yes. Eating – yes. Sleeping – maybe. Working – most definitely – 24/7” (para. 13). Zombies don’t breathe or eat (unless you count brains). As facetious as that comment may sound, the image that Wright weaves of autism is of a fate worse than zombification. A fate where you are conscious and existing, but are not living life because of your autistic child.

She then begins a series of bolded sections that read “This is autism” (para. 14, 16, 25) where she gives an example of something families have to live with when they have an autistic child and then says “This is autism.”

Her first example is that “Life is lived moment-to-moment. In anticipation of the child’s next move. In despair. In fear of the future” (para. 15). It is at this moment that I began to ask myself, is this autism or is this just parenthood. Most parents beings live moment-to-moment, anticipating their child’s next move because children are, well, children. This means they will do stuff that no adult would ever do, but that is because they are children.

I have difficulty believing every single family of an autistic child lives in a constant state of despair. And if they do, it is probably because of ableism (or depression), for which they should recognize is within socially created and not caused by their child’s autism. Most human
beings are also afraid of the future because we don’t know what it holds. So, is this autism? No! This is a little thing called humanity.

The next paragraph further explains what Wright means by “living” when she says, “On the good days my daughter Katie and all the other moms out there – 70-million around the world – see the sun shine. They notice the brilliant colors of the autumn leaves. On the bad days, they are depleted. Mentally. Physically. And especially emotionally” (para 17). Is this autism? Is this just a little thing called life? Are good days and bad days determined by autism or are they determined by the vagaries of life? The latter is my opinion and there is absolutely no shame in having bad days! But there is shame when there bad days are blamed on the autism in the child.

The next few paragraphs actually sort of have something to do with autism,

Maybe they [the parents] have been up all night caring for their teenage child who’s having a seizure.

Maybe they are up yet again changing the sheets because there’s been another bed wetting accident.

Maybe their child has been trying to bite them or themselves.

This is autism. (para. 18-21)

However, the first one is more common in autistic people, NOT autism itself. Seizures can happen in autistic people, but they are a symptom of epilepsy, not autism. Can the second or third paragraph happen to a child without autism? Yes! A child without autism may wet their bed until they are in the teens or beyond depending on like how much they drank before going to bed or a traumatic experience they had. Perhaps non-autistic people don’t bite themselves, but some teenagers without autism have self-injurious behaviors like cutting. So, is this what autism
is? No! Not every autistic child will have these behaviors and these behaviors are not only found in autism.

The last four have absolutely nothing to do with autism:

Maybe they [parents] can’t afford the trip to a doctor specializing in autism.

Maybe there is a waiting-list for ABA, speech and OT.

Maybe their insurance won’t pay.

Maybe they don’t have the money to pay a special lawyer to fight for school services

This is autism. (para. 21-25)

This is not autism! These are all examples of how low socioeconomic status and insufficient institutional support systems impacts families with autistic children. However, Wright would argue with that by saying these families are at a low socioeconomic status because their children have autism based on her quote, “We’ve let families...go broke” (para. 7).

For thirty-nine paragraphs, Wright expounds on how autism causes parents of autistic people to suffer by:

● making families to split up
● making families to go broke
● making families to struggle through their days and years
● making families to simply exist rather than live
● making families to live in despair
● making families to live in fear of the future
● making families to be mentally, physically, and emotionally depleted because
○ making families to be up all night because their child had a seizure
○ making families have to change the sheets after a bedwetting accident
○ making families have to stop their child from biting them or themselves
● making families to not be able to afford a trip to the autism specialist
● making families to be on a waiting list for services
● making families’ insurances to not pay
● making families to not have enough money to pay for a lawyer to fight for school services.

To cure autism, then, relieves the parents suffering, thereby helping the parents. The parents are the ones in need of help in this story.

The thirty-nine paragraphs dedicated to the parents, however, are sharply juxtaposed with the one paragraph that is dedicated to how autistic people are affected—and that paragraph is a gross overgeneralization of autistic people. Autism prevents autistic people from:
● Taking care of themselves
● dressing themselves
● Eating independently
● using the toilet
● crossing the street
● judging danger
● judging temperature
● picking up the phone
● calling for help
That means that autistic people like me, according to Wright, cannot take care of ourselves at all—we live in a state of eternal infancy, driving our parents to despair.

Finally, let’s examine the terminology Wright uses for those who care for the Autistic (e.g., the parents): care-takers. This is sharply juxtaposed to the term caregiver used in the AARP PSA. The definition of caretaker is, “a person who is in charge of a place or thing, esp in the owner’s absence” (“Caretaker”). While there is another definition of caretaker that includes taking care of a person, the dominant understanding and usage of this word is one who takes care of a place or thing. The definition of caregiver is, “An individual, such as a family member or guardian, who takes care of a child or dependent adult” (“Caregiver”).

So, the use of care-taker implies autistic people are things, not people. This fits with the image of Autism that Wright creates. A car cannot take care of itself just as a body cannot take care of itself. The owner of the car can take care of it when they are there, just as the owner of the body can take care of it when they are there. But if something were to happen to the owner of either, say a kidnapping, grave illness, or eternal infancy, then the car and the body would not be taken care of. So, a caretaker comes and takes care of the car and a caretaker comes and takes care of the body of the Autistic.

But autism cannot be separated from the autistic. As Jim Sinclair puts it, autism colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person—and if it were possible, the person you’d have [sic] left would not be the same person you started with. (Autism is Not an Appendage para. 1)

Therefore, seeking to cure autism is seeking to cure us of our identity—to eradicate us...to eradicate me.
And so, I realized why I felt uneasy. I had spent 8 years thinking I was autistic, and for all 8 years, I didn’t want to be autistic because I didn’t fit this narrative of “the Autistic.” I wasn’t an eternal infant, so I obviously wasn’t autistic.

Finally, after looking at Autism $peaks critically using rhetorical tools, I saw their true nature: a pseudo-advocacy organization. My working definition of pseudo-advocacy is supporting one group of people at the expense of another. In this case, Autism $peaks is supports parents, setting them up in the role of hero and savior, while demonizing and monstracizing autistic people as villains who make life nearly impossible for the hero. But they also set up the parent as a martyr, as a person to be pitied, as an undead person not really living. Perhaps Autism $peaks doesn’t even advocate for parents.

It was around this time that my advisor and I discovered and talked about Karpman’s idea of codependent relationships. In Fairy Tales and Script Drama Analysis, Karpman looks at several fairy tales looking at the characters and where they are in three roles: persecutor, rescuer, and victim. If we would apply these concepts to Wright’s article, we can see that the persecutor is Autism, the victim is the parent, but who is the rescuer?

Suzanne Wright, co-founder of Autism $peaks, wrote this article published on Autism $peaks website, demanding a national plan so we can help the parents. She effectively puts herself and her organization into the role of the rescuer. She rescues the very victims who she narratively put into the positions of persecutor and victim.

So empowered from this new perspective on something I had seen unquestionably for 8 years, I sought a diagnosis. In September of 2015, I received my autistic diagnosis and realized something.
I realized that for 8 years, I shied from defining myself as autistic because of the implications. It meant I was the tool autism was going to use to destroy my family and make my parents live in despair. It meant I was neurologically associated with a monster that just wants to “watch the world burn.” It meant that I needed to be cured of who I innately was, of my identity—that I needed to be prevented. But what was most demoralizing of all was that, once here, I needed to be eradicated.

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2.5 Cluster Analysis

According to Blakesley, “the primary purpose of cluster analysis is to determine the precise nature of the act, the poetic act in particular” (104).

Upon running Wright’s article through the web application voyant (which does a distant reading by giving statistics on how many times a word is used), I noticed several patterns emerge. The word “autism” is used 13 times, whereas the words “national” (10 times), “america” (5 times), “country” (5 times), and “Americans” (2 times) are used a total of 22 times. It is interesting that words about this country are used more than the word autism.

Wright uses the word national as her go-to word for demanding the “national plan.” Every time she uses it relates to the national plan. Sometimes this word has to do with the curriculum every autistic student should be taught, whereas other times, it has to do with creating a city just for autistic people (Yeah, these are valid—and expected—options for the national plan).

She uses the word America to really drive home the pathos (emotional appeals) in the article. “America will fully wake up to the autism crisis”, “three million children in America”,
“America has always been about its great people”, “think about an America where three million Americans.” It’s an appeal to the national pride of her audience.

But who is her audience? Since the title is “Autism Speaks to Washington,” one could assume that her audience is Washington government officials. However, this seems to not be the case: “Tomorrow in Washington, D.C. we will gather an unprecedented number of bipartisan officials, congressional leaders and experts in every area of autism for a three-day summit. We will demand a national response” (para. 8). When “we” is used, it is basically the author and the audience together. The way she uses “we” implies that the audience is not government officials, but the entire country.

Another factor that I noticed was that the word people is only used twice, one of which is referencing the 500-thousand autistic people we should build a city for. This is compared to 15 times that children, child, or child’s are used. This implies, at best, that autism is only in children or, at worst, that autistic people are perpetual children, never growing old or maturing. However, there is another purpose in using this term: it builds the pathos. People have more feelings about a child than they do about an adult. Children generate more (as the internet community puts it) “feels.”

The term “unable” is used 5 times in the course of the paragraph on how autistic people are affected by autism. We are unable to “dress”, “use the toilet”, “cross the street”, “judge danger”, or “pick up the phone.” Interesting, I didn’t know that I couldn’t do these! Not only that, but when “unable” is only applied to autistic people, it sets up a dangerous precedent that autistic people are not able to do anything whereas non-autistic people are able to do anything. It adds to infantilization of the autistic person.
Armed my rhetorical analysis of Autism Speaks, I began to tell people that I was autistic. Prior to my diagnosis, I had read stuff from autistic people of people who would come up to them and tell them things like, “But I like you,” or “You must be very high functioning.” But for some reason, I thought I would be immune to that experience. Nope, I was not...at all.

The day after I posted my diagnosis as autistic on Facebook, an acquaintance at work, who I was Facebook friends with, told me, “But I know someone with autism and you aren't anything like them.”

Taken aback, I asked them, “How do you know they are autistic?”

“Well, I don’t. I just know.”

“So they are not out as autistic?”

“Correct, I think they are autistic.”

So, I can’t be autistic because someone they know who they think is autistic isn’t like me. Rather than say that, I said, “Right.” Slowly, methodically, and with as much subtext as possible.

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3. Autistic Self Advocacy Network (ASAN)

ASAN responded a day after Wright published her article. In it, they discuss the logical flaws within her article and appeal to policymakers to include disabled-run organizations when discussing a plan.

3.1 Pentadic Analysis

Act: “reach out to organizations run by and for Autistic people ourselves” (para. 4)

Scene: When policymakers make a decision regarding autism

Agent: Policymakers and disability community leaders
Agency: disabled-run advocacy organizations

Purpose: help people who need help

The article really focuses on the act and the agent. It is appealing to the policymakers (agents) to be the change society needs by specifically reaching out to disabled-run organizations (act) so everyone can be supported.

3.2 Critical Analysis

The main issue with this article is that it only talks about what is wrong with Wright’s article and does not reveal what autism is or what ASAN believes. The audience, then, hears only about Wright’s article and nothing about ASAN’s opinions besides being the antithesis (opposite) of Autism $peaks and Suzanne Wright.

George Lakoff talks about this phenomenon in “Don’t think about an elephant” when he discusses the problem behind the moderate political party. Republicans and Democrats both attack them and they respond only to those attacks. “you want to tax everyone,” would be a criticism and the moderate party would respond, “We don’t want to tax everyone.” The audience only hears the repetition of the Republicans and Democrats say about them.

The same thing is going on here, the audience is not being told what ASAN’s belief about autism is because they only respond to Wright’s article. While this is fine, to an extent, a good argument includes explaining what autism is. ASAN does have sources on their website that does discuss what autism is, but if someone were to look only at this article, they don’t see what autism actually is.

I wondered if there were groups that talk about what autism is in a way that challenges the arguments in Wright’s piece without specifically talking about what she says?
I went to a conference on the intersection of Autism and Sign Language at Harvard University in December of 2015. The goal of the conference was to begin a dialogue on autism. Of all of the presenters and invited participants (I was not one of them, I was just an observer), about 50 in total, 5 were actually autistic. That’s a statistic of 10%, a ratio of 1:10 (for every 1 autistic person, there were 10 non-autistic people). Most of the non-autistic people were doctors, psychologists, neuroscientists, etc.

So, at a conference that was attempting to begin a dialogue on autism, there were 5 autistic people out of 50 who were invited. How is this going to begin a dialogue? I wondered to myself. The dialogue on autism is, yet again, being controlled by non-autistic people.

One of the two culminations of the event was a panel discussing, “How do we talk about disability?” There was an autistic man on the panel of 5, and he declared that he was not disabled and he hated talking about terminology, so he didn’t know why he was there. There was an invited autistic rhetorician at the conference, but she was not part of the panel.

A panel of no one who identified as disabled then had a discussion on “how do we talk about disability?” Most of it was silence because they didn’t know, so they asked the audience. Many, who were again mostly non-autistic, said we should never use the term “disabled” or “disability.” I wanted to speak up, but because I wasn’t an “invited attendee,” I was not allowed to speak. So I heard all of this with horror because here was a roomful of non-autistic and non-disabled people deciding that we should never say disabled or disability.

This is the problem with the discourse surrounding autism. It is all about autism, but completely controlled by non-autistic people. It’s controlled by Autism $peaks, it’s controlled by Autism parents, it’s controlled by non-autistic people.
And when we, actually autistic people, try to speak up, we are told to be quiet, we are told we don’t “have the kind of autism that my son has,” we are told, “You’re a fake.” We are silenced, and our voices a cacophony of forced silence beg for change, but the silencing does the opposite of what it should. We move beyond “begging for change” to demanding change. By trying to silence us, they have given us power, power that can only be found within ourselves.

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4. Grassroots

A week after Wright’s piece was published, a group of autistic people came together and wrote 250 blog posts on a flashblog. A flashblog is like a flashmob, but online. The autistic community has done this type of resistive campaign several times to elicit changes. For example, in the beginning of 2013, Google’s auto-fill search results for “autistic people should...” Were “be killed,” “be exterminated,” and “die.”

After several autistic people complained to Google and were told that nothing could be done, they created a flashblog revolving around the prompt “Autistic people should...” Several days later, Google changed their search results emptying the hate-speech results.

As an aside paragraph, Autism Speaks thanked Google on their Facebook Page for changing the search results, while completely ignoring the flash blog and the work of the actually autistic advocates to change the results. After the autistic self-advocates fought for recognition, Autism Speaks added a sentence (one!) to the post mentioning the flash blog. In it, they thanked autism advocates, not autistic self-advocates.

In the flashblog on Wright’s article, they focused on her five “This is autism” statements. The call for posts was as follows,
Tell us what "This is Autism" means to you. You can write a paragraph or a blog post, contribute a poem or a video, make a comic or a graphic. Use your imagination. Let's tell the world what autism is in the words and works of autistic people and those who love and support them. (“What should I submit?”)

In the flashblog, they did not address what autism wasn’t according to Wright’s article. They wrote about what “this is autism” meant to them. Autism is a community, autism is love, it is friendship, it is beautiful, it is what makes us us.

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At the same conference, a board certified behavior analyst said the “optimal outcome” for autistic people is to lose their diagnosis. This was decided in several studies that where parents were asked what the optimal outcome would be for their autistic children.

That is, the optimal outcome for autistic people was decided by non-autistic people, the parents in this case, as opposed to actually autistic people.

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5. Original Idea

5.1 Autism $peaks

In much of Michel Foucault’s work, he traces an idea or concept back as far as he can go. He calls this genealogy. The main flaw of this strategy is that it only talks about the input and the output, but not at the process between the two. This is where archaeology comes in. Archaeology studies how discursive practices shaped the input to become the output.

In this section, I will be combining Foucault’s archaeology and genealogy with Bruno Latour’s concept of a Black Box and Kenneth Burke’s concept of Terministic Screens to analyze the original idea behind Autism $peaks.
5.5.1 Genealogy of Autism Speaks

I am going to start at the root and continue to Autism Speaks. It begins with a different way of interacting with the world (through language, empathy, social interactions, etc.). Autistic people interact with the world in a different way.

This is put into a black box (A process I will expand on in a bit) and out comes capital-O Other. Capital-O Other oppresses and marginalizes those with a different way of interacting with the world. This means someone struggling to understand other people’s facial expressions is marginalized and treated like shit because they aren’t human, they are just capital-O Other.

This capital-O Other idea enters another black box and out comes autism. This is the word autism, not the underlying conditions of autism. The underlying conditions of autism are the “different way of interacting with the world” that we started with.

This is pathologized autism, the kind of autism that Wright talks about in her article, the kind that we have to cure, the kind that is defined by non-autistic people. The idea here is that the disabling aspects of autism rest within the person with the autism.

Then, when we put autism into a black box, theory of mind pops out. Theory of mind builds on top of this capital-O Otherness and this pathologized autism (capital-O Othered Autism?). It rhetorically implies that autistic people cannot have an identity—that autistic people are not human. It does this without people questioning it because it is a “scientific theory.” Scientific theory has an extrinsic, ingrained ethos (credibility) that many in society automatically give it before it has even done anything.

When we put theory of mind into a black box, we get Autism Speaks coming out the other end. They build opinions and practices on the “facts” and implications behind theory of mind. Because theory of mind dehumanizes autistic people, Autism Speaks can more easily put
parents into the position of victim and autistic children in the place of persecutor while maintaining that they advocate for autistic people.

They can do this because they are the “world’s leading autism science...organization” (“About Us” para 1). Just like theory of mind had ingrained and extrinsic ethos, so too does Autism Speaks. Before they even do anything, we trust them because they are claiming to advocate and speak for those who have autism.

5.5.2 Archaeology of Autism $peaks

But how did we get here? What are the black boxes? What’s in the bloxes? Latour says that black boxes basically act as something that is so complex that we don’t try to comprehend it. They effectively make someone look somewhere else, just like a terministic screen.

What is more complex of a process than convincing someone to look at something a particular way? For the purpose of this genealogical analysis, I am going to use terministic screens as a way of looking at black boxes. This is not always the case; sometimes, black boxes are a piece of computer code. It is not always terministic screens, but terministic screens let us analyze and break open these black boxes.

5.5.2.1 Different Way of Being to Capital-O Other

So, we start with a different way of interacting with the world and that turns into capital-O Other because of the terministic screen of “Ableism.” This different way of interacting with the world is viewed by an ableist society that determines that the person is wrong, just wrong. Thus, this natural way of interacting with the world is turned into capital-O Other.

5.5.2.2 Capital-O Other to Autism

When we put capital-O Other into the black box, we get back autism. This black box is “Ableist Science.” Science takes ableism’s output of capital-O Other unquestioned, retaining
ableism from one layer down. This is seen in the use of the pathologizing, or medical, model regarding autism.

It is ableist because medical professionals and scientists, not actually autistic people, are controlling the definition of autism. Because autism is a different way of being, medical professionals and scientists look at it as capital-O Other. This leads to the assumption that autism is a bad thing, something to be fixed and eradicated.

5.5.2.3 Autism to Theory of Mind

Autism is then put into the black box and out comes theory of mind. This black box is “Science.” Frontier science is scientific research that is incredibly new, however, it is also full of flaws (i.e. biases, errors, dishonesty, etc.) (Bauer 45). A neurotypical bias is deeply seated within theory of mind literature. Because autistic people don’t think like neurotypical people, they cannot pass a test where the prerequisite is to think like a neurotypical and therefore don’t have a theory of mind.

Frontier science is not bad, in fact it is a very good thing where most of our scientific breakthroughs happen. But Bauer says that there is a knowledge filter that is supposed to filter non-scientific stuff like biases, errors, dishonesty, mistakes out of scientific knowledge. This takes time and many studies done by many different people. However, Simon Baron-Cohen is an author in nearly every study that I found.

Not only that, but there is still the language bias, the neurotypical bias, and all of that. Now, why am I bringing this up? I am bringing this up because the one of the last stages of the filter, once all of the extraneous stuff has been taken out, is textbook science. This is scientific knowledge that is presented as fact in textbooks.
Theory of mind has somehow bypassed the filter and gone straight from frontier science to textbook science. Look at most textbooks on autism and they present theory of mind and autistic people lacking theory of mind as a fact—unquestioned, done deal.

5.5.2.4 Theory of Mind to Autism Speaks

When theory of mind is put into the black box, out comes Autism Speaks. This black box is “advocacy.” It has layer upon layer of ableism underneath it, so its advocacy as a term, but ableist advocacy underneath. This ableist advocacy can be seen in their messages, such as their PSA “I am Autism,” which portrays autism as a horror icon in a similar vein as Jason Voorhees or Michael Myers.

This ableist advocacy can also be seen in what they are advocating for. They advocate for the cure to autism, to cure me of who I innately am, to make me act neurotypical. All of this stems back to the original black box turning my different way of being in the world into capital-O Other.

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I went to a simulation event on disability at Saint Cloud State University. I got there and was surprised to find mentally ill people leading the mentally ill simulation, people with spinal cord injuries lead the spinal cord injury simulation, blind people lead the blind simulation, and so on.

As I had experienced many times before, usually, it was non-disabled people who did anything disability related, so I was pleasantly surprised. However, then I went to the autism simulation. There were three people standing on the center of the stage and one of them started speaking, “Welcome to the Autism simulation. I am Joanne and I am a professor at Life College down in the cities. These are my students, Alexandra and Abigail and they are autistic.”
We went through the simulation and Joanne walked around and talked to people and randomly walked away. After the experience, she explained what she was doing, “I was trying to be as disrespectful and rude as possible because that’s what many of our students with autism do.”

I stood there, jaw almost touching the floor in utter shock. Not only had she said that I am disrespectful and rude (possibly on purpose), but she had just outed herself as not autistic. I almost broke down weeping right there. How is it that ADHD simulation is led by ADHD people, cerebral palsy by cerebral palsy people, mental illness by mentally ill people, etc. but autism was led by a non-autistic?

Yet again, for the third time, I had experienced non-disabled people deciding what it was to be disabled. In each of these experiences, it was regarding autism. What’s going on here? I wondered.

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5.2 ASAN & Grassroots

5.2.1 Genealogy of ASAN & Grassroots

The original concept behind ASAN and Grassroots is the same as Autism $peaks: a different way of interacting with the world. But then they completely diverge. Once put into a black box, a different way of interacting with the world remains a difference. This is in contrast to capital-O Other, which views difference bad. Difference is similar to diversity, it is just different and that is okay. Some people like Reebok, others like Nike, that’s a difference, but it’s okay. So it should be with different ways of interacting with the world.

When difference is put into the black box, capital-A Autism comes out. This differs from the lowercase-a autism because it doesn’t pathologize. It gives a name to the behaviors, but
doesn’t view the behaviors as something to get rid of. Instead, they are valued for the diversity they add to the world.

When capital-A Autism enters the box, advocacy exits (Advocacy as defined in chapter 4: it supports everyone involved and helps those who need help). It’s goal is to support everyone involved without throwing anyone under the proverbial bus.

5.2.2 Archaeology of ASAN & Grassroots

The black box that turns a different way of interacting with the world into difference is “the neurodiversity paradigm.” The neurodiversity paradigm says that neurodiversity (different brain types) is just as valuable as other forms of diversity (different skin colors or sexes). So, this different way of interacting with the world is not something bad or unacceptable, it is a natural diversity of the brain that must be embraced (Walker “Neurodiversity…”).

The terministic screens applied to difference to turn it into capital-A Autism are the neurodiversity paradigm combined with science. This is a science that recognizes that the different way of being in the world is a natural and okay occurrence, and therefore is not inherently bad or in need of fixing.

Capital-A Autism turns into advocacy when the terministic screens of advocacy, science, and the neurodiversity paradigm are applied to it. Advocacy in the sense of supporting everyone involved and helping those who need help.

6. Conclusion

In this chapter, I found the original idea behind Autism $peaks, the Autistic Self Advocacy Network, and Grassroots advocacy organizations by combining Foucault's concepts of archaeology and genealogy, Latour’s concept of the black box, and Burke’s concept of Terministic Screens.
As I was finding this idea, I wondered if I could find the original idea behind advocacy. Could that be the key to disrupting the interpellation process, thus giving disabled people back our agency and allowing us to advocate for ourselves?

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I sat in my thesis proposal meeting, a pen in one hand and a mechanical pencil in the other, clicking them as fast as I could in terror. Every part of me wanted to hide and go home because I didn’t know what to expect.

Then, Rex Veeder said what can summarizes the narrative of this entire chapter. “You are able to identify as autistic, but you cannot define it.”

I was sent out of the room so my committee could discuss whether I passed, passed with revisions, or rejected. I remember standing outside the classroom, thinking that when non-autistic people are allowed (expected) to control and dominate the conversation about autism, it completely silences us, the actually autistic people. But, with this thesis, I could begin to autistically and rhetorically define autism. But I needed permission first (from non-autistic identifying people).

I walked in and was greeted by the words, “Congratulations, you passed with no revisions.” Now, the real challenge was upon me. How do I begin to define this thing that has not only been defined, but been defined in an attempt to infantilize and silence me?
Works Cited: Chapter 4


(NOT REALLY A) CONCLUSION

Agency is defined as “the condition of being in action” (“Agency”) or the ability to act upon something and change it. Louis Althusser says agency can be given away through interpallation, which is the moment we give it up. He gives the analogy of a police officer who tells you to stop and you stop. You are giving up the agency of continuing to move to follow the police officer’s direction. I’ll give another example, one you’ve already heard that involves a police officer telling me to put a student into physical hold.

If interpallation is a moment, then agency can never be had again once given up. In Chapter 1, I discussed how the disability label is an interpallation. But how can you advocate for yourself without agency? Most of my friends and I in the disability community have embraced the label of disabled, yet we advocate for ourselves.

Let’s bring back Foucault’s genealogy and archaeology.

1. Genealogy of Advocacy

It begins with a label, an interpallation where you give up your agency. In the specific case of this thesis, it is “you are autistic and disabled.” Here, interpallation means you can embrace being disabled and autistic, but you cannot define those—they are defined by the dominant group: people who are not disabled or autistic.

The first step to taking back agency, of disrupting the process of interpallation, is recognizing the warrants (assumptions) we hold about these labels. It is only once we recognize our assumptions of these labels that we can begin to critically think about them. For an example of this, see chapter 1’s deconstruction of disability.
After critically thinking about the warrants, we can see the consequences of these labels: consequences in science (chapter 2), education, therapy, medicine, communication (chapter 3), and advocacy (chapter 4). Ableist science develops theories that dehumanize autistic people (i.e. theory of mind), which education uses to (mis)understand autistic people (i.e. autistic people cannot be academically successful without a theory of mind).

Therapy (i.e. ABA) and medication (i.e. anti-psychotic drugs like Risperidone) are used to “fix” autistic people. This is really just teaching (forcing) them to pass as a neurotypical, much as a gay person may try to “pass” for straight.

All of this leads to the assumption that autistic people can’t have anything to say because they are not communicating in expected, dominant ways. And finally, all of this leads to advocacy organizations who are steeped in this process advocating for the eradication of autism.

But what about archaeology, what is the discourse that changed the input into the output here? That’s in the narrative, which follows my own journey through this rhetorical process of advocacy.

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After I wrote the section above, my giraffe pointed out that I used “they” instead of “we” when referring to autistic people. In sier words,

Why do I feel the need, writing academically, to distance myself from my identities? Why is this expected in academia?...I will not feign the distanced impartiality of an outside observer: it would be erasing my own Queer Autistic voice to do so! (Hillary 121)

I thought about going back and changing all of the “they’s” to “us/we/our”, but I feel that it is just as powerful to leave it as it is because when I wrote narratively, I found myself using
“us/we/our,” but when I wrote academically, it turned into “they.” Why do I do this? I am proud
to be an autistic person, yet I linguistically distance myself in academic writing.

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2. Autistethnography

I chose to write this in an autistethnography style because, in the Spring of 2015, I took
Research Methods. In the class, I read an article that discussed Muted Group Theory (MGT).

MGT says “muted or subordinate groups must use the language of the controlling power
in order to be heard” (Bordelon 339). The article examined discourse from the first two female
presidents of the National Council of Teachers of English and how they subverted the dominant
discourse in the president’s journal that they made during their respective presidencies.

While the article viewed women as a muted group, I saw how it could apply to other
groups like African Americans, the queer community, and most specific to my research interests,
disabled, neurodivergent, and autistic people.

According to this theory, in order to be heard, neurodivergent people need to use the
language of neurotypicals. In order to pass English classes, they are expected to write in the
dominant, neurotypical style. This theory reveals a neurotypical bias in academia.

So, again, why did I write this thesis as an autistethnography? My thesis uses the
dominant academic discourse style while also having a narrative that allows me to use my
natural voice and writing style, which plays double duty: 1) it documents my personal journey
towards my thesis, and 2) it documents my personal journey through the rhetorical construction
of advocacy. I subverted the dominant discourse and neurotypical bias through this narrative.
3. (Not the Final) Conclusion

This is the part of a thesis where I am supposed to draw my conclusion, where I am supposed to wrap up everything from the previous 5 chapters into a nice, neat, and succinctly beautiful bow on top of the present that is this thesis.

But I will not wrap and tie the bow over this proverbial box, for advocacy is not pretty, it is not neat, it is not succinct, nor is it nice. But most of all, it is not easy. It is not easy because it is a fight. A fight that we must face against a society intent on muting us, against our loved ones who we thought would be there for us, and even a fight against ourselves and the muting messages that have been ingrained in us.

Advocacy is not easy, and so to wrap this thesis up in a tight, beautiful, simple bow would be a disservice to all of us who fight for the right to advocate for ourselves. To define ourselves. To be ourselves.
Works Cited: (Not Really a) Conclusion


Works Cited: Combined


Baron Cohen, Simon, Sally Wheelwright, Jacqueline Hill, Yogini Raste, and Ian Plumb. “The ‘Reading the Mind in the Eyes’ Test Revised Version: A Study with Normal Adults with


Kindle File.

Fisch, Gene S. "Autism and Epistemology IV: Does Autism Need a Theory of Mind?"


Appendix I

Figure 1

Figure 2
Appendix II: Deleted Scenes

Autistethnography

This thesis is an autistethnography in the style of Melanie Yergeau’s “Clinically Significant Disturbance: On Theorists who Theorize Theory of Mind.” In the article, she tells a personal story that she expands on bit by bit and connects to her scholarship; they complement and build off of each other.

There are several reasons I am using an autistethnography as the narrative structure of this thesis. I come from several minority groups, chief among them being a group where I can “identify as autistic, but cannot define what it means to be autistic” (Rex Veeder, personal communication, December 3, 2015).

This is because non-autistic or “passing” clinicians, psychologists, and doctors define what it means to be autistic, not autistic people ourselves. This is clearly neurotypical bias. Is it appropriate for white people to define what African American means, or Christians what Judaism mean? They are not part of the group, yet they define both the group and the people within the group.

Upon beginning my search for a theoretical framework that fit that fits my experience of being in multiple marginalized groups, I found Muted Group Theory.
**John Elder Robison’s Response**

Two days after the publication of Suzanne Wright’s article, John Elder Robison responded to Wright’s article and announced his resignation from Autism $peaks. While he was not the first person to speak out against Autism $peaks, he had a large impact because even his tokenized position on the science board as an autistic non-scientist gained him the attention and possible respect of some supporters.

**Pentadic Analysis**

**Act:** “develop ways to meet the very diverse range of needs our community has” (para. 11)

**Scene:** Society that accepts that everyone has needs

**Agent:** Everyone (both autistic and not)

**Agency:** A society that helps people who need help

**Purpose:** Help people who need help

Robison focuses on the act, scene, and agency within his article. They are intricately and explicitly connected in his article. By having a society that accepts that everyone has needs (scene), we are ensuring that our society “develops ways to meet the very diverse range of needs our communities has” (para. 11) (act), which, in turn, helps people who need help (purpose).

**Cluster and Terministic Screens Analysis**

Robison says, “there are many ways autistic people can choose to live their (our) lives and all are valid and deserving of respect” (para. 11). Autistic people can choose to live their lives, not have their lives chosen for them by Autism $peaks and the parents that Autism $peaks advocate for.
“We [autistic people] are not problems for our parents or society, or genes to be eliminated. We are people” (para. 15). This is the point where Robison explicitly points out and challenges the image of autism that Autism Speaks weaves.

He points out something that most in the mainstream public don’t know, “Autism Speaks is the only major medical or mental health nonprofit whose legitimacy is constantly challenged by a large percentage of the people affected by the condition they target” (para. 20).

Finally, he drives the largest nail in the coffin of the whole post when he says, “Any group that hopes to be accepted in service to autistic people must make autistic people its #1 priority, with no exceptions. The priority cannot be autism parents, or autism grandparents. It’s got to be actual people with autism” (para. 21). He explicitly points out who Autism Speaks really advocates and works for: the parents or grandparents of autistic children.

In the next paragraph, he says

I celebrate the gifts autism brings us, and I have discussed at length the emerging realization that autism – as a neurological difference – confers both gift and disability on everyone it touches. It’s the fire the moves humanity forward, while simultaneously being a fire that can burn us individuals as we try to make our way. (para. 5)

This is a vastly different representation and narrative of autism. It is crafting an image of autism as something that holds disability, but it also holds gift. Vastly different to the image that autism is only a disability that drives parents and society to despair. However, his analogy is concerning: autism is a gift, but it is also the fire that burns us. When I think of fire, I think of how it destroys everything it touches. So, autism is a gift, but it can also completely destroy you? It is a tad confusing.
In the next paragraph, he seems to contradict himself. So far in this article, autism is both a gift and a disability. However, he then says,

If I act a bit different because I’m autistic, I think it’s my right to do so without being mocked, bullied, or discriminated against. At the same time I realize people are people, and if I act like a jerk, I will be treated as one. I understand I have a responsibility to learn how to behave in ways others will find acceptable or even appealing. (para. 8)

Difference is not okay because autistic people have a responsibility to act “in a way others will find acceptable or even appealing” (para. 8). It contradicts his idea of “changing society to make it more accommodating for people who are different” (para. 7). Why isn’t it society’s responsibility to learn how autistic people behave and be okay with it? In other words, what role does society have in the narrative of the autistic? Robison seems to be saying that autistic people must change, not society.

Robison, an autistic man who worked to change Autism Speaks from within, quit the organization and publicly posted his letter of resignation pointing out that Autism Speaks’ #1 priority is the parents or grandparents of autistic children, rather than autistic people. This should have opened the doors, but it didn’t. Not many in mainstream society have heard about this.

My final thoughts on Robison post is that he challenges Autism Speaks’ narrative of the autistic person as useless and unable to care for themselves by 1) simply writing as an autistic person, and 2) logically taking Autism Speaks to task on their image of autism.
Juxtapositional Rhetoric - Robison and Wright

A pattern emerges in both articles. They share a core mentality of autism, but to differing degrees. Wright looks at only the suffering and negatives of autism, while Robison contends that there are gifts of autism. However, Robison maintains that parts of autism should be fixed. He seems to be saying we should have a plan for how to fix the parts of autism that make people suffer, perhaps a national plan that involves creating a city for just the 500 thousand autistic people who will be growing up?

The core problem here is that they are both looking the autism that was crafted by Autism $peaks. Autism $peaks crafts this image of autism as capital “O” Other by influencing the representation and narrative surrounding autism.

Another thing that is very striking when you actually look at the two documents side-by-side is the choice that Wright makes of using very short paragraphs. On average, her paragraphs have 20 words. She only writes three paragraphs longer than 55 words, all discussing how bad autism is. The first shows how autism is bad for parents, the second laments that we don’t have a national plan for the autism crisis, and the third depicts how autism is bad for autistic people.

What is the purpose of writing like this? It could be argued that this is just her writing style if you lacked familiarity with her other work. However, any transcript of her speaking shows she is very eloquent and goes into depth to support what she says. It doesn’t show in this article. So why is this? This is a masterful rhetorical move because it is (1) simple to read and (2) simplifies a complex situation to under 20 words in a paragraph.

Robison’s average 55 word paragraphs are sharply juxtaposed with Wright’s 20 word paragraphs. In his paragraphs, he goes into depth to support what he says, creating logical appeals against what Autism $peaks is doing.
So, this was a response to Wright’s article. Did any other organizations or groups of people also respond?

**Conclusion/Epilogue**

My thesis has been a long journey; two years, while not so long on paper, feels like an eternity because I have come so far. It began with identity because I had none. It had been ripped from me by discipline and punishment at the hands of colleagues, professors, and supervisors. “You cannot be that!” Yet I was. But I partook in the destruction of my self-identity. So, in an attempt to distance myself from that, I researched identity and deconstructed the medical model’s version of disability. Disability is socially constructed, and therefore, not a problem that lies within me.

I then moved on and looked into theory of mind for quite a few months where I found that identity was, indeed possible. And with that, I began to slowly form my own identity once more. I set up an appointment to see if I could be medically recognized as autistic and signed up to get my autism certificate.

During that summer, I struggled figuring out where my professors were coming from. I didn’t understand their logic or their argument, but by the end, I had helped give them a new insight. And by the end of the summer, I had a new insight into myself as well: I am autistic.

In the fall, I began the arduous process of coming to terms with an uncomfortable feeling regarding my autism diagnosis. I found that Autism $peaks basically wants to eradicate me and autistic people like me because we are blights on society; we are monsters. But that was garbage because I was not a blight on society (nor now).
Finally, I looked at advocacy groups and rhetorically analyzed their articles responding to Suzanne Wright’s piece. I found that Autism Speaks is founded on the idea of autism as capital-O Otherness whereas groups like the Autistic Self Advocacy Network and Grassroots are founded on the idea of autism as diversity.

I think about this experience and how it has helped me heal from the psychological trauma I had experienced while teaching. I’m not wrong, I’m not bad, I don’t need to be eradicated...I just need to be my best me.

1 is 2 many PSA

TW: Sexual Assault

This is a transcript from a campaign run by the White House regarding sexual assault.

Benicio del Toro: We have a big problem, and we need your help.

Dule Hall: It's happening on college campuses, at bars, at parties. Even in high schools.

Steve Carrell: It's happening to our sisters and our daughters

Daniel Craig: Our wives and our friends

Seth Meyers: It's called sexual assault, and it has to stop.

Dule Hill: We have to stop it, so listen up.

Benicio del Toro: If she doesn't consent or if she can't consent, it's rape, it's assault.

Steve Carrell: It's a crime. It's wrong.

Joe Biden: If I saw it happening, I was taught you have to do something about it

Benicio del Toro: If I saw it happening, I'd speak up.

Daniel Craig: If I saw it happening, I'd never blame her. I'd help her.
Dule Hill: Because I don't want to be part of the problem.
Seth Meyers: I want to be part of the solution.
Joe Biden: We need all of you to be part of the solution. This is about respect, it's about responsibility.
Barack Obama: It's up to all of us to put an end to sexual assault. And that starts with you.
Daniel Craig: Because one is too many.

- **Act**: Stop sexual assault
- **Scene**: Society
- **Agent**: The audience, us
- **Agency**: The audience, us
- **Purpose**: Help people who need help

Again, this PSA focuses on the agent, purpose, and act. We, the audience, (agents) help someone who needs help (purpose) by stopping sexual assault (act). Everyone, be they directly involved or not, is supported and empowered in this PSA. The women who could have been sexually assaulted is supported by the agents who “doing something about it” and “never blaming” them. The agent is supported by resources on the White House’s website. People in society are supported by now being aware that resources are available on the White House’s website for ending sexual assault.

There are, however, two flaws in this PSA that don’t have anything to do with the Pentad. 1) The narrative is only told by male-presenting people and 2) this should still apply to a woman who does not have a dad, brother, child, or husband. Focusing on the second point, there are trans people who are raped, so is this PSA saying they are women. Not only that, but what about
non-binary people, who are neither man nor woman? They can’t be raped because they aren’t women?

Of course they can and this PSA doesn’t necessarily say that they can’t, it just doesn’t include them. Which is just as flawed as otherwise stated.

END TW.