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# WHAT I MEAN WHEN I SAY AUTISM: RE-THINKING THE ROLES OF LANGUAGE AND LITERACY IN AUTISM DISCOURSE

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*WHAT I MEAN WHEN I SAY AUTISM:*  
RE-THINKING THE ROLES OF LANGUAGE AND LITERACY  
IN AUTISM DISCOURSE

by

Bernice Maisy Olivas

A THESIS

Presented to the Faculty of  
The Graduate College at the University of Nebraska  
In Partial Fulfillment of Requirement  
For the Degree of Master of Arts

Major: English

Under the Supervision of Professor Robert Brooke

Lincoln, Nebraska

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*WHAT I MEAN WHEN I SAY AUTISM:*  
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IN AUTISM DISCOURSE

Bernice Maisy Olivas, M.A.

University of Nebraska, 2012

Advisor: Robert Brooke

Literacy studies are deeply intertwined with issues of identity. Olivas explores the ways that public discourses of autism have constructed an autism “Identity kit,” as defined by James Paul Gee, which harms autistic students and communities more than it helps. This is particularly true for adult autistics. Considering the growing presence of the autistic learner in the composition classroom, it is important to understand how public discourse influences classroom dynamics. Drawing heavily on her own experience as the mother of autistic sons and on Melanie Yergeau’s “Circle Wars: Reshaping the Typical Autism Essay,” Olivas explores how her children have been affected by public discourse and how her own identity as both a member of the autistic community and a teacher of composition has shaped her views on that discourse

*What I Mean when I Say Autism: Re-thinking the Roles of Language and Literacy in  
Autism Discourse*

by Bernice Maisy Olivas

*Shaking Hands*

I do not want to write about children with Autism and I don't want to write about Language or Literacy, at least not in the sense those imposing capital letters convey. I don't want to try to prove the definitive value of anything. I don't need the last word. I just want to introduce you to my sons, who are autistic<sup>1</sup>. I want to invite you to explore the ways we speak about autism in rhetorical public spaces; spaces like books, articles, and television; spaces like posters hung on bulletin boards and in the news; spaces which, by their very nature, make an argument. I want to ask you to reflect on how the rhetorical practices which are normal in these spaces affect autism identity and the ways people with autism are treated in everyday life. I want to invite you to consider how mainstream ideologies of language and literacy have participated in shaping the ways we use those rhetorical public spaces.

I am asking you to consider the ways in which the autistic identity is constructed by what is held to be true in these spaces and how the discourse affects the autism community. And I mean community in its largest sense. I mean people with autism and their families, their friends, their lovers, and their children. I mean the doctors and

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<sup>1</sup> Autistic, Autie, Auspie, member of the ASD community, person with autism, autistic person are all terms used in this paper to indicate a person living with or diagnosed with Autism, Aspergers, and a number of other disorders that fall in on the Autism spectrum. I try to refer to the each member of this community in the same language that he or she refers to themselves. Like many communities which are not the "normative," the ASD or AS community is not monolithic in nature. Therefore the ways in which they think, speak, and write about their identity is not monolithic. I respect their right to make these decisions and so will take on the languages used by the individuals in question. As the mother of two autistic children I choose not to use people first language in regard to my boys because I do not believe that their autism is something separate from their personhood and hope to raise them to be proud of their autistic identity.

therapists, educators and researchers; the paraprofessionals in classrooms and teachers and coaches. I mean bloggers and activists, policy makers and advocates. I mean all the folks who live in worlds where autism is present. I just want to take a moment, reach my hand out, slip my palm against yours, squeeze gently, and come away a little bit less of a stranger.

### *Relearning Normal*

Gareth takes almost thirty-six hours to be born. He gets stuck on my pelvic bone and with each contraction he moves a grating inch forward, when I stop pushing he slides back. I am unaware at the time that this is Gareth's way of being in the world. He will approach each milestone carefully, slowly, with stops and starts. As he cognitively develops, his every shift forward will be swiftly followed by a shuffle-step backwards, leaving his father and me constantly breathless.

In the first weeks of life, Gareth is the perfect baby in the daytime and the perfect nightmare after six p.m., when he begins to wail. He cries like he hurts, like he's experiencing a grief too big for his body to hold. It breaks me to hear it. Some nights I cry with him, others I lay him in his crib and walk around the block until I can no longer hear him, just for a minute. This goes on for two weeks, and then my mother comes to the rescue with a baby sling. I strap my son to my chest, murmuring senselessly to him as I go about my day, and he sleeps. I wear him like a kangaroo Joey for almost two years; I learn to sleep in a rocking chair and to shower with him facing away from the water.

At first he doesn't look at me or cuddle, but after a while, he begins tracking me with his eyes and leans his head to my chest to listen to my heart beat. Gareth meets his

earliest milestones triumphantly. It is in the pouch he first begins to coo and giggle. He says dada at just under a year old; and it is in the pouch he begins to go silent. He will be almost four when he says his next words, including mommy, and he is nearly six when single words begin to stretch into sentences. Gareth is diagnosed with Asperger's Syndrome around age three. Although he exhibits many symptoms on the autism spectrum, he has no problem with physical contact or affection. He is my cuddle bunny. To this day I attribute the close physical and emotional connection with my son to that baby sling, those kangaroo days.

Now Gareth is seven. He has big brown eyes and messy brown hair. He speaks what I joke is Gareth-ese. Recently he has become fascinated with Menards Hardware store and will repeat their slogan randomly. *Save big money at Menards*. He says, "Do you want to play computer," when he means "May I play with the computer?" When upset, he loses sentence structure. "No bedtime, just computer time." Other times he gets straight to the point and says, "Want computer!" At the same time he seems fascinated by words. A conversation with my son often turns into wordplay. I will say, "Time for breakfast."

He responds, "Time for dinner."

And I will say, "No it's breakfast. We have breakfast in the morning, not dinner. Stop being so silly."

He laughs and laughs until he is out of breath.

Osiris comes into the world swiftly, rushing headlong into the hands of an intern. He is first baby she has ushered into the world. There is wonder on her face when he raises his hand to her cheek. This is how my big, sturdy boy will do everything. He is a

physical baby. His knows the world through touching it, squeezing it, pulling it apart so he can see inside. Even in the beginning he is a quiet baby. Too quiet. When he is two weeks old he loses a frightening amount weight, and the doctor suggests he may be susceptible to failure to thrive because he never cries to tell me he is hungry. I am tired and depressed because he is having trouble breastfeeding and it never occurs to me that he might be in danger. We switch to bottle-feeding and soon he is roly-poly and pink. But he never really coos or babbles. Now at five, he is the climber, the bouncer, all elbows and digging toes. He is my little mechanic who can figure out how to disassemble locks and baby gates. He is Destructo boy. He was diagnosed with Autism at about two. At five, he is still *almost* entirely nonverbal. When he speaks he most often uses single words like cheese or drink. Recently he has begun adding words like want and need. If coached, he will string together a sentence, “I want drink, please.” Mostly he just raids the refrigerator.

Gareth and Osiris are both what could be called normal at birth. They both have ten little fingers and ten little toes. They are healthy and pink. They pass the Apgar test. But by the time Osiris is diagnosed we know what autism looks like and what it sounds like—which contrary to popular belief, isn’t silence; it sounds like a sigh, a deep sigh, rich with the frustration of being misunderstood. The four of us begin to rebuild our expectations and to redefine the terms like able, capable, and independent. We begin to relearn normal.

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One difficulty in discussing or defining or understanding autism is that, “there is no known single cause,” (Autism Society) and it has, “no medical test, like a blood test, to

diagnose the disorders,” which, “affect each person in different ways, and can range from very mild to severe,” (Centers for disease control and prevention). What this means is that we don’t know how or why autism happens. We do know it affects a sizable portion of the population. The Centers for Disease Control and Prevention recently released statistics that say 1 in 88 children, across racial lines, have been identified as having an ASD disorder and that boys are five times more likely to be on the spectrum than girls (Centers for disease control and prevention). One definition of autism that I think really encompasses the complexity of the disorder is the following from the Autism Spectrum Disorders (ASD): Nebraska State Plan, Presented by the Nebraska Special Education Advisory Council:

ASD is a lifelong neurodevelopment disability, a behaviorally definite syndrome that is recognized by the manifestation of behavioral characteristics across multiple areas of functioning. Characteristics are observed, to varying degrees, in social relationships, communicative competence, pattern and range of interests, and sensory responsiveness... (Nebraska Special Education Advisory Council).

ASD is medically defined as “a group of developmental disabilities that appear early in a child’s life” (Centers for disease control and prevention). Currently the medical field recognizes ASD as a group of developmental disabilities that encompasses levels or ‘spectrums’ of how ASD impacts the individual including:



- Autism disorder (sometimes called “classic autism”), which according to the CDC is defined by significant language delays, social and communication challenges, and unusual behaviors and interests (Centers for disease control and prevention).
- Asperger’s disorder which CDC defines as a milder form of autism disorder which includes social and communicative challenges as well as unusual behaviors and interests but is not usually defined by language delay or intellectual disability (Centers for disease control and prevention).
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS; also called "atypical autism") is a diagnosis often used to define members of the ASD community whose symptoms meet some of the criteria of autism or Aspergers but are often more mild or “atypical” (Centers for disease control and prevention).
- Rett syndrome, which “is a neurodevelopmental disorder that affects girls almost exclusively. It is characterized by normal early growth and development followed by a slowing of development, loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, problems with walking, seizures, and intellectual

disability.” (National Institute of Neurological Disorders and Stroke)

- These disorders are diagnosed by a physician using the *Diagnostic and Statistical Manual of Mental Disorders (DSM,)* [which] is the standard classification of mental disorders used by mental health professionals in the United States (CDC, 2012). It is important to note that a new version of the DSM (the DSM-5) will be released in May of 2013. This version has been rewritten to account for the new understanding and new information concerning ASD. The DSM-5 will greatly impact how the medical field interacts with members of the autism community

What this means is that people with autism, their parents, teachers, and caregivers are living and working in a situation with a lot more questions than answers.

### *Braiding Identity*

My mother, when visiting in the summer of 2011, braids my long hair. Her fingers work nimbly. She twists some strands, smooths others, folds separate things together so they merge into a whole. Her fingers are as familiar against my scalp as my own. I’ve sat at her feet since I was child. I learned to braid, first my sisters’ hair and then my own, by watching the intricate dance of my mother’s brown hands. We have done this a thousand times. My back settles against her body and her breathing synchronizes with mine as she works. In this moment Gareth slides down from his perch on the couch, sits between my

legs. I place my hands in his shaggy hair and he leans back. Osiris, not wanting to be left out, snuggles up beside him. Our breathing synchronizes. I scratch their scalps gently. We are, in this moment, a living metaphor of the ways in which identity is shaped and formed. We are braided together by blood and bone; by story, lived experience, memory, and love. My skin is her skin; their skin is my skin. We are branches of the same tree, scarred in different ways by the same storms, channels of the same river working our way along different paths to the same destination. My mother's fingers work busily in my hair, and mine works in theirs.

What you cannot see is the way we work each moment to braid into being this thing we call identity. We braid together the stories we hear, the voices we hear, and our own lived experiences into the ways we view and understand ourselves. For each of us, it is the work of several lifetimes, beginning in the hands of our caregivers, long before we are ready or able to take up the task and work the strands ourselves. Like my mother before me, I take seriously my job to work into existence a healthy identity, which will act as a lifeline for my sons as they navigate this difficult world. My husband, my parents, all of the people who make up our community work alongside me; our fingers never rest. In this moment our bodies silently speak love, comfort, reassurance and acceptance to each other, and I am deeply aware of how strands of public discourse shape identity. These strands are often slippery or snarled; hard to see, hard to name, harder to grasp, but they are connected to real people. Tugging too hard or pulling too urgently causes real pain. With that in mind, I tug gently at the public discourse of autism, which because my sons are autistic, will always be a strand in our braid.

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After Gareth is diagnosed with Asperger's I read everything I can get my hands on. And there is so much of it. I begin with the what-is-autism and the what-to-do-after-diagnosis type narratives. They are astounding in their diversity. I read how autism could be a mental disorder, pathology, genetic, the result of a bad pregnancy diet or of immunizations. I read about heavy- metal poisoning and allergies. What I see most often are narratives that say that autism can be any of these things or a combination of them but diagnosis means that your life is fundamentally changed forever. One author writes, "I would rip off my own arm and eat it raw if it would make my child normal" (Damon 3). In these narratives children are stolen, invaded, taken, or lost to autism. Once in a while I see narratives that are more focused on day-to-day-life or humor. These are almost always focused on the early years and often written or co-written by parents looking for answers to their questions. Even in the angriest, most bizarre, most frustrated narratives, my heart goes out to these parents as they struggle to find a new way to live with the changes in their worlds.

Some parents turn to God in search of answers. One such parent says, "He [God] has chosen you to parent him [the autistic child] for a specific reason. He sees your potential to nurture this special being that He has placed in your arms to help him become all that he intended him to be." Then she reassure us that "we will more than survive the battle; we will conquer the autism with an overflowing and abundant joy in our lives such as we have never known" (Langston). Some turn to nature and holistic medicine, some turn to science, but for each of them life is utterly different than it was before the diagnosis.

In one instance I read that my sons' diagnosis will send me spiraling into the same grief patterns as a parent who has lost a child. I am supposed to be angry, depressed, try to negotiate with God and the universe, until finally I accept my new reality. I read reports that say autism will be the dingo that eats my marriage and my money. I wade through all 100 days of a kit, which begins by reminding me, "It is important to remember that your child is the same unique, lovable, wonderful person he or she was before the diagnosis."

The kit includes a section called, *Ten Things Every Child with Autism Wishes You Knew*. "#1: I am first and foremost a child. I have autism. I am not primarily 'autistic.' My autism is only one aspect of my total character. It does not define me as a person." Except that it seems to me that my sons and their autism are melded together so that I cannot tell where one ends and the other begins. I read narratives of people living with or working with people with autism like *Courage, Heart & Wisdom: Essays on Autism: By Physicians, Psychologists, Educators, Speech and Language Therapists, Occupational Therapists, Music Therapist, Social Workers, Parents and Students*. Books that focus on siblings like *Autism and Me: Sibling Stories* and books that include a variety of community members like *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, And Professionals Share Their Wisdom*.

When I've finished with the "after diagnoses narratives," I skip the pseudoscience, and outright quackery defined by authors with no medical degrees or research training in Autism studies, education, or social science that seems to litter the conversation of autism. I pass over titles like, *The Soul of Autism: Looking Beyond Labels to Unveil Spiritual Secrets of the Heart Savants*, and *The Autism Prophecies: How an*

*Evolution of Healers and Intuitives is Influencing Our Spiritual Future*, but marvel at their numbers. Then I read about cures: raw food, and whole food, and one night in a bar a stranger gives me his card because he is sure that he can cure my son with his chiropractic trick of adjusting the fragile bones in his neck. I read about journeys and expeditions, about shamans and acceptance. I read about warrior moms and relentless dads. Jenny McCarthy writes, *Mother Warriors: A Nation of Parents Healing Autism Against All Odds*, and her story becomes part of a group of narratives that focus on parents who find some amazing way to “fix” their kid in spite of the diagnosis, in spite of everything. I read accounts of amazing love, accounts of incredible pain, and accounts of deep frustration.

Much of this reading is deeply frustrating to me because I’m not grieving; I don’t feel irreversibly changed. I have no desire to put my son in a hyperbaric chamber and oxygenate him until he comes out normal. I remember the grief and nightmares, the heart wrenching, bone-level ache of loneliness that enveloped my family after two of my young cousins died in a house fire. I *know* that having an autistic child is *not* like losing a child. Nothing, *nothing*, is like the hollow space left behind by the loss of a child. *Nothing*.

My sons’ diagnosis is a new and sometimes scary way of understanding them. Autism is an identity marker that is mostly blank and hazy. As with all identity markers autism comes with a historical context, a body of scholarship, and a public discourse which is both prescriptive and descriptive. Because I don’t know this thing called autism intimately, because I do not embody it, and have never known anyone who does, I turn to books, articles, and research. I look for it in the media and listen for it in conversations.

Reading about it and seeing it on television and hearing about it in conversations creates an understanding of autism to which I can compare and contrast my own experience.

Often what I see emerging makes me uneasy but at the time I have no way of understanding or articulating why.

Then a friend, also a mother of a child with autism give me Temple Grandin's *Thinking in Pictures* and for the first time I am confronted with an adult with autism, an adult telling her own story, an adult offering me her lived experience. Like many autism parents, I was deeply affected by hearing her story in her own words. Her work sends me in search of more voices like hers. Online I find blogs, journals, and a body of work from adults and young adults that problematizes much of what I think I know. I am struck when one of the first things I read is an online article titled *Ten Things an Autistic Adult Wishes You Knew*:

#1. I am autistic, not just an adult with autism. It is part of who I am. Autism is a part of who I am. I was born this way. I would not choose to change that. Acknowledging my autism as a part of me is entirely compatible with respecting me as a person with thoughts, feelings, and talents. I am a human being like everyone else and deserve the same dignity and respect that any one else deserves. Please consider whatever term I prefer and do not use language that suggests I suffer from an unfortunate disease.

It is in this moment that I decide that I will raise my sons to understand that I do not believe that autism is something separate from their bodies or their minds. Instead I choose to raise them to understand that I believe that autism is part of who they are. Being autistic will not be easy but it is not without its rewards, and I would not change it. However, I also respect that people first language has come into being expressly to counter discrimination and othering of people with disabilities and I deeply grateful that such work has been done, but like the autistic self-advocate above I would ask you to try to understand why I choose not to use people first language in this essay. When my children begin to develop an opinion I will adjust so that I can validate the way they see themselves.

As I explore the internet I learn that the Autistic Self Advocacy Network defined autism in 2007 as “a neurological variation that occurs in about 1 in 150 people and is classified as a developmental disability” (the information concerning these statistics have changed over time) and they say that

While all Autistics are as unique...they share some characteristics typical of autism in common. These characteristics are:

- Different sensory experiences [like] heightened sensitivity to light, difficulty interpreting internal physical sensations, hearing loud sounds as soft and soft sounds as loud, or synesthesia.
- Non-standard ways of learning and approaching problem solving.



- Deeply focused thinking and passionate interests in specific subjects.
- Atypical, sometimes repetitive, movement. [Including]"stereotyped" and "self-stimulatory" behavior such as rocking or flapping, and also the difficulties with motor skills and motor planning associated with apraxia or dyspraxia, which is a disorder of the brain and nervous system in which a person is unable to perform tasks or movements when asked, even though they understand the request, are willing to do it, and have no physical impairment to doing the task
- Need for consistency, routine, and order.
- Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal. Difficulties in understanding and expressing typical social interaction

Then I find “Circle Wars: Reshaping the Typical Autism Essay,” by Melanie Yergeau, a doctor of rhetoric and composition at the University of Michigan who is also a woman with autism and self-advocate. She names the frustration I am feeling as a reaction to witnessing people with autism being othered by the public discourse of autism. By this I mean that the way so many of the books, television shows, talks shows and other public forms of speaking frames people with autism as outsiders and other. Her frustration is echoed in online journals and blogs where I find adults with autism that do

or do not speak and may or may not be independent but are defining and naming their world through their own experiences. I find a self-advocacy movement, not just about autism, but about ableism, and about many different ways society sees and treats people whose bodies, whose ways of thinking and being are different. I learn about the injustices perpetuated against folks whose difference lies in the ways they see, hear, feel, think and move. I learn about the struggle for the rights of blind folks and deaf folks. I learn that I belong to the privileged class of the able-bodied. I learn that the self-advocacy movement of the autism community is part of a proud tradition of resistance against prejudice, discrimination and injustice. However, the bodies of works containing the narratives, experiences and arguments of autistic adult only seem to exist on the fringes of rhetorical public spaces, while the spaces that are most accessible to the public are dominated by a body of literature that focuses heavily on the deficiencies and deficits of autism. As a parent, the narrative of these young adults and adults weren't hope because I wasn't hopeless, instead they were beauty and joy, and above all affirmation that all the wonderful moments I shared with children *weren't* imagined, or wishful thinking, they were real and even if they never talked, or lived independently, we were going to be okay.

One self advocate, Julia Bascom, writes:

Sometimes being autistic means that you get to be *incredibly happy*. And then you get to *flap*. You get to persevere. You get to have just about the coolest obsessions. (Mine are: sudoku and *Glee*. *I am not ashamed*.)... It's that the experience is so *rich*. It's

textured, vibrant, and layered. It exudes joy. It is a hug machine for my brain. It makes my heart pump faster and my mouth twitch back into a smile every few minutes. I feel like I'm sparkling. Every inch of me is totally engaged in and powered up by the obsession. Things are clear.

It is beautiful. It is perfect (Bascom).

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### *Braiding in Circles*

Yergeau argues that "The Typical Autism Essay" represents the mainstream American mode of understanding autism and the typical autism essay dominates the public discourse. Which is why it is important that we understand that Yergeau's is using the term essay not to refer to an academic paper or classroom term paper, instead she is contextualizing the essay as any thesis driven argument that "perseverates on the most tired of tired autism tropes" (Circle Wars). In fact Yergeau says that:

. . .[T]he typical autism essay is its own **genre** (a text, broadly defined, that conforms to certain "acceptable" features and styles and commonplaces and discourses and that represents and enacts social action of real human users) (Bawarshi et al.). It has its own **discourse** (a subset of genre, an "identity kit," a way of knowing the world and/or a culture by means of *language*, broadly defined) (Gee).

And it has its own **author(s)** (real people who govern discourses and genres) (Circle Wars).

Therefore when she argues that the typical autism essay is the most common mode of understanding autism within public discourse, what she means by mode is that the typical autism essay is the genre most often produced and offered to the public in autism discourse. When she says discourse she is evoking James Gee who said, discourse is “a socially accepted association among ways of using language, of thinking, and of acting that can be used to identify oneself as a member of a socially meaningful group or social network” (Gee 543).

It’s also important to note that her argument does not negate the positive work that the parents, the researchers, the medical field and the educators have done or are doing. Nor does she argue the need to gain new knowledge about autism. She isn’t arguing that the typical autism essay is only way people are working and writing about autism, only that it is the most common and because it is what the public sees the most, it has a real impact on the lives of people with autism.

Part of the problem is that the language, ideologies, and practices often showcased in the typical autism essay come from or are affected by outdated, refuted theories, or from a mangled version of complex theories that are still being tested. When Yergeau says:

According to the typical autism essay, the world's population is slowly heading the way of neurological disfigurement — because of vaccines, because of genetics, because of excessive television watching, because of airborne pollutants, because of gluten and casein and

artificial sweeteners, because of, quite literally, *your mom*  
(Circle Wars).

She's referring to theories that have shaped the discourse not just as they were read, but as they were misread. For example the theory of the mind can easily be read as if to say people with autism don't understand that other people can think or feel. One theory of the mind scholar writes:

A theory of mind remains one of the quintessential abilities that makes us human (Whiten, 1993). By theory of mind we mean being able to infer the full range of mental states (beliefs, desires, intentions, imagination, emotions, etc.) that cause action. In brief, having a theory of mind is to be able to reflect on the contents of one's own and other's minds. Difficulty in understanding other minds is a core cognitive feature of autism spectrum conditions. The theory of mind difficulties seem to be universal among such individuals. (Baron-Cohen 3)

And there are a lot of theories. I read the *trapped in a dark space theories*, the, *it's all your fault theories*. I read the *it has nothing to do with you and you can't control it theories*. I read the *it is God's will, bad luck* or the *evil eye theories*. There are the long been refuted refrigerator mom theories – this one says a cold unloving mother creates autism in her child. There were once theories that autistic children were feral children said to have been raised by wolves or bears or locked away from humanity so that their

minds shuddered and cracked under the isolation strain. While the medical, research, and educational members of the autism community have long since disproven these theories, and continue to tirelessly to work to erase the perceptions left behind, these theories still influence public autism discourse.

Among these disproven theorists are Bruno Bettelheim who, in 1959, described autistic children as "...typically...unable to relate themselves in the ordinary way to people and situations from the beginning of life. Extreme aloneness shuts out anything that comes to them from the outside. Some acquire the ability to speak, while others remain mute. But language is not used to convey meaning to others" (Bettelheim 455). He also says, "Our experience with the parents of autistic children, many of whom are well educated, good, middle-class people, leaves little doubt that in their deepest emotions they wished to be rid of them [autistic children] and for very good reasons" (Bettelheim 457).

There is also Leo Kanner who, in his case study, concludes that, "The combination of extreme autism, obsessiveness, stereotypy, and echolalia brings the total picture into relationship with some of the basic schizophrenic phenomena," but admits that the most interesting thing he found was that, "in the whole group, there [were] very few warmhearted fathers and mothers" (Kanner 99-101).

And Bruno Bower, who in 1981 wrote this of autism:

It is a rare disorder, afflicting about 5 out of 10,000 children, and is four times more common in boys than girls.

It is also a confusing disorder, because its symptoms often resemble other ailments, such as childhood schizophrenia, mental retardation and phenylketonuria. But it is certainly not new, having been described by physicians as far back as 1809 (Bower 154-155).

Another core issue of the typical autism essay, according to Yergeau is that the typical Autism Essay “assume[s] that autistic people either cannot represent themselves or cannot represent themselves as effectively as neurotypical<sup>2</sup> people can represent them” (Circle Wars). If an autistic person can speak for themselves, then they are the exception, not the rule. Yergeau also points out that typical autism essay is “neurotypical” in that it “it feels the need to situate a bunch of neurotypical readers who, generally speaking, are incredibly situated in autism and its concomitant rhetoric (Circle Wars),” which means that the typical autism essay isn’t directed at people with autism, but at the larger community. So the typical autism essay frames people with autism as being unable to speak for themselves for an audience made up mostly of members of the community who are not autistic.

Yergeau’s argument is that the genre of the typical autism essay enacts ableism is particularly important when we look at the long history of ableism and the way it impacts lives. In ancient Greece and Rome people with developmental of intellectual disabilities were considered inferior as were people who had physical disabilities. This view was the

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<sup>2</sup> Neurotypical is a term used in the ASD community, which means neurologically typical and often refers to people who are considered “normal.”

norm for centuries and is still part of the underpinnings of the ways in which people with disabilities are discriminated against.

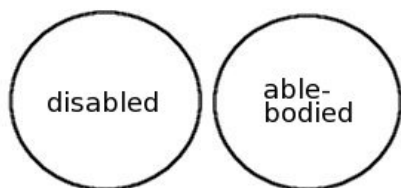
In 1798, Thomas Malthus (1766-1834), a British clergyman and economist, published the "Essay on the Principle of Population," which argued that population multiplies geometrically and food arithmetically. Therefore, the population will outstrip the food supply. In addition to cutting the birth rate by sexual restraint and birth control, Malthus advocated that all people "defective" in any way, who look or behave or function differently than the rest of society, should be identified and eliminated. Therefore, only those who are "normal," those who can make the greatest contribution to society, would survive (Minnesota Department of Administration)

Issues of ableism and discrimination, are, unfortunately not confined to the distant past. In the 1970's and 1980's the People First Movement emerged which defined itself as "...a personal and political philosophy – a movement primarily of and by persons labeled with mental retardation who are making their own decisions, speaking for themselves and for others with disabilities, and taking control over their lives (Minnesota Department of Administration)." In many ways the autism self-advocacy movement is synch with the People First movement because they are fighting for the same rights and freedoms. Yergeau, however makes the distinction that many autistics see autism as a



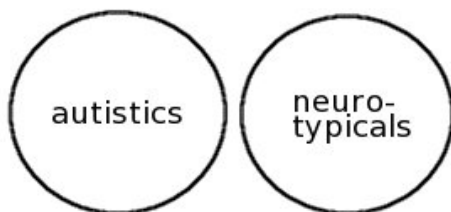
part of their essential personhood and a part of their identity instead of something they live with. It's very important distinction.

So when Yergeau criticizes the ways in which the typical autism essay works to define autism she is specifically pointing to the ways the typical autism essay begins by situating autism as a puzzle to be solved, a broken item to be fixed, or as embedded in cure-oriented rhetoric. The autistic brain is presented as being separate from the typical brain and autism is presented like a poison—like an outside substance that has damaged the human inside. Yergeau goes on to say the typical autism essay is rich with the “most tired of tired autism tropes...the epidemic, the suffering parents, the bodily imprisoned auties and the socially inept and clumsily genius aspies, the celebrities with neurological ESP” (Circle Wars). According to Yergeau the typical autism essay usually begins like this:



**Figure 1: Two circles sitting side by side. One circle is labeled "disabled" and the other is labeled "able-bodied." The circles do not overlap**

Or sometimes it begins like this:



**Figure 2: Two circles sitting side by side. One circle is labeled "autistics" and the other is labeled "neuro-typicals." The circles do not overlap.**

The typical autism essay gets messy when it tries to encompass as much as it can hold of the spectrum, like Asperger's vs. Autism and labels like high-functioning and low-functioning. It gets even messier when it tries to account for theories like, it's a mental disorder, a genetic disorder, pathology, a toxin-induced state, or demonic possession. However, in the typical autism essay the circles encompassing the neurotypical and the autistic never touch or overlap. The space in between belongs to the neurotypical. This is never questioned. The autistic can never travel that space unless they do so through the line which Yergeau labels "omg cure," which transforms the autistic into the neurotypical and effectively releases him from his circle.

The typical autism essay never begins without circles; it is always based in the difference between the neurotypical and the autistic. It never assumes that the autistic brain is just another part of the autistic body, which is just a part of the autistic human. It never asks the reader to begin without circles. Yergeau argues that the typical autism essay, "isn't about autistics — at least, it's not about autistics-as-humans inasmuch as it's about autistics-as-specimens. The typical autism essay is a sealed jar without holes poked in the lid" (Circles.)

While the typical autism essay, cannot, on its own, construct people into autism, because as she says:

discourse alone can't *name* these things, can't *claim* these things. These facets... of *human* individuals — autistic cousins or not — only fit within these circles because someone has squished them there, has proclaimed generalization as the new world order. Low-functioning

autism exists because the *people* who write the typical autism essay say it does: *they* make the circles; the circles themselves don't independently create themselves; the circles aren't material objects that exist or breathe or birth or contain people, all neatly sorted; the circles have *human* help (Circles).

The typical autism essay can offer the public an easy answer to a wicked problem; it can basically say, autism is bad, let's cure it or fix it and that allows us to ignore the more complex issues at hand. Issues of ableism, of discrimination, issues of support and inclusivity are hard issues. Self-advocates are saying, but wait—I am autism, what does it mean to fix or cure me, and why do I need to be fixed in the first place? The outcomes of this conversation are terrifyingly real. Jill Bascom illuminates those outcomes in an open letter to autism parents, when she says:

This is not a “disagreement.” You  
know what people disagree about?  
Pizza toppings, ice cream flavors,  
what Shakespeare meant in the third  
stanza. Things with small  
consequences.

You know what happens when we  
“disagree” about disability?

People die. People get aborted, people get institutionalized, people get sterilized, drugged, and neglected, people go without necessary support and services, people are dehumanized, people are abused, people are silenced, ignored, and erased, people suffer emotional and mental trauma and distress with life-long consequences.

Just as “disability” has become an ugly word for a physical fact, so “disagreement” is being used, here, as a polite word for an ugly thing.

I call bullshit (Bascom).

This is why Yergeau’s argument is so important and why it is so important to illuminate the ways the discourse functions to influence and shape way the public views autism. Every nonprofit ad focused around images of loss, pain, and despair, every image of a child alone on a swing or a child screaming contributes to a public narrative of autism that leaves no room for a empathy. Every mother in tears, every father speechless with pain as he looks at boys, boys without autism, playing baseball, and every child with big, downcast eyes, obviously alone in a roomful of people, creates autism the monster. And in our society monsters should be killed, eradicated, or at the very least locked away.

In understanding how the typical autism essay functions as a genre, and gaining a better understanding of the way it frames autistic identity we can better understand how the typical autism essay effects the public view of autism. The typical autism essay is deeply negative, even toxic. It is a narrative of despair and loss, which frames autism as killing or infecting or possessing the normal human mind inside the autistic body. It is the dark fairy tales in which the big bad wolf eats Little Red and the huntsman never comes. The typical autism essay crafts autism as an invasive, alien presence that blocks the human inside from connecting with the outside world, trapping them inside autism. These types of narratives encourage the mainstream to focus on the need to beat, conquer, or win against autism, instead of asking them to make the mainstream world inclusive and open to autistics, which would include providing support and cultivating an inclusive view of the differences in behavior or needs of autistics.

In 2010, a mother in the UK smothered her six-month-old baby because he *might be* autistic. She was suffering from postpartum depression and was suicidal and “did not want to 'burden' her husband with an autistic child.” She stated that she believed, “having an autistic child would emotionally and financially 'ruin' her life.” She was not charged with a crime (Thompson). In Texas, a year later, a mother kills two, a boy and a girl ages two and five because, “They are autistic. I don't want my kids to be autistic” (CNN Wire Staff). In 2012, when a mother in Sunnyvale California shoots her 22-year old autistic son and herself, her neighbors say that they “understood” why she might have done it (Fernandez and Rodriguez). These are extreme, but not uncommon situations and I see them in news frequently.

There are less extremes moments, like when a mother in a fundraising ad says, with her autistic daughter in earshot, that she once considered driving off a bridge with her autistic daughter in the back seat of her car, but didn't because she had another non-autistic child at home (Autism Everyday). Or when an opinion writer refers to "the insidious nature of autism and *the way it robs its hosts* [emphasis mine] (Rubinoff)"... or when I come across a new book concerning college age autistics which says:

We are re-entering the fray, having proven that children and adults with dyslexia can be taught to read, that children and adults who are second-language learners can be taught to read and write academic English, that children and adults who speak a non-academic dialect of English can be taught to read and write academic discourse, that people with handicaps can be taught despite the handicaps, and often even be re-taught to read and write after brain injuries, and now we are again arguing the case for students with Autism, Aspergers and other autism spectrum disorders to do college level reading and writing...(Gerstle, Val, and Walsh )

It's through the lens of such horror stories that we can most clearly see the impact of allowing the typical autism essay to direct and control the public identity of autism. A mother of a six month baby was so terrified of the specter of autism she chose to kill her child. Why? I believe that part of that answer is because the narrative of autism she heard

in her public spaces painted a picture of hopelessness. The typical autism essay was part of the reason she believed that death was better than life with autism. Yet voice after voice of autistic adult tells us that life as an autistic can be beautiful, productive, and joyful. Would that young mother have hesitated to kill her child if the discourse of autism around her reinforced a more realistic, diverse, and rich picture of autism identity?

Considering the ways discourse impacts reality it is crucial to understand that Yergeau and other self advocates are not arguing that autism does not exist, or autistics do not face real, heartbreaking challenges, or that members of the ASD community do not need support to meet the challenges they face. Nor is Yergeau arguing that scientists and researchers should stop studying autism. It's not about the validity of this treatment or that treatment, this education practice or that education practice. Yergeau's is arguing that it is dangerous and ableist for the most common public rhetoric in mainstream America to separate autism from the human mind and body of the autistic, creating space for the autistic to be generalized into a single helpless image which creates an us /them binary and a dynamic that places the neurotypical as normative and offers us an easy answer to a wicked problem without asking for true empathy or understanding.

The real discourse, the conversation happening between people with autism, their families, the medical community and the education community reflects a much more complex reality than we see in the typical autism essay. Teachers, scholars, and medical researchers have opinions and practices as varied as the autism spectrum itself and many of them are staunch supporters and allies of self-advocacy but we don't see or hear that conversation in public spaces. I believe that part of the reason the typical autism essay is

so hard to speak back to is because autism, in all its complexity, forces us to question the ideologies surrounding two things most people consider the hallmark of being human. Language and literacy. The typical autism essay creates an us/them binary embedded in the way we privilege talking as language and as the most human way of communicating and the way we construct literacy as a measure of competence. To question the typical autism essay is to question much of what we believe to be true about language and literacy, which might mean we have to question how we've constructed what it means to be human.

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### *Braiding in Language*

The ideologies and practices surrounding language are a particularly messy part of autism discourse because communication is a core issue in the discussion of autism. Understanding, supporting and expanding the ways we communicate with each other is vital in the relations between autistics and neurotypical members of the community. Unfortunately the typical autism essay, again, strives to simplify a complex situation by taking one form of communication, speech, and constructing it as the best, and in many cases, only option.

Even though extensive research has been done on the various ways that people with autism acquire and develop language, the spectrum nature of autism often makes developing therapy, support, and treatment a very difficult task and time consuming task. Because we do know that communication is crucial in our relationships with people with



autism, how literature and pop culture frames people with autism and their relationship to communication and language becomes central to how the public understand Autism.

In a 2011 publication, “*Child Language Acquisition: Contrasting Theoretical Approach*,” the authors attempt to create a comprehensive overview of evidence based theories of language. They write

Our goal is to identify the key debates in each of what we consider to be the ‘core’; domains in language acquisition (by monolingual, typically-developing speakers) and to outline the empirical evidence for and against each theoretical proposal, in an even-handed, systematic and (as far as space permits) comprehensive manner.

Then they say:

The majority of the debates that we will encounter in this book, each of the competing proposals will generally be aligned with one of the two major theoretical approaches to language acquisition. These are (a) the nativist, generativist, Universal Grammar (UG) approach and (b) the constructivist, emergentist, socio-pragmatic, functionalist, usage-based approach (Ambridge, Lieven).

In extremely simple layman terms the nativist approach assumes that certain aspects of language are innate to the human mind because the capacity for language is hard-wired into the brain. The constructivist approach argues that language is not innate, even if the ability to learn language is innate. Language itself is a learned behavior. In between these

two approaches there are many different theories concerning exactly how we acquire language. However we do know what that acquisition looks like in most children.

Here is what we know about how language emerges in neurotypical children:

According to the Linguistic Society of America children respond to language from birth. Children acquire language in stages and different children reach the various stages at different times. Language comes in stages. These stages are often referred to as “milestones,” and when a child does not reach each milestone within a certain time period then it is suggested that they are observed for developmental delays. A missed milestone is often the first indication that a child may be autistic or have a developmental delay (Linguistic Society of American).

The order in which these stages are reached is usually the same.

1. Since birth a child cries.
2. At six weeks a child begins making vowel sounds.
3. At around six months a child will begin to make “strings of consonant-vowel pairs like boo and da.”
4. At around age twelve to eighteen months a child will make single words with meaning.
5. At about two years old a child will begin making two word sentences.

6. Between three and six years of age a child will acquire a “vast majority of rules and sounds of language” (Birner).

For people with autism language doesn't happen always that way, and so language is a big part of the complex challenges they often face. This episode of Supernanny, a popular reality TV show, is a good an example of the way a typical autism essay lifts speech up as the most important form of communication and oversimplifies the diverse and varied methods, technologies and therapies that have been developed to help people with autism find different ways to communicate.

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The house is large comfortable and looks loved. The kids are cute. Mom and Dad are exhausted. In the first segment we learn all about autism and the how hard it makes life for this family. They never leave the house, their friends never come over, they are overworked and sleep deprived. They are terrified that Tristan, our autistic star, will “get away” and get hurt. Tristan engages in self stimulating behavior like flapping and spinning, which is usually referred to as stimming. He cries and escapes in the first half of the show. Then it's Supernanny to the rescue with a household schedule and a specialist to teach the parents a training method to help Tristan's speech. It is called the “communication technique” and is supposed to help him understand the connection between using words and getting rewards. The steps to this technique are 1.) Find something the child enjoys. 2.) Engage the child in the item or toy 3.) Take away the item and withhold it, until he attempts to speak. This technique should be used as often as possible the doctor says. The doctor says, “ the important thing is that if he does get

upset, and is trying other things to communicate, like crying, that they don't give it to him," because "we don't want him to be like this at twenty-one."

In the next segment:

"Cookie, cookie," says the doctor. Her tone is slow and rises slightly at the end. Three-year-old Tristan smiles and reaches for the cookie; he is blue-eyed and blonde, pixie-faced. She pulls it out of range. "Cookie," she says again, slower this time.

Tristan smiles, giggles, and reaches again.

"Cookie!" She is more insistent. Still smiling, Tristan reached again.

"Cookie!" She says pulling it away from his fingers.

Tristan bursts into tears. He grabs for the cookie and the doctor pulls it away. His mother is upset, but Supernanny pats her on the shoulder and reassures her that Tristan has to learn to say cookie. She argues that he is simply throwing a tantrum, which is "just like," any tantrum his sisters or another child might throw. It is in Tristan's best interest for mom to withhold the cookie because the "one thing that could make a massive change for this family is to develop Tristan's speech" (Frost, Jo).

In the course of the day Tristan is put on the swings and then "prompted" to speak until he is in tears and finally has to be taken away from the swings, which his mother calls the "highlight of his day." He never gets the cookie. Finally he says tickle "on command," and is rewarded. But at dinner he must pay for each bite of Pizza with, "yum, yum." He gets a few mouthfuls but gives up in frustration and leaves the table once again in tears. This is, according to the nanny, progress.

While watching this episode I notice the doctor does not suggest other ways to help him communicate, like sign language, or the Picture Exchange Communication

System [PEC] in which the child is given a set of picture cards so he can show his family what he needs. She doesn't suggest technology or discuss the way new technology has developed in the area of autism support. Nor does she suggest scheduling this therapy for a specific time frame. Learning to talk is hard for many autistic children, exhausting, and a little scary. When Gareth was diagnosed it was suggested that he be put in intensive therapy for forty hours a week. He was three. That's a full-time job, for a three year old. The doctor does not suggest a developmental pre-school or play group, she doesn't suggest reading to Tristan or using technology like TapToTalk software, which allows the parent to write out sentences that the computer will "speak" when the child taps the picture that goes with the sentence. She doesn't suggest installing a white board at his height so he can write or draw, and she doesn't suggest digital literacies like typing. She never suggests that Tristan may remain nonverbal, or always struggle to speak, and she certainly never suggests that being nonverbal doesn't mean unable to communicate.

All of this is strange to me because these are the things we talked about with doctors, specialists, and educators. The specialists' who have worked with my boys have changed our lives. I also know that much of the research that informs the practices of such experts has proven that giving children with autism a voice, if not words specifically, has extensive positive outcomes, but the research has also shown that there are many ways to help a child find his voice. So my concerns, as watched I this, wasn't that the specialist was too focused on helping Tristan find his voice but that the episode had been purposely shaped to convey the idea that speech was most important thing Tristan could learn instead of conveying what was really important; that Tristan learn to *communicate* with or without speech, with or without symbolic language. I was left assuming that the

specialist probably did cover a varieties of ways to help Tristan, offer an variety of strategies, but the episode concentrated on one basic message—they taught Tristan how to speak and this would change everything.

The concern I have with this episode is that it constructs speech as the only possible form of communication. This renders all other forms of communication outside of ‘normal’ which is unfortunate because the producers of the show could have, instead, used the opportunity to normalize a different way of communicating. Considering my own experience with autism specialists, with doctors and educators, I’m assuming we were not allowed to see all the work the specialist did with Tristan or all of the conversation between her and his parents. I imagine she talked about all of the possibilities but we were only see the finished product, the big moment when Tristan talks, because those are the moments that turn the episode into a typical autism essay which is what the public is used to and expects to see.

The construction of speech as the only possible answer to communication issues is a problem because it encourages people to privilege speech, rendering those who do not speak as other and it does not encourage us to imagine a world with many diverse modes of communication. For example in a discussion about autism I mentioned that my son uses word strips to communicate and a member of the conversation asked me if it was feasible to expect the “real world,” to accommodate that mode of communication outside of the classroom. I’ve thought about that a lot, and my answer is yes. I can imagine a world where people are willing and able to accept that another person communicates through technology like the written word or a computer without casting a value judgment on their personhood or ability to think because of it.

Considering the numbers, 1 in 88, and considering that many autistics have a troubled relationship with speech, it's a future worth imagining. So when the typical autism essay frames speech as communication, it disregards non-verbal members of the community who are already using different ways and technologies to communicate. Tracy Thresher, for example, a man who types to communicate and who was appointed by the Governor of Vermont to the State Standing Committee on Developmental Disabilities, exclaims, "My ideas are important for you to hear, but I am not always able to communicate. I am a man in a body that does not do what I want it to do. I struggle with my verbal speech, and this is a huge challenge for me. Saying and doing are issues I have with my body."

Amanda Baggs, a self-advocate who is autistic and does not use speech as her primary mode of communication says,

...[My language] is not about designing words or even visual symbols for people to interpret. It is about being in a constant conversation with every aspect of my environment...I find it very interesting, by the way, that failure to learn your language (speech) is seen as a deficit, but failure to learn my language is seen as ... natural. We are even viewed as non-communicative if we don't speak the standard language but other people are not considered as non-communicative if they are so oblivious to our own languages as to believe they don't exist.

Amanda uses a computer program which translates her writing into speech. These kinds of assistive technologies have become more and more available over the year. The Apple

iPad has actually begun to focus producing applications that are specifically designed to help people with autism. In a blog post Amanda says this about her relationship to speech, “I can never or rarely form useful speech. My utilitarian (as opposed to just random sounds) speech skills vary from none at all to assorted grunts and the occasional word or phrase. And the occasional perfect French sentence that leaves me wondering how on earth I got wired like that, but that has very little practical value.”

If , however, we take the typical autism essay as truth then there is only one answer, “the *one* [emphasis mine] thing that could make a massive change for this family is to develop Tristan’s speech” (Frost, Jo). At the end of the episode I am left wondering what will happen if Tristan never learns to talk in a way that is “normal,” or if he never learns to talk at all. Does that mean he will spend the rest of his life grabbing for cookie, a bite of pizza, or the hugs and tickles he craves, only to have them withheld because his way of asking isn’t quite “right”? After the episode I cuddle Osiris and offer him a cookie. He claps his hands and reaches for it. I give him the cookie.

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When I think of my children’s minds I think of deeply complicated ecosystems, rich with visuals, sounds, tastes, concepts and thoughts that are all interacting in a constantly shifting, swirling dance. Language doesn’t *just happen* here. Language in this ecosystem requires that the dance stop. Here language must be constructed, not of the alphabet or of sounds but of the bits and pieces of the ecosystem itself. Like whole sentences lifted from his favorite story, “I’ll huff and puff and blow your house down!”

Like words that only fit sideways.



Or the actions made that make new words, like saying “Erase apostrophe T!” which means, “CAN!” Like *can* stay up late, *can* watch T.V. “Not Can’t! Erase apostrophe T!”

And sometime the dance can’t stop, can’t be interrupted to do all the work required to assemble words and talk. Then language and communication happens with loud hands shoved against my mouth, reminding me to listen, listen, listen to the sound of his breathing, to feel the his skin against mine, and a head butt means helloIloveyoupleaseletsplay. In this ecosystem of lights that feel like pinpricks on the skin, of the way gritty sand feels rumbly if you rub just your palms over it, of the goodness of biting down on a silicone spoon, words are a component, a part of the way my sons think and feel and communicate with me—not a representation of the whole of their ability to think, feel, and communicate.

I remember being red-eyed and livid in a linguistics class when the professor said that a person would basically have to tie a kid up, shove them in a closet, and leave them there utterly isolated to stop them from learning how to talk, because language and talking is an essentially human trait. I wanted to ask the professor what it meant when language is nonsymbolic communication, which may sound like silence, but isn’t. When it happened in the hands, or in the way Osiris tilts his head to the side and then bops to music only he can hear. Or when language was echolalia, in which the speaker repeats words and phrases he hears rather than constructs meaning with words.

Like, “I canNot believe it!” from Little Einstein’s, over and over again.

Or when language is scripted, in which the speaker repeats frequently heard phrases like, “Hugs please!”

Or when language includes pronoun reversal, or issues with tone or speech patterns. What did it mean to him, with his PhD, his educated understanding of what means human, when language was hard and scary.

But I didn't have to ask because before I could control myself enough to speak he told me, "Of course in the case of intellectual disabilities or developmental delay disorders like autism, language delays are usually the first sign of a problem, but in normal children language just happens." Suddenly I understood exactly what Gareth felt like when he had no words and an intense desire to communicate with his teeth, his hands, or his feet. I closed my eyes, took a deep breath and envisioned how the room would react if I went up to the professor and bit him. Just bit his hand and then went back to my seat.

It took time, patience, and a great deal of help from the professionals who worked with us to reframe our understanding of communication in way that worked for each child. The parenting books had told us to talk to baby Invitro, to sing, coo and chat with him since birth. Baby was supposed to begin cooing back as early as two or three months old and by two years old he was supposed to have an almost perfect grasp of his native tongue. Their minds were supposed to be like felt boards where they assembled the sounds and letters we gave them, and when they opened their mouths, words were supposed to come, seamlessly, easily, naturally. I wasn't supposed to do anything but talk, and they were supposed to talk back. It was supposed to be the easy part. The hard part was supposed to come later as we struggled to understand each other's perspectives and worldviews, and how *be home at ten*, didn't mean, I don't trust you. But when confronted with the typical autism essay I was afraid because it validated the many ways

talking in our society is constructed as being deeply linked to what means to be human. If the typical autism essay constructs speaking as a measure of humanness than what does that mean for my two little boys who have such a hard time making words?

Dawn Prince-Hughes, an autistic writer says “... [W]riting was my salvation. I have said in the past, and I have since heard it repeated by other autistic people, that written English is my first language and spoken is my second. Since I was five years old I have written all the wonderful and terrible things that I could not bear to share in conversation.” The idea of spoken language as a secondary language, where written language or physical movement as communication is the first “language” understood, the first set of symbols arranged in a way that makes meaning, complicates and disrupts the argument that the typical autism essay makes in favor of speech as communication and communication as speech. More importantly it opens up a way of speaking back to the *typical*. When I read Prince I want to coin a new phrase, TSL instead of ESL, talking as second language.

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### *Braiding in Literacy*

Literacy is another particularly messy and rough strand in this braid. I am using the term literacy to denote the many ways of knowing that people have developed, used, or passed to their children. In this context it isn't just reading and writing, literacy encompasses languages, print, digital space, and play; it's the maps we build in order to travel the vast systems information in the world. It is not a singular definable space, action or practice; instead, it is an interconnected ecology that has sprung up around our need to be understood by one and other. James Gee articulates literacy as an “identity kit”

which has the instructions and appropriate gear, which allows you to fit into certain discourses that have real world significance. The ways that we are allowed to participate in shaping the discourses we own, embody, or inherit, are critical because as Gee points out, discourses are “inherently ideological.” In order to be part of the “in” crowd of a certain discourse a person must, “speak and act” in accordance to the ideology—at least when interacting with other members of the discourse. If the in-crowd is “normal” folks, what does that make autistics?

In *The Violence of Literacy* J. Elspeth Stuckey maintains that there is a deeply embedded ideology of literacy in America, which treats literacy as if it is universal, uniquely human, and unaffected by politics, agendas, or discourse. Literacy, through this lens, is always a force for good. Stuckey argues that there are ways in which this ideology can be manipulated and subverted to support systems of oppression and systems of marginalization, and when this happens it’s nearly impossible to see:

It is possible that a system of ownership built on the ownership of literacy is more violent than past systems, however. Though it seems difficult to surpass the violence of systems of indenture, slavery, industrialism, and the exploitation of immigrant or migrant labor, literacy provides and unique bottleneck. [To be literate] is to be legitimate; not to be literate is to beg the question. The question is whether or not literacy possesses powers unlike other technologies. The only way to address the question is

to be literate. What more effective form of abuse than to offer clandestine services? (Stuckey 18)

And this is the heart of the problem with the way the typical autism essay frames literacy. If there is only one way to be literate, and that literacy is the standard of normal, how then do we even begin to build a truly inclusive society that respects the personhood of autistics, even if they aren't "normal?" Julia Bascom addresses these issues when she writes:

The thing about not-being-a-person is:

They will say *those people* and the price of being a person is to nod and agree that yes, *those people* aren't people at all.

They will have no idea who they are talking to.

You yourself will start to forget, too.

They will say a million small things that sow the seeds for violence done against you, and you will smile and let them.

You will do math, constantly.

How much do I want to be a person today? How much do I want this project to succeed? How much honesty can I afford? How much dishonesty will kill me? What is the cost of coming out? Is there a way to delay, soften, transmute? How long can I survive as half a person?...

Your dreams will be reduced down to breathing.

And you will be grateful....

And no one else will know. And so it won't be real.

You will become an expert at folding away pieces of yourself, quietly and automatically and with perfect obedience.

The issue of literacy is particularly thorny because like all discourse, literacy discourse is resistant to internal critiques because being “in” means being in compliance. Ideology functions in relation to the discourse, and together they act to empower some views and values and marginalize others. Most importantly literacy discourse frames the “literate” as normal and good and the “illiterate” as abnormal and bad is “intimately related to the distribution of social power and hierarchical structures in society” (Gee 540). So when Yergeau rails against the ways the typical autism essay defines autism, she is resisting the inaccessible and deeply troubling identity kit others have built around the idea that people with autism are unable to speak for themselves. Literacy when defined as contributing to the “distribution of social power” takes on weight that has real life and real world consequences. Literacy becomes one of the ways a person’s authenticity is judged by the public eye and that means it becomes a big part of the ways things like funding for support, or medical care are distributed. In the typical autism essay the autistic that can “pass” and is literate enough to function well and speak for themselves in typical society, “are constructed as not being severe enough, as being too high-functioning, as not really having autism at all, as being their own little self-contained, unique circles” (Yergeau).

And those who are not literate in socially accepted ways are constructed as being unable to communicate effectively enough to speak for themselves.

Literacy is like an arts and craft kit, given to a child at birth. It's packed with cultural identity markers, a language, a history, stories, and narratives. It's packed with the discourses that accompany those markers; the discourses of gender, pink or blue blankets, Ken or Barbie, of race, of class. Kids are expected to build a life using their kits, which is why so many people have a vested interest in how those kits are put together. In the discourse of autism, literacy is the golden apple. Achieving literacy—and for children, that means school literacy,—is the bar the typical autism essay sets for people with autism to jump in order to “pass” as competent. This means a child with autism must figure out how to navigate the actual work of school—reading, writing and so on -- but unfortunately the typical autism essay creates a vision of autism that is hopeless and by doing so reduces the chances that innovative educators will be motivated to re-imagine what it means to teach autistic children to read or write. The typical autism essay creates no space for re-seeing the world in new ways.

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The boys spend a short time in daycare, an experience that makes me very nervous as kindergarten looms before us. I spent several months looking for a place I could afford and offers some support for children with autism. Finally I find what looks like the perfect daycare. They have a graduate student on staff who is a special education major. She is studying autism. She hopes to work full time with autistic children in the future. They have two developmental therapists who work one-on-one with autistic

children when they are not working at the daycare. The center is brightly colored, books line the walls, posters add color and “reading nooks” are designed into the playroom. There are no televisions. I am excited because there is a mini computer, and Gareth and Osiris love the computer at home and spend lots of time reading, spelling, and playing writing games on it. I am terrified because this is the first time in four years we will be separated for such long stretches of time, and they will be left with people who don’t know that a gentle headbutt means “hi,” but a hard headbutt means “hey pay attention,” and biting just means, “hold up things are happening to fast and I can’t handle all this right now.”

I tell the director of the daycare that I want them to spend as much time with books as possible. This is almost entirely selfish, as a reader and lover of the written word I have a deep-seated desire to share this world with my sons. At home they are learning to play gently with books, instead of ripping them. Gareth is beginning to “read”—running his finger below the words while saying nothing, or singing wordlessly. Osiris still eats books, but they both love me to read to them. We read every night and as often as I can get them to sit still. At the end of particularly long days when we are all run out from the park and the library and the zoo, I will lay on my stomach in the center of the living room, book open in front of me. Gareth settles himself in the arch of my back, his head on my shoulders, his heels on my behind, while he reads his own book. Osiris lies on his tummy next to me and reads mommy’s book.

On the first day they are miserable as I leave and miserable when I come back; this continues for the first week they are at daycare. Then Osiris adjusts but Gareth fights me when we get ready to go. He says, “No, no, no!” In week two I get a phone call to



pick him up early because he is having a melt down. It takes me awhile to get to the daycare, and I am thrilled that I can't hear him screaming as I walk into the office. He is not in the playroom; instead he is in a room I had not seen in my tour, a small open space with big windows. There is no door, but he is still separated from the large play room with its books and letters on the walls, its posters and child-size computers. He sits on the chair and runs his hands restlessly over a pile of pale beige wooden building blocks. Osiris is with the babies and older infants.

“Why is Gareth in here all alone?” I ask.

“Well, he has some trouble interacting with the other kids. He doesn't want to play with them, and when he gets upset he knocks things off the tables and makes a mess. We can't make him listen.” She looks tired and stressed. I feel for her because I know how hard it can be to get him to focus. I know he's bitten her.

“So, he is in a time out?” I had discussed time outs, breathing techniques, a “least restrictive environment” and reinforcements with the director. We never discussed isolation.

“Not really, he just seems more comfortable here.” She is the only adult in the room. There are at least ten kids in the adjoining room.

“How long has he been in here?” I ask, and I can't quite keep the anger out of my voice. She looks nervous now.

“Most of the day, except when we go outside.”

Gareth is here for six hours and their outside time is only about two hours all total, except when it rains.

“And has he had these same toys all day? Have you given him other toys or books?” I ask. I can’t imagine my active, climbing, get into everything, danger baby just sitting with those beige blocks.

“We offered, but he didn’t seem to care. He didn’t respond.” I wondered how they asked him.

“He is autistic, he doesn’t talk, and his social skills aren’t very well developed. It’s your job to make sure he is exposed to other kids, and books, and toys.” I say. She looks baffled. Looking back I wish I had taken a moment to have a conversation with her, to say some of the things I am saying now. I wish I had the vocabulary and education to explain to her why isolation was the wrong choice. I wish I could have asked her to coffee and discussed it at length because even then I knew she meant no harm, she just didn’t understand.

“But he doesn’t really read them; he just touches all the pages, and rubs them on his face,” she says as if this explains everything.

“He’s three.” She is still baffled and at this point Gareth has seen me and rushed to headbutt me. I hug him tight. “Can you just get his backpack, please!” I take him home and when we get there we blow bubbles and we sing the alphabet song.

### *Braiding outside circles*

Dr. Melanie Yergeau is also Aspie *Rhetor*, an autistic blogger who is deeply committed to self-advocacy. I love her blog because she’s a great writer and a member of my field. At the same time I am reading her article she blogs:

During my second week as a new faculty member, I was involuntarily committed to the psych ward at the university

hospital. I would say that I make this statement against my better judgment, but such a sentiment presupposes that I *have* better judgment. (Which, according to my ex-doctors, I don't) (Aspie Rhetor).

*Jesus...* She was strapped onto a gurney, removed from her classroom. Her clothing was taken and her belongings—all without her permission. Then she was put in room without the right to call a friend, or her headphones which help her control the sensory input she deals with. I might understand this action if she were a junkie, if she had tried to commit suicide, if she had harmed someone – all the same reasons a “normal” person might be involuntarily locked up—but she is none of these things. She is autistic.

Aspie Rhetor continues:

I was disembodied. Objectified. Powerless. I was freezing, hunkered up against the wall in my new doorless home, watching an eight-year-old kid being forcibly removed from his parents. How do I *not* headbang? How do I *not* bite myself? How do they *not* see our humanity? (Aspie Rhetor)

It is the image of this smart, capable woman, locked away even for a night without her permission that haunts me as I prepare my sons to go to school, which will be their first real step into the world of typical folks. No one will speak Gareth-ese, and in order to communicate he will need to learn to speak some form of normal and his teachers will need to learn a little Gareth-ese. Osiris will probably learn what it means to be stared at when he dances to music no one else can hear and his teachers will need to help the other

children understand that it's okay to dance by yourself, but it's better to dance together and encourage them to dance with him. Neither boy will grow up with autistic super heroes or artists to look up to; both will learn that normal people "talk with your mouth, not your hands." They may even learn shame, pain, and fear, unless we, their community of family, teachers, therapists and doctors, can find a way to give them a different discourse, find a way to braid an identity too strong to be broken and voices full of love and acceptance that are too loud to be silenced.

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Gareth goes to the developmental elementary school for an evaluation in order to learn if he qualifies for any early intervention services. The state of Idaho offers free pre-school for kids with developmental issues. He just needs to pass an evaluation, or maybe he needs to fail it. I'm not sure. His little hand, with its fine bird bones and dirty fingernails is clammy. I hold him tight. We are both sweating. He looks up at me with limpid brown eyes, opens his mouth and says nothing.

I ruffle his dark brown mop; I only trim around his face because the scissors make him crazy. He squeezes his eyes tight and tries again. Nothing, no words, just sounds, frustrated gibberish. I pull him forward. He digs his heels in and pulls back. Then he lunges, teeth aiming for the skin and fat between my index finger and thumb. I'm ready. I tap his lips with the tips of my fingers, "No bite!" He crumples.

His face is sweet with pouting lips, wrinkled forehead, and tears trapped in plush eyelashes. He is compliant now and we walk; him with his head down, still sobbing, me grim and determined. I pull him into the school. At the desk I need to fill out paperwork, and I turn him loose, just long enough to grab the pen. It's too long. He's gone. He's

halfway down the hall; his arms are pumping, his feet eating up the greyblue-speckled carpet. He ignores my cries, ignores everything except the goal, a large set of double doors at the end of the hall which lead outside.

“Gareth, Gareth, STOP!” I run after him. I catch him as his outstretched hands hit the door; he catches just a glimpse of playground before I have him in my arms. He looks at me and sighs deeply. Everything about his body tells me he doesn’t want to be here. He hates having his day interrupted. At home he was happily watching Max and Ruby sing in Spanish about colors. He was singing along and playing with his legos. His brother was playing with a toy that sends little yellow balls up and out of a spout. They both love that toy.

We are herded to the gym where they check his motor skills, fine and gross. He won’t even pick up the ball. At home one of his favorite things to do is carefully stack blocks as high as he can so he can play *monster baby* and knock them all down while growling and stomping, or play bowling for cups when I set up plastic cups and let him knock them down with a can of corn. They try to get him to pick up one foot, he refuses and I try to get him to play the hokey pokey; another of his favorites. I try to get him to play happy and you know it clap your hands and he has one of his rare moments of utterly clear nonverbal communication. He looks me in eye and his scowling face says, “Are you kidding me? I’m unhappy and we both know it.” This is not recordable; there is no box for baby sarcasm on the check-list.

In the library they check his verbal skills, he is wailing now and utterly incapable of language. At home he has words. In the classroom they ask him to line up wooden blocks, try to get him to recognize colors and shapes. He fails this too.

With the puzzles I find my voice. “He can do this! He loves puzzles; we do them all the time. He can. Baby, let’s put the puzzle together, okay? Let’s try this one.” The woman smiles gently, and then takes the puzzle piece from me

“He’s just stressed. It’s hard to evaluate based on this one experience. That’s why we have the questionnaires.”

We fail those, too, and they take him to a playroom so that the counselor can tell me in private what I already know. He will need developmental pre-school, speech therapy, occupational, physical, and developmental therapy long before he will be literate enough for Kindergarten. They are most concerned with his speech. In fact, one woman, possibly the speech therapist, tells me that even if he had passed all the other tests his speech delay would have qualified him for special education services. I think she meant it as comfort, as a way of helping me understand that because his speech concerns were so severe the school would be able to offer me services, which would be pivotal in his development. In fact through the Boise School District we meet some of the most amazing teachers, specialists and Paras. They change our lives. At the time, because of my exposure to the typical autism essay and discourse that frames autism as a devastating event, I was not ready to take that comfort. Before I take him home we go out to the fenced playground and soccer field. He runs, arms pumping; he circles the playing field. Then he runs back, and this time his head is up and he is grinning as he gets close I hear his voice. He is laughing pure tones, like gospel.

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I know that I’ve asked a lot of you. I’ve asked you to look at this wicked, tangled up problem of autism discourse, asked you to re-see literacy and language in ways that

seem to offer no answers. I've encouraged you to ask hard questions and given you no answers. Thank you for bearing with me. I wish I could give you more, wish I could cut through tangles and hand you a solution, but I can't. However, I believe that I have cleared a rhetorical space, an opening, found a few threads to tug that might, in time and with help, unravel this knot. That place begins with the self-advocates, the voices of autistic adults, their narratives, their voices, and their lived experience. They offer a vibrant, powerful counter narrative to the typical autism essay. If we quiet our voices, stop talking about what we know, and listen to what they have experienced, what we might hear is:

...the Autistic Self Advocacy Network is ...insisting like many disability rights organization before it, "Nothing about us without us." Advocating a concept of neurodiversity, its members reject the relentless and nearly hysterical pathologization of autism, and they unapologetically evince pride in who they are.

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Aspie Rhetor says, "We live in a world that conflates disability with undesirability. It is more convenient that we cease being disabled than it is for the world to become more inclusive of disabled people." And she's right. So much of autism discourse is geared to making autistics more like the rest of us and so I want to take a moment to articulate what I mean when I say I want to braid a healthy autistic identity for my sons. I want to articulate what I want for them when they become autistic adults. I want to put into words, explicit words, my deep concerns about the shape of the current

public autism discourse because this essay isn't about asking for more resources for my children, or for more access, or for even for more understanding. This essay is request for a true re-visioning of the way we discuss, frame, and define autism in rhetorical public spaces.

I want my sons to be adults who go to job interviews or college classrooms and can, without fear of being ignored or disregarded say, "I am autistic and these are things I need to thrive in this space." I want them to know who they are and what they need in any given environment. I want them to understand themselves well enough to know when they need to stim, or chew, or find a quiet space, or private space to get naked. I want them to be able to answer questions about their identity by saying, "Autism means I think differently, have you seen [insert movie title of film that accurately represents an autistic individual], I'm a little like [insert name of the hero of the film] but I'm also a little [insert autistic musician, artist, writer, social commentator, politician, or religious leader] but I'm unique because I [insert the things that make him utterly different from other autistics and neurotypical folks]." I want them to be proud of their hobbies, their favorite things. I want them to find the one thing they love most and figure out a way to make a living from it. I want them to surround themselves with people who *get* that sometimes hello can only be said with a gentle headbutt and those people will headbutt back because they understand that their first language isn't really talking. It's fluttering hands, or spinning, or just silence. These people will have taken the time to become semi-conversational in Gareth-ese. Conversations between my sons' and their closest friends will be a beautiful mix of speech and flapping. This is what I want for my sons. The current public discourse of autism makes this vision of their future nearly impossible



because it burdens them with an identity that was built by folks who only speak for them, not with them. In order to change that dynamic we, the neurotypical, the parents, the medical field, the educators, and especially the advocates, must stop seeing ourselves as the driving force of the autism community and instead become allies; we must begin by learning second languages and being willing to hear and see Autistics, Aspie's, and Autie's and people who are autistic; stop seeing Autism.

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At 7:30 in the morning a plaintive voice drifts from my boys' bedroom, "want computer!" A moment and then, "want fish!" and more recently, "want Spyro." This may sound strange and disconnected to the outside viewer, but I know that it means that Gareth wants to play on the computer and he wants to play with Zac Browser—a browser designed for ASD children by a man whose grandson has ASD—or the with the Playstation. Zac Browser offers kids a selection of games that focus on language acquisition and social interaction and at the same time shuts down the keyboard and other functions of the computer in order to protect the system from the inquisitive child. My kids are hands on learners who interact with the world by taking it apart and putting it back together again. A special key combination turns everything back on.

I call back, "Potty first, then breakfast and then computer."

"Okay," He calls back. Gareth, at age seven has discovered conversation and talks incessantly. He reads, writes a little, types a lot, and sings songs he makes up himself.

Then Osiris skids out of his door at full speed. He runs to the middle of the room, spins around, once, twice, three times. He spins like a child playing ballerina, hands up and over his head. Then he sits at the computer and a *Veggie Tales* “Silly Song” begins blaring from the speakers. He used the history stored in the GOOGLE search bar to find his favorite YouTube video. He doesn’t say anything.

We were introduced to Zac Browser by my sister, a special education teacher, who thought it might help us distract Gareth with something fun that didn’t include climbing my bookshelves, the kitchen counters, or basically creating havoc. Gareth took to it immediately, and at first, I simply assumed he was doing puzzles or just watching the graphics or listening to music. Since Zac Browser blocked him from accessing anything else on the computer, I felt safe in letting him play while I enjoyed the freedom to do my own homework or do dishes while he was engaged. Then one morning I noticed the game he was playing, *Jay Jay’s Loosy Goosy Rhymes*. It asked Gareth to read along as it read a nursery rhyme and at some point a letter would disappear and then Jay Jay asked the player to find the letter – giving them three options. Gareth was getting it right six or seven out of ten times.

Another of his favorite games mixed up the ABC’s, made him put them in order, and rewarded him with the ABC song. Other games asked him to place words in sentences, or finish sentences, others connected dots into letter shapes. Some prompted him to read out loud by highlighting words and asking him to find that word out of a list. It prompted him to “ask” for help if he got stuck. When he “fixed,” the sentence, the game read the whole story out loud, integrating the new sentence. The videos and stories read and sang to him about reading, writing, or social behavior.

For Gareth, the computer is pure play. Since two and a half years old he has received excellent services through Idaho state programs, which means much of his day is work. One program, SL Start, provided a behavior therapist that came to our house, picked him up, and took him into the world—places like the park and the store. She helped him to better understand how to interact with those worlds, and many days he came home exhausted. Miss Casey, his therapist, is like family and gently demanded the best from him. Twice a week he had occupational therapy, which helped with his sensory concerns, and speech therapy.

In his first year of school they are blessed with Ms. Carol, a veteran of many years, Gareth looks at her like she's better than Spiderman, it's in her class that he first begins to use a white board and in her class when he learns how much he loves music. At home we work to encourage him to communicate. We don't use behavior modification therapies but we do want them to find ways to meet their challenges and find ways to function in the world at large as independently as possible. We focus on finding ways to make this possible without expecting them to give up things that make them unique. Things like learning to dress themselves, using proper table manners, cleaning their rooms, and respecting rules and boundaries are all expected of my children and they work hard. Computer time offers Gareth a physical space he controls, time to relax.

At the computer he isn't working through his inability to communicate, nor is he anxious about the inherent demands that are placed on him in social interactions. There are no strange perfumes to distract him, or sudden unexpected coughs or laughter, or unexpected physical contact. The tone and tenor of the computer voice is exactly the same each time it speaks to him; he doesn't have to readjust to a different tone each time

he interacts with the game. In addition, he is in complete control of his physical surroundings. He can sit or stand, cuddle a blanket or chew on a chewy, he can stim when he becomes excited or frustrated, which he does in a number of ways. Clothing is optional for both boys at home and most of the time they are happily naked. In essence, his environment is anxiety-free and meets his sensory needs. These are things those of us who are outside of the ASD community are allowed to take for granted, while my son is constantly aware of the ways his body is responding to the environment, to other people, and to the demands of the social interaction around him.

Every night for a year we've read *Llama Llama Holiday Drama* because that is the one they want. Some nights Gareth reads it to me, and just last week, when I sang *You Are My Sunshine*, Osiris sang along. In other ways, ways that include their body, their behavior, and their voices, they tell us what they need. We try hard to respect those needs and to create an environment that they can be comfortable in; an environment that respects their various needs, wants, and desires. We work hand-in-hand with an amazing team of teachers and administrators to help them figure out how to navigate this world as autistics. We've redefined normal within our four walls, and we're working to redefine it at school, and the playground. We plan to expand and re-define normal in as many spaces as we can, in every place we touch, and everyone we meet. So let me re-introduce you to my sons.

This is Gareth and this is Osiris and they are autistic. That means they think a little differently, and that what you might consider normal talking is their second language; one they are just beginning to learn. It's hard but they are trying. Gareth speaks commercial, song, story, and repetition. Osiris is fluent is spinning, flapping, dancing and

laughter (occasionally inappropriate laughter). They both speak body. Would you like to learn a few words in their languages? Did you know that a headbutt has almost ten different meanings in Gareth's language? It's not hard to learn, and body is quite fun to practice. The boys are multilingual and they speak a bit of "normal." It's nice to meet you.

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