
Senior Projects Spring 2021

Bard Undergraduate Senior Projects

Spring 2021

Instructing Normalcy

Anna R. DeRosa
Bard College, ad7790@bard.edu

Follow this and additional works at: https://digitalcommons.bard.edu/senproj_s2021



Part of the [Philosophy Commons](#), and the [Public Affairs, Public Policy and Public Administration Commons](#)



This work is licensed under a [Creative Commons Attribution-Noncommercial-No Derivative Works 4.0 License](#).

Recommended Citation

DeRosa, Anna R., "Instructing Normalcy" (2021). *Senior Projects Spring 2021*. 174.
https://digitalcommons.bard.edu/senproj_s2021/174

This Open Access is brought to you for free and open access by the Bard Undergraduate Senior Projects at Bard Digital Commons. It has been accepted for inclusion in Senior Projects Spring 2021 by an authorized administrator of Bard Digital Commons. For more information, please contact digitalcommons@bard.edu.

Instructing Normalcy

Senior Project Submitted to
The Division of Social Studies
of Bard College

by
Anna DeRosa

Annandale-on-Hudson, New York

May 2021

This project is dedicated to Richard Regosin

I would like to thank Katie Tabb for helping me figure out how to write something longer than 15 pages, my mom for her constant and occasionally unwanted feedback, and Dylan and my dad for being subjected to constant readings about which they had neither context nor interest.

Table of Contents

Introduction.....	8
Chapter 1.....	11
Chapter 2.....	24
Chapter 3.....	41
Chapter 4.....	56
Conclusion.....	64
Bibliography.....	67

Introduction

Hello. I am an autistic person. However, beyond some nontraditional body movements, horrendous motor coordination, and tendency to look *past* people when talking to them, it seems that nobody who is having a casual conversation with me would be able to tell. I happen to believe that I'm really easy to clock -- and yet when I do finally tell people, they are always surprised. To me, this says a lot about how little autism is understood by the general public. I'm pretty textbook; you could go down the list of "symptoms" in the DSM-V¹ and I meet all of them. Yet somehow, because I am a traditionally functional person, people assume I could never have what they consider to be a profound disability. In truth, autism and more generally, neuroatypicality is a very wide spectrum. Yes, profound disability exists on one end of that spectrum, but the other end is just perceivably normal people who experience life a little differently.

I was lucky. My parents and teachers always perceived me as quirky and eccentric, but never disabled. For that reason, I was not placed in special education. It seems a little crazy to think that a high functioning child might be a candidate for such a program, but it is actually rather common. Throughout my time working with autistic children, I have met a number who even I could barely register as autistic. If a parent or teacher feels a child's behavior deviates too far from the norm either socially or intellectually, any person can be sent to special education. Now, I don't mean for special education to sound like a bad thing. I've worked as an aide in special education classrooms for five years and have seen much joy and significant progress among students. I'm simply writing this paper to call into question if applied behavior analysis (ABA), the central method in many such classrooms, is consistently functioning as it should.

¹ That's actually how I was diagnosed by my psychiatrist.

Hopefully, by the end of this paper, you will agree that while ABA is a highly effective mode of teaching, it should not be the main method by which we educate our autistic children. The nature of autism means that children are subjected to the wills of their parents in ways that children enrolled in “typical” education are not, and in this instance, it leads to an issue of the overcontrol of behavior. I will take you through this argument by making two central points: one that is metaphysical, about the nature of autism, and the other which is ethical, about the way we should educate autistic children.

First, we will explore the world of ABA as a program advertised as a solution to the problem of parents, and not necessarily that of the autistic children it is supposed to serve. Using the philosopher Ian Hacking’s discussion of autism activism and especially his concept of the “looping effect,” we will look into the relationship of different members of the family to autism. From here, we will explore the meaning of an autism diagnosis -- how it affects a child and their family and the divergent ways individuals react to it using the framework of what I will call positive and negative looping.

In Chapter 2, we will examine how myths about what a child “should” be color the curriculum of applied behavior analysis, and the effect that this has on our collective idea of normalcy. We will look into the medical and social models of disability and explore how they affect our perception of what is “normal.” We will introduce the vocabulary of “the manic pixie dream child” as a helpful dichotomy with the “rhetorically autistic child” in order to prove that neither truly exist. We will explore the autistic child not as a person with a disability, but as what I will call “an existential other.” From here, we will look at how ABA attempts to make children *appear* normal through a focus on the mastery of conversational spoken language.

In Chapter 3, we will explore ideas of function and how it relates to schooling as a whole, looking more specifically at ideas borrowed from Michel Foucault and John Dewey, in order to offer an analysis of the concept of pleasure in education. Notably, we will compare the ABA classroom to Bentham's panopticon, and see how the notion of social and existential forms of learning are applied in the autistic classroom.

Finally, in Chapter 4 we will use the framework we have developed throughout the paper to come to a conclusion about how we can reform special education to ensure that our schools are serving children for the sake of themselves, and not simply trying to normalize them for the comfort of others. We will use all the terms we have defined in order to create a holistic picture of the struggles parents face and the divergent paths this leads them down.

Chapter 1

Autism and the Problem of Applied Behavior Analysis

When I think of special education, I think of classrooms filled with laughter and bright colors, where students are learning the skills necessary to live fulfilling lives. I see children with Down Syndrome, Autism, and various other disabilities all learning collaboratively -- sharing and growing together. Fortunately, many special education classrooms are like this, joyful vibrant spaces wherein students learn valuable lessons about life and how to navigate the world. However, there is a subgroup of special education that arose out of a generation of parents' frustrations with the lack of consistent schooling for their autistic children. This program, what we now call Applied Behavior Analysis, or ABA, exists exclusively for autistic children, and uses the methods of its namesake, behavioral analysis, to try and analyze behavioral patterns in order to modify student behavior. It is rigid, individualized, and highly effective in changing behavior. Herein is where the problem lies, autistic life is inherently unknowable. We assume routine and rigidity are preferable for autistic children because they can not communicate otherwise with us. However, we don't know for certain that this is the best way to educate autistic children. Because we see routine as helpful to the autistic we take it to its extreme with ABA, and thus make it harmful to our children.

First off, to understand why the modern form of schooling is failing autistic children, we must ensure we understand what autism *means*. I say means and not *is* because the truth is, we don't really know what autism is. The scientific community has tried to figure out its causes for decades, but to no avail. Over the years it has been speculated that autism might be caused by emotionally distant mothers, diet, allergens, genetics, disruptions in fetal development from SSRIs, and even the ever infamous vaccine (Rosenblatt, Carbone, 19-40). In truth, we have no

clue what causes autism, but that doesn't prevent non-profit organizations from fundraising millions upon millions of dollars a year to put towards autism cure research. Autism is the most well funded disorder in the world, and yet very little of that money actually goes towards caring for autistic children (Hacking 2015). The majority goes towards either research trying to find the cause of autism, or research trying to find a cure for autism. Philosopher Ian Hacking discusses this strange phenomena in his essay, "On the Ratio of Science to Activism in the Shaping of Autism," asserting that this ratio is "1% science, 99% activism" (Hacking, 32). Hacking gets into the problem of this more explicitly in the section "Divergent Activisms," wherein he explores the irony of having the narrative of a disorder be constructed by those who are affected by it as opposed to those who have it. Here, he cites the goals of these activists as being to eliminate autism as opposed to helping those who experience it, saying of Bob and Suzanne Wright,

Why did the couple found Autism Speaks? He is often quoted: "I want my grandson back!" He's using the not-uncommon metaphor that his once normal happy little boy was abducted -- by aliens -- and has become an alien. (Hacking, 334)

The funding for groups like Autism Speaks is massive and just seems to be growing every year (Hacking, 334), but the question remains: *for what?* A cure? Research? All of this money is poured into autism research and yet we still know almost nothing about it. Instead of spending the money on actually improving the lives of the living autistic, we focus on the desires of future parents. The organizations are not "for" the autistic, they are for the p-c-a.

Here is what we know for sure about autism. It is a very wide spectrum that can range from mild sensory and social issues to profound disability. It's symptoms can (but very importantly do not have to) include: sensory issues, an inability to make eye contact, panic or depressive disorders, social issues, the making of repetitive sounds or motions, highly

specialized interests, obsessive behavior, and self-injurious behavior. These are simply the most common, there are many more. There is no diagnostic test for autism, one simply experiences enough² of these symptoms and is proclaimed to have it by a medical professional. Many high functioning individuals with autism (women specifically) can go most of their adult lives without receiving a diagnosis if they are ever given one at all. Many women with high-functioning autism are frequently misdiagnosed with Social Anxiety, ADHD, or even depression (Arky, 2019). There is a hesitancy among the medical community to prescribe people that are perceived as “functional” with Autism Spectrum Disorder -- especially women who are frequently misdiagnosed (Arky, 2019). This can be a catch-22 for many autistics who have been masking their symptoms since childhood -- because they do such a good job pretending to be normal, they are unable to get the help they need.

However, the focus of this paper is not on higher functioning autistic individuals, but rather on mid to lower-functioning school age autistic children. These children are often wonderful and loving. They sometimes experience behavioral problems like aggressive or self-injurious behaviors and emotional meltdowns which can be triggered by a great many number of things, from bowel problems to sensory issues. Many children who experience more severe forms of autism are non-verbal. Pretty much all of them engage in self-stimulating behavior, which those in the know with autism call “stimming.” This is repetitive behavior or vocals that children use to help them focus inward -- stims include hand flapping, pacing, short screams repeated over and over again, sometimes even actions like nose picking. Importantly,

² Another issue that is somewhat outside of the scope of this paper is how many symptoms are considered “enough” for a person to be autistic. The DSM-V says, “To meet diagnostic criteria for ASD according to DSM-5, a child must have persistent deficits in each of three areas of social communication and interaction (see A.1. through A.3. below) plus at least two of four types of restricted, repetitive behaviors (see B.1. through B.4. below)” (CDC, 2020) For what reason were these numbers chosen?

they are not harmful to anyone. If they were to hurt the child or someone else, they would be classified as either self-injurious or aggressive behaviors. Autistic children love sensory stimulation and will seek out certain textures that they find pleasing³.

With these children, parents typically see a “regression” of functionality around age three, when children begin to show signs of autism. Autistic children progress normally in terms of developmental milestones until age three when they begin to lose some of the social, emotional, and sometimes motor skills they have developed. As with all indicators, this does not always happen, but is a common experience for the parents of more severely autistic children. This is called regressive autism (Rosenblatt, Carbone, 48), and can be quite traumatic for parents. It adds to the perception mentioned earlier by Hacking that autism is a villain, something alien that is “stealing” their formerly healthy child and replacing them with this autistic child.

For new parents of children with autism, a diagnosis can feel overwhelming. Immediate worry for the wellbeing of their child, their marriage, or themselves sets in. They have a completely normally developing child up until age three, then all of a sudden their child starts losing skills and seeming emotionally distant. Many parents describe this as “losing” their children and express a desire to get them back. This is the reason so much of autism funding goes towards finding “cure.” The shock of having an autistic child and the mourning of the child they had leads parents to believe that child is still trapped somewhere inside, being held back by their autism. This kind of narrative is one that is consistently reinforced by the major non-profit organizations for autism. Let’s say a parent were to google “My child was diagnosed with autism now what.” The first resource that appears is an article from Autism Speaks entitled *The Do’s*

³ Hair is one they tend to enjoy. I learned this working in ABA when one of my favorite students snuck up behind me while I was recording data and locked his hands into my hair. It wasn’t out of anger, he was so happy to be touching my hair he was gleefully exclaiming while pulling and twisting. He’s still my favorite.

and Don'ts after an Autism Diagnosis. This article reads like a horrid prophecy from the Marvel Cinematic Universe -- trying to tell parents that autism will try to destroy their faith, squash their hope, and rob them of their joy. It urges them to “remember that sweet baby you fell in love with. He/she is still *that* child! Don't become so caught up in the present or so fearful of the future that you forget what's important.” (Smith, 2016). Here we see her asking parents to try and remember their neurotypical child, as opposed to loving their autistic child as they are now. It is very logical for parents to feel distressed and upset at an autism diagnosis -- it completely subverts what is expected when a person is to have a child. However, the narrative of “remembering that sweet baby” ignores the many parents out there who are creating alternative narratives wherein their children are loveable now as autistic individuals.

Now, we are going to take a look into an infamous battle in the autistic community -- ASAN vs. Autism Speaks. ASAN, or the Autistic Self-Advocacy Network, is a community of individuals with autism and their loved ones that seek to push back against the reality that those without autism have control over the narrative of the disorder. ASAN privileges autistic voices and is recognized as a trailblazing group in the disability rights community. Savvy with media and technology, ASAN ensures that the voices of autistic individuals are present in conversations about autism, loudly proclaiming their slogan, “Nothing about us without us” (autisticadvocacy.org, 2021).

Essentially, by looking at these two organizations we see the two sides of the world of autism that are constantly in conflict -- autistic individuals vs. people affected by autism. A big piece of this argument is the question of stimming -- for many parents, stimming is somewhat undesirable. They do not want their children repetitively flapping their hands or making noise because it is seen as disruptive and draws negative attention in public. For people who are

autistic, these behaviors are pleasurable and there is nothing inherently harmful about them -- they are not bothered by negative attention. However, although this tension exists, in the classroom it is up to parents whether or not their child's stimming is constrained. The wishes of autistic adults who were formerly in the program are ignored in favor of those who have autistic children.

Ian Hacking refers to those whose lives are affected by another with autism as "People Connected to Autism," or "p-c-a." In his mind, the p-c-a are parents, other immediate relatives, or caregivers -- they are individuals who feel that they understand the world of autism by association. While ASAN is seen as a community by and for the autistic, Autism Speaks is considered an organization for p-c-a. For an outsider, the world of autism can be very scary and isolating, and I can see the value in finding people who share your fears. However, many autistic individuals fear that organizations like Autism Speaks serve as an echo-chamber for individuals to confirm their biases as the norm and construct a dominant narrative for the world of the autistic (Luterman, 2020). This phenomenon can be explained by looking at Hacking's theory of the kinds -- the indifferent kind and the interactive kind.

First of all, Hacking explains kinds as ways of categorizing aspects of life. He sees these kinds as necessary to individuals' understanding of themselves and others, saying:

Author and Brother are kinds of people, as are child viewer and Zulu. People of these kinds can become aware that they are classified as such. They can make tacit or even explicit choices, adapt or adopt ways of living so as to fit or get away from the classification that may be applied to them. (Hacking, 34)

Essentially, kinds are a big way in which we organize and process our world. Hacking splits these kinds into two different categories, indifferent and interactive kinds. My dog Duke is an

indifferent kind. For a long time we just classified him as a mutt and because he has no concept of dog breeds as humans see them, he truly cannot care about the methods with which we categorize him. Then we realized he was a combination papillon-pomeranian (or paperanian if you want) and he still didn't care. Duke's perception of himself does not change if he is a mutt, or a paperanian. Duke is an indifferent kind because the way he is categorized does not affect him existentially. Tomorrow we could find out that he is actually a cat and he still wouldn't care. He is "indifferent" because his behavior will never waver no matter the way in which we identify him (though it may be impacted if we choose to treat him differently on the grounds of our identifications). In this sense, a lot of individuals with more severe forms of autism will not change their behavior in response to their diagnosis -- for the most part, they are indifferent to the various labels they are given and act how they do regardless of the social and cultural context of their diagnosis.

The other kind is the interactive kind, the opposite of the indifferent kind. The various diagnoses received by members of an interactive kind have an effect on their behavior. Hacking refers to this effect as "looping," which he explains in the following way:

Think of what the category of genius did to those Romantics who saw themselves as geniuses, and what their behavior did in turn to the category of genius itself. Think about the transformations effected by by the notions of fat, overweight, and anorexic. If someone talks about the social construction of genius or anorexia, they are likely talking about the idea, the individuals falling under the idea, the interaction of the idea and the people, and the manifold of social practices and institutions that these interactions involve. (Hacking, 34)

In this quote, Hacking explains that looping is the act of an individual classified as an interactive kind considering their social position and behaving in reaction to that social positioning. Take, for example, a person who is diagnosed with Celiac Disease. Once they receive that diagnosis, they change their behavior by eliminating gluten from their diet, as it causes them gastrointestinal distress. Their new avoidance of gluten as a result of the recognition that gluten is the cause of their stomach issues causes them to start reading food labels very carefully. Perhaps they decide that it is easier altogether to shop online, so that they have unlimited time to read over food labels. These new behavior modifications in response to a diagnosis are examples of looping. We have already established that individuals with severe autism are an indifferent kind -- they are content to live their vivid internal lives and do not expend much energy on the world outside of themselves. However, we can take Hacking's interactive kind a bit further. While he intends that the "kinds" refer to the individual who is being diagnosed, we can expand his theory to encompass p-c-a.

If we apply the framework of the kinds to p-c-a, we find that they fit rather neatly into the interactive kind. For example, Hacking says "What was known about a kind may become false because people of that kind have changed in virtue of what they believe about themselves" (Hacking, 34). If we are to look at autism as a whole, we find that it is defined by virtue of the p-c-a, and not the autistic individuals. You might be wondering: *What does this kind of looping look like?* Take the parent of a three year old child who has been newly diagnosed with autism. Now, that parent will begin to modify their behavior by seeking out information about the diagnosis. Let's say they are to google the phrase *My child was diagnosed with autism now what?* and find themselves on the Autism Speaks website looking into the dos and don'ts after an autism diagnosis. Perhaps they feel that this article speaks to a lot of the fears that they are

currently feeling, and they decide to join the organization. Maybe they start to connect with other parents who feel the same way over Facebook, where they become active members of an autism parenting group. In this group, they might start to hear about different ways that parents have seen positive results in their children. These could be through special diets that remove gluten, through acupuncture, or even through applied behavior analysis. Encouraged, parents might try these things with their children -- adjusting their diets, taking them to herbalists, or enrolling them in ABA.⁴ All of these behaviors, from the Googling, to the Facebooking, to the eventual lifestyle changes are examples of the looping effect. However, in instances such as these, we see the effect go to work on the caretakers, and not the person who is diagnosed. This is noteworthy because it means that the majority of information available online is being generated and disseminated by the p-c-a as opposed to the autistic. Because of this phenomenon that Hacking describes, much of the narrative of autism as a whole is controlled by those in proximity to it, as opposed to those who actually experience it.

Parents who experience *positive* looping, on the other hand, see their child's autism not necessarily as a disability in the sense of the social⁵, but as a state of what I will call "existential otherness." For these individuals, as they learn more about autism, and in turn their children, they find that the autistic community is a diverse group of existential others. This term, existential other, is something we will explore a bit more deeply in the next chapter, but refers to those on the spectrum of neuroatypicality who experience life not in a way that is bad or wrong, but in a way that is different from the "typical." Parents who experience positive looping understand the value of an existential other. This type of parenting is codified in books like

⁴ These are by no means the only methods of "curing" autism recommended in such places, but they are examples of some popular therapies amongst the p-c-a community.

⁵ There are many legal and medical reasons because of which it is helpful if not necessary to identify as "disabled." However, many in the world of disability see the term both as necessary, but problematic because it suggests a literal lack of ability (Garland-Thomson, 2005).

Differently Wired by Deborah Reber, who vows to change the narrative of parenting itself, saying:

I believe that we -- you and I and every other person raising an atypical kid -- have the capability to truly change this paradigm from the inside out. Even more than that, we're the only ones who *can* do it. When we voice our reality, educate others, and stand up for what we and our family need from a place of compassion, strength, confidence, and peace, the whole outdated, ineffective, intolerant parenting paradigm that we've lived with for decades is going to come tumbling down. (Reber, 18)

Reber is a spectacular example of positive looping, which would increase positive emotions in autistic children like joy and confidence. Not only has she changed her behavior in regards to her own identity and the way she raises her child, she also has changed her attitude about what it means to be a parent and shares it with others. Deborah Reber's son's diagnosis of severe ADHD⁶ has led her to loop enough to try and change the philosophy of parenting for good.

On the opposite end of this spectrum are the parents who experience negative looping (so called because of its increase in negative effects on the autistic child, self-hatred, shame, etc) effects from their child's diagnosis. These are the parents who get sucked into the fear-spiral that is Autism Speaks -- whose ultimate desire is for their children to be cured of their disability. For these parents, applied behavior analysis is seen as a means of escape from the strange and unfamiliar world of autism. They may even begin to see the child that they "lost" to the disorder begin to come back again. With this type of looping, it seems that parents are obsessed with curing their children, with the idea that they can bring them back. Hacking calls this into question, wondering what finding a cure or a cause for autism might mean, saying:

How would the discovery of [the cause of autism] affect how autistic children and their

⁶ Which exists on the spectrum of neuro-atypicality

families conceive of themselves; how would it affect their behavior? What would be the looping affect on the stereotype of autistic children? Which children, formerly classified as autistic, would now be excluded, and what would that do to them? (Hacking, 121)

Here, Hacking calls into question the nature of autism itself. The narrative is just that, a narrative. Parents who use it to define themselves and their children while searching for a cure are doomed to an eventual disappointment and loss of identity. Because autism is now seen more as a state of being than as something pathological, individuals are starting to come to the realization that there is no cure for autism. An individual who bases their life in the search for the child they had before they were “stolen away” by autism is not actively able to enjoy their child as they are because they still hold firm to the belief that one day their child will eventually emerge from their autism.

No matter the type of looping they experience, one thing is always true -- parents are the vectors by which their children are reached, especially in instances of autism. Because their children inherently have trouble communicating their wants and needs, it is up to parents to be their translators. The type of looping the parents experience inevitably transfers into the behavior of their children. While autistic children may not experience the sort of primary reactionary looping that their parents do in response to their diagnosis,. More specifically, that parents of autistic children have a unique level of control over the perception and care of their children. Hacking uses three points to explain the particularities of Autism Spectrum Disorder:

A first reason ... is that so many of the pioneering scientists have been p-c-a.

A second reason has to do with activists and advocacy groups. It is to be expected that activists are p-c-a. What is unusual is the extent to which they have been effective in shaping the perception and the experience of autism.

A *third* unusual feature of autism is that there are very great cleavages among advocacy groups, pursuing very different agendas, and having very different ideas about what autism “is.” (Hacking, 327)

As we can observe through Hacking’s analysis, autism is a peculiar kind of disability because of the way the community around it, the p-c-a, have such significant influence over the narrative of the condition. This power over narrative has an effect on every aspect of their child’s life. When parents experience positive looping, they allow their child to be an existential other and see the inherent joy in their child’s way of being. When they experience negative looping, they see their child’s behavior less as a fact of their existence, and more as a disease that can be cured. This type of negative looping is one of the factors that leads to the continued prevalence of ABA as a method of teaching autistic children.

At this point, I owe you an explanation about what applied behavior analysis is. This program (also known as ABA) is pretty much ubiquitous in the world of autism. The name, ABA, refers to the method of behavioral analysis and management that is used in order to modify behavior. ABA is technical -- it requires staff members to have highly specialized training in teaching and using positive and negative reinforcement. A sample lesson might go like this:

A student is presented a photograph of a classmate (Jordan). The student is then asked by the staff member, “Who is this?” Depending on the level of prompting the staff member will wait x number of seconds before saying “Jordan.” If the student has completed the task (in this instance, identifying the photo as Jordan) to the appropriate level as determined by a BCABA (officially referred to in the discipline as a Board Certified Assistant Behavior Analyst), they

receive a reinforcer. Often this is a piece of food, but sometimes it is around 10-20 seconds of play time with a preferred toy.

The reality of ABA is that it's pretty much this cycle continuously throughout the day. It takes the theory that autistic children do better with a routine to the extreme. Every aspect of the day is regimented in some way, even bathroom time, meals, and play. Students earn reinforcers throughout the day and eventually work their way up to bigger rewards -- for some this is time with the I-pad, in the play area, or a walk outside the classroom. As far as the classroom setup goes, students each have their own "station" where they complete all of their work. Every half-hour to an hour, a new aid comes to them to work. They have a daily schedule where all of their required activities are tracked so there is no overlap, and where aides can quickly check what activities have already been completed. The students do not spend much time together, the majority of their learning is highly individualized. Whether or not children are allowed to interact through play is determined by their level of functionality. A high-functioning child will be able to have observed play with a friend or two, whereas a low-functioning child will have their play managed by an aid. Every aspect of each child's day is prescribed by the BCABA and monitored by the staff who report back to them. The goal of ABA is to change behaviors seen as problematic, and replace them with behaviors that are more socially acceptable.

Chapter 2

Semantic Communication as an Educational Imperative

In the previous chapter, we talked about the nature of autism spectrum disorder, how hard it is for parents who have a newly diagnosed child to find realistic information, and how the fear-inducing machine of non-autistic-led organizations push parents to fundamentally misunderstand their children's condition by allowing them to believe that their child can become "normal" with the help of certain therapies or diets. In this chapter, we will explore the very idea of "normalcy" in the context of autism -- what it looks like, why we value it, and how we try and get autistic children to behave "normally" through the implementation of specific practices in applied behavioral analysis (ABA). The purpose of exploring normalcy in this chapter is to highlight the differences between what I will call "social" and "existential" learning, which function as the distinction between learning that exists for children and learning that exists for the benefit of those *around* the children. We will use this distinction to highlight the failures of ABA as a learning style.

Before we can begin to examine what normalcy "looks like," we must first try to understand why it is something we value at all. In general, people love a non-conformist. Film critics have described the trope of the "manic pixie dream girl" (Rabin, 2007), who wins the attention of the boring male protagonist through her propensity to sing in the grocery store, or the way she collects discarded cigarettes, or how she demands her paramore join her to lie in the street as it rains. Her nonconformity is appealing because it flouts societal standards that, to some, feel oppressive -- why *can't* we sing as we please?

But what happens when a misfit is not standing out in the right ways? When we pass by a man masturbating at the bus stop, we are not delighted by the way he shakes his fist at society as if proclaiming, “you cannot deny me my right to pleasure!” We are horrified by this man, and rightfully so, as we have determined that public acts of sexual behavior are gross at best, and traumatizing at worst. While the manic pixie dream girl fights against our worst impulses towards oppressive normalcy, the bus-stop pleasure seeker is rebelling in a way that all of us generally agree is inappropriate. So, while the pixie is hailed as a romantic heroine by single twenty-somethings, the man engaging in self pleasure at the bus stop is likely sent to jail for public indecency.

This crude example aims to illustrate how important it is to understand the nuances of the social contract we have put forth for ourselves. The man at the bus stop could easily be a person with a disability who doesn't understand that his behavior is inappropriate, but the police arresting him may not care about that. In fact, this example itself is drawn from real life. In Andrew Solomon's *Far From the Tree*, he describes a similar incident experienced by a man with Aspergers⁷: “When the pretty woman at the counter at McDonald's asked what he'd like today, he said, ‘I'd like to touch your crotch, please.’ He was completely befuddled when the police were called; he had answered her question and said ‘please’” (Solomon, 232). This example shows us how a simple semantic misunderstanding can have serious consequences. The manic pixie dream girl might violate the social construct in a similar way -- perhaps she goes into a McDonald's and asks for foie gras -- the difference between the two is that she is hyper-aware of what is “the norm” and actively pushes against it, to the delight of her male counterpart. The man who walks into McDonald's and asks to touch the woman's crotch is not

⁷ Although this term has been removed from the DSM-5, I am choosing to keep it as a categorization for individuals with higher-functioning ASD because it remains an important means of self-identification for many people.

playfully subverting the norm, he is completely misunderstanding it. In this particular instance, it has worrisome consequences -- the police are called.

This is the more noble of the reasons parents of autistic children push for normalcy in their education, because in our world normalcy is a way of life, one we must learn as children. When our parents tell us it is unacceptable to hit someone when we're angry at them, or that if we want to go outside we must wear pants, we are learning the language of normalcy. But it's not just parents. I remember a time way back in elementary school when I once was called out for the way that I flapped my hands erratically when I spoke. I can still recall the biting shame that accompanied the realization that I was not behaving in a way that my classmates saw as normal, and I made every attempt to legitimize my "strange" behavior.⁸ Whether our behavior is corrected by adults or peers, this is how we become fluent in the language of normalcy. However, with autism, you have a person who is speaking a fundamentally different language than that of everyone else. Normalcy is not a way of life for the autistic child so much as it is an inconvenience.

Normality itself is a complicated phenomenon, one almost too murky to truly understand. When we imagine "the normal," oftentimes we ignore the average. The thing is, normalcy is not something we can legitimately define -- it is something inherently rooted in the social makeup of our society. Ron Amundson, in his piece *Against Normal Function*, encourages those in the field of psychology to reject the outdated "normal" as a mode of understanding the pathological. If one is to think about "the normal" as it applies to disability -- we must look no further than the social model of disability. Amundson describes the way that this model illustrates the normal, saying "The Social Model makes disability *entirely* an issue of social context, arising from the

⁸ For many years I told people that I was simply talking with my hands because I was Italian. Eventually, I was able to stop the behavior altogether.

disabling ways in which certain kinds of human variation are dealt with in society” (Amundson, 48). Essentially, according to Amundson and the Social Model of Disability, “normal” function is only as it is because society has constructed the category of disability.

Think of it this way: what if, if all of a sudden, two thirds of people awoke one day to find that they had the ability to telepathically communicate with one another. This would begin as something exciting, where everyone is exploring their newfound abilities, but would eventually lead to structural changes in society. Perhaps those who had this new ability would decide to forgo verbal communication altogether. All of a sudden, there is a new normal, simply because it is what is favored by the majority. Now, all of those in the minority who did not gain this ability are disabled, because the others have abandoned the form of communication that worked for everyone. In this world, verbal communication goes from being “the normal” to abnormal remarkably quickly. It reminds me of a section early in Plato’s *Republic*, when Thrasymachus flies into a rage at Socrates’ inability to form a substantive definition of justice. Socrates asks him to give his own, and Thrasymachus says, “Justice is simply the interest of the stronger” (Plato, 35). Although justice and the normal are not necessarily the same thing, one could argue that, in a realistic sense, we cannot decide what is just without consulting what is the norm. I am inclined to agree with Thrasymachus in this sense. He is shot down in the book because he represents “the stronger” and Socrates does not believe that he is correct. However, the stronger (in our sense this would refer to the majority) are the arbiters of what is normal. While this may be what is true, that does not mean that it is in any way indicative of what *should* be true in Socrates’ opinion. I am, of course, speaking more objectively about what normalcy means in terms of how our society functions practically. “The normal” is whatever the majority decides it is. This is the issue with “the normal” as any sort of objective category -- it can never

be one because it always reflects the will of the majority. They want to be the manic pixie dream girl, and they abhor the bus stop masturbator. This is why the manic pixie dream girl is allowed to fit into the realm of “the normal:” because she delights the majority. The bus stop masturbator is seen as abnormal in a way that is problematic because his behavior strays so far from what the majority has deemed acceptable. Both of these groups are minorities, and yet both are common tropes that are exaggerated due to the ways they subvert “the normal.”

In the spectrum of manic pixie dream girl to bus stop masturbator, the normal is somewhere in between, and it does not only apply to adults. In the same way that there is a manic pixie dream girl, there is a manic pixie dream child. Whereas the adult version of this trope serves to bring about a sort of sexual awakening in a repressed twenty-something man, the manic pixie dream child is also meant to facilitate an awakening of sorts. It is remarkably common to be told (especially as a young woman reaching what could be considered child-bearing age) that a person is never “truly alive” until they have a child. Confusingly, this is a logical fallacy at the most base level: I have no children, and yet I consider myself fully alive, in both a literal and metaphorical sense. And yet, this expression is so pervasive that I am hinging your understanding of this section on your having heard it before, and I feel no hesitancy in doing so. In an ideal world, the manic pixie dream child is the catalyst in a sort of existential awakening for their parents. There is a natural understanding of the roles of the two -- the parent is to care for the manic pixie dream child, and they do the same, by facilitating the journey from mere adulthood to parenthood. The manic pixie dream child possesses an inhuman level of emotional intelligence. They are able to sense their parents needs and desires and adjust their behavior accordingly. For these reasons, the manic pixie dream child is the idealized form of the child, one that parents expect their children to be.

Often, adults make the decision to have children not for the sake of those children, but for themselves. The prevalence of the trope of the manic pixie dream child is a reflection of this cultural mindset. Like the manic pixie dream child, the manic pixie dream girl is a sort of trope that describes a non-existent individual. Coined by film critic Nathan Rabin as a response to a Kirsten Dunst character in the film *Elizabethtown*, the manic pixie dream girl, “exists solely in the fevered imaginations of sensitive writer-directors to teach broodingly soulful young men to embrace life and its infinite mysteries and adventures” (Rabin, 2007). Like their older counterpart, the manic pixie dream child exists as a vehicle for the personal growth of those around them. A parent expects their child to fulfill this cultural and existential awakening for them, and the manic pixie dream child does that and more. Possessing an almost inhuman level of social comprehension, they effortlessly toe the line between needing care enough to make their parents feel valued, and being self sufficient enough to make their parents feel accomplished. Obviously, there is no child in the world that behaves with such intentional nuance, but the point is not that this child exists -- it is that this is the child that parents have come to idealize as “the normal”. Young adults do not sit around and daydream that one day they will have a child who will vomit on them as they cry in an airport bathroom. Parenthood is unimaginably stressful, and yet we still idealize it⁹.

If there is a manic pixie dream child, it must have a foil in the same way as the manic pixie dream girl. However unflattering this next comparison may be, in the eyes of parents the bus stop masturbator is comparative to the “rhetorically autistic” child. I say this not only because public masturbation is a not uncommon behavior for a person with an intellectual

⁹ I assume, in many ways, this arises out of biological necessity -- people wouldn't want to have kids if they only thought about how stressful and challenging it would be.

disability¹⁰, but also because the horror we feel at seeing the bus stop masturbator parallels the shock of parents expecting to give birth to a manic pixie dream child may feel when they wind up with an autistic child. Of course, the thing that is most important to remember about these two types of children is that they are simply constructions. There is no manic pixie dream child just as there is no child that can be reduced to simply their autism. The “autistic” child functions more as a rhetorical tool than as a reflection of reality. John Donne famously said, “no man is an island” (Donne, 2020), and he is right in more ways than he intended. No person with autism spectrum disorder is entirely separated from the rest of humanity, even though we may perceive them to be that way. There is always a desire, even in the lowest functioning person with autism, to be loved and accepted. The notion that an autistic child does not feel love¹¹(which is common among the rhetoric of those p-c-a who find themselves negatively looping) is a false narrative through and through. Autistic children love with gusto, they just do it in a non-traditional way. There is much more nuance to autism than most are interested in considering.

Anyone who has been around a child knows that when they are in meltdown mode, they are not effective communicators, but what is one to do when this is their only window to communicate about something? With a nonverbal child there is limited opportunity to try and correct the behavior after the fact, because they do not comprehend verbal language, based on any one child’s semantic understanding of language, which varies greatly and is not easy to discern if a child is nonverbal. Parents can take certain actions to show their children that a

¹⁰ Or any child, for that matter. Children are inherently curious about human sexuality in a way that is entirely innocent.

¹¹ This notion was originally put forth by Dr. Leo Kanner, in the 1940s when he described autism as “the idiosyncratic, self-centered thinking he saw in people who had schizophrenia,” one of the main characteristics of this being a “total indifference to other people.” This was furthered in the 1950s when Freudian analysis popularized the theory of the “refrigerator mother,” which suggested that autism was caused by emotionally distant parents. These theories are now rejected by those in the autism community, but remain present in contemporary discussions of the disorder. (Rosenblatt, Carbone, 5-6)

particular behavior is unacceptable, but it is much more challenging to try and change an autistic child's problematic behaviors than it is to change the behavior of the "normal" child. Some of these behaviors are downright dangerous and require intervention.

When I was working in a public school I was placed in a classroom with almost exclusively nonverbal students. There was one boy in particular who would fly off the handle and slap, bite, or scratch his instructors seemingly at random. He was generally a spectacularly happy child, one of my favorites, but nevertheless, he would have these moments where all of a sudden, he wasn't himself and would lash out wildly at whoever was near him. Luckily, because he had been in the program for so many years, we knew that he had bowel issues and when he lashed out, he was likely in pain and needed to be taken to the bathroom. While here the student demonstrates his ability to communicate semantically, he is not necessarily doing it in an acceptable way. This child was only getting older, and while I was trained to avoid bites and deflect punches, the general public is not. The great majority of the Applied Behavioral Analysis students in my school district were housed in the elementary school, and we worried about this student taking a swing at another child on the playground or in the hallways. It was clear that the behavior needed to be corrected, but the actual correcting was complicated when clear communication was almost impossible. We were almost entirely unsure how much of our instruction this student was able to understand semantically.

This is a situation in which ABA is particularly effective. We would analyze the triggers that would cause this student to lash out, and the behavioral consultant¹² would create a plan for everyone to follow based on the principles of applied behavioral analysis. For this particular student, that was to do a compliance activity until he became calm, then to take him to the bathroom. The compliance activity was a mundane task that the student had already mastered,

12

specifically chosen to be an easy project that required a certain amount of focus and distracted the student from whatever they were upset about.

ABA is fantastic when it comes to eliminating a child's more problematic behaviors because it is based on science. It is precise by its very nature -- telling instructors what and how to say and do. In the ABA classroom, they demand accuracy. This demand means that all students are treated in a systematic way when they are in a negative behavior. The student has their triggers studied and their response to different approaches to calm them analyzed. This results in a highly effective positive and negative reinforcement of behaviors. However, just because it is effective does not necessarily mean that it is ethical. ABA can quickly become a stressful environment both for instructors and students. If it seems like an instructor is not meeting a quota of activities in a period of time, they have to discuss with the head of the classroom or BCABA.¹³ This means that there is an air of urgency that hangs over the classroom, with teachers trying to complete as many activities as they can in their time slot,¹⁴ and students suffering from that urgency. One thing that truly suffers in ABA is the loss of communication of wants and needs from teachers to students and vice versa. The teachers are not encouraged to communicate with students about anything non-essential (basically anything not related to what was happening in ABA at that exact moment), and the students weren't given the tools to communicate pleasure or displeasure about a given situation with teachers.

One of the central hallmarks of the manic pixie dream child's emotional understanding is their ability to communicate their desires and needs to their parents through the use of verbal language. One could argue that the great majority of parent/child conflicts arises from one or

¹³ God forbid...

¹⁴ Speaking from personal experience -- in my classrooms, aids would compete to try and rush through easier tasks so they could avoid the harder (and often more necessary ones) that would cause a student to have a behavioral issue.

both parties misunderstanding each other. Of course, when we have a person who is semi-verbal, these misunderstandings are more common -- a baby can cry and its mother will not understand that it has a diaper rash until she goes to change it, whereas a toddler might throw a tantrum and verbally indicate that it is because they are not allowed to go outside in the rain. With a non-verbal child, trying to semantically communicate feelings can feel like trial and error, whereas with a verbal child both parties can better understand the other's emotions and desires by discussing them through the medium of a shared language. The parent of the tantruming toddler knows that their child is upset because they cannot go outside, and can communicate to them that a tantrum is not the appropriate way to respond to being told no. Even if the child still misbehaves after they are spoken to, their adult still has the ability to communicate with them about their behavior later. With an autistic child, there may be no verbal way to communicate, and the expression of desires from parent to child can only occur simultaneously with a problem behavior. It calls to mind a section from *Far From the Tree*, by Andrew Solomon, where a parent recalls a meltdown her son, who had a history of using self harm as a mode of semantic communication, had at a mall. Solomon describes the incident as such:

When Ben was a teenager, Bob and Sue took him to RadioShack, his favorite store. He panicked on the escalator, and at the bottom he sat down cross-legged, and began smashing himself in the head with his hands and screaming as a crowd gathered. Sue always carried an FC¹⁵ keyboard, and when she took it out, Ben typed, *Hit me*. 'And I thought, "Oh yeah, in the middle of the mall with a security guard, and you're black and I'm white,'" Sue recalled "And then he typed out, *Like a record player*." Sue suddenly flashed on a stuck needle; she struck him on the edge of the shoulder with the heel of her

¹⁵ FC stands for "facilitated communication," and is accomplished using a keyboard and having an aide physically support the arms of the typer so that they can communicate.

hand and said, “Tilt.” Ben stood up and they walked calmly on across the mall.

(Solomon, 247)

In a moment such as this, it doesn't make sense for Sue to try and communicate to Ben that self-harm is not an appropriate form of problem-solving, although that is ultimately a conversation that needs to be had. This situation is an example of how it can be dangerous in the moment to try and have a semantic conversation about behavior and intentions. People with autism could be killed by law enforcement during meltdowns¹⁶, and it is important to ensure that they are handled quickly and effectively.

Parents of children with autism have a child expecting that child to facilitate that existential awakening for them, and instead find a child that not only does not possess the emotional intelligence they desire, but is on a fundamentally different plane of understanding. Disability scholar Rosmarie Garland-Thomson refers to physical disability as “corporeal otherness (Garland-Thomson, 5)” to suggest that there is nothing inherently negative (as the word “disability” implies) about being differently abled. In this same vein, people with autism are not functioning incorrectly, or dysfunctionally. Instead, one could say that the autistic experience life through the lens of what I refer to as *existential* otherness. There is nothing alien about the autistic child: we have just come to understand them that way because they are an other. If the manic pixie dream child were to exist, they could also from a theoretical standpoint be considered an existential other, but that would not likely be the case, because the type of otherness that we refer to when we talk about the “autistic” child is not the fulfilling otherness

¹⁶ In a report published by the Ruderman Family Foundation, they say “Disabled individuals make up a third to half of all people killed by law enforcement officers. Disabled individuals make up the majority of those killed in use-of-force cases that attract widespread attention” (Ruderman Family Foundation, 2017).

displayed by the manic pixie dream child. The manic pixie dream child is the foil to the “autistic” child, with normalcy functioning as the median between the two.

The difference between these two tropes of children is their understanding of semantic communication, and their translation of that semantic understanding into socially relevant verbal communication. The importance of the distinction between verbal communication and semantic communication is one that cannot be overstated. Verbal communication, while something that is regularly practiced in ABA, is more for the sake of the person outside of the world of Autism. Verbal communication is practiced in the classroom with activities that encourage rote call and response. An example of this would be if I were to say to a student, “Hello, Jimmy! How are you?” They would have memorized the response “I am fine, how are you?” and would repeat it back to me. With these kinds of verbal exercises, it is unclear if the student understands the meaning of what they are saying; they just know that they are rewarded for saying it. One has to wonder who this kind of activity benefits, as it could be argued that it is not the student. Instead this kind of learning serves to benefit the onlooker, to make the autistic child appear more like the manic pixie dream child. A “normal” child would rarely have so formal a response, and what’s more, the parroted response completely ignores the child’s feelings, instead encouraging them to feign happiness for the sake of the onlooker.

In opposition to verbal learning, semantic learning strives for understanding, and is not necessarily as accessible to the general public. Semantic forms of communication would include things like P.E.C.S. which stands for the Picture Exchange Communication System. With this mode of communication, students carry around either physical books with laminated pictures or an iPad that has digital pictures in it. The goal is that the student is able to indicate wants and needs by pointing to certain images. Aides are taught to say each selected word aloud, or if an

iPad is used, it says the words aloud when touched. These images, called “PECS” are a form of communication that focuses on mutual understanding, using images for the autistic child and verbal language for those communicating with them. The ultimate goal of PECs, like a lot of ABA, is semantic understanding, and to their credit, PECs are considerably less abstract than verbal language. It is this more direct form of communication that makes PECs a much more viable option for learning for students with autism, and yet we still insist that children attempt to communicate verbally. As is explained in the American Academy of Pediatrics Book, *Autism Spectrum Disorder 2nd Edition*, “Introducing augmentive communication to children with ASD who are not *yet*¹⁷ using verbal communication, does not keep them from learning to talk” (Rosenblatt, Carbone, 84). This sentence is very telling. Even with this augmentive communication that facilitates interactions where both parties are semantically understood, the use of verbal communication is still pushed on autistic children. All of this is to suggest that verbal language is the modality of communication in which parents are the most comfortable, which is so why it is so prevalent in the classroom of the autistic child.

It is the constant tension between the verbal and the semantic that led to the great paradoxes of applied behavioral analysis, the conflicting beliefs that verbal communication should be both heavily privileged and also severely restricted. When I worked in applied behavioral analysis during the summer of my sophomore year in college, I was placed in a classroom with a confusing sign over the door to the breakroom. It read, “W.A.I.T.” in big red letters. When I asked a member of senior staff what it meant, they explained to me that it stands for “Why am I talking?” and admonishes classroom staff to avoid speaking to children unless absolutely necessary. In ABA, sentences are shortened, articles removed in the name of clarity (Schloss, Smith, 72, 93, 146- 152). “Touch the ball” becomes “Touch ball.” Specific behaviors

¹⁷ The emphasis here is mine.

are translated shortened commands; “Grab it,” “Sit nice,” the completion of which are rewarded with reinforcers.¹⁸ I was shocked by this -- in a program whose main goal seems to be the normalization of behavior, why would we try and restrict students’ access to models of normal behavior? The idea of creating a pedagogical system in which the goal is to create “normal” children is, in itself, a misguided practice, but it is problematic then to deny those children the opportunity to observe what it is they’re supposed to be emulating. We are telling children that they must fit in to survive, while at the same time making true integration into society impossible for them.

The very premise that normalcy is something to be desired has been called into question many times, and there is no clear argument as to why we value it so heavily. This is truly a lose-lose situation, but it extends beyond the model of social behavior. Autistic children are forced to learn a language that they are fundamentally uncomfortable with, only for us to teach them a bastardized version that has very little function outside of the home and classroom for the comfort of those around them. As Amundson says:

The disadvantages experienced by those who are assessed as “abnormal” do not derive from biology, but from implicit social judgments about the acceptability of certain kinds of biological variation (Amundson, 33).

Here, he asserts that the barriers we place on autistic children are socially imposed because we don’t find their level of deviance from the norm to be acceptable. Children who go through A.B.A. are not coming out of it as manic pixie dream children, suddenly capable of holding

¹⁸ Where I worked these were little pieces of candy we cut up in the morning and put in tackle boxes. This in itself is problematic because it meant the kids were eating sweets and junk food all day long, and because the social pressures telling them that health was something to be desired were not there, the good majority of them were overweight; not something inherently bad, but it compounded with other health issues to create problems.

deep, complicated conversations about feelings and desires, they are simply autistic children, their differences made more apparent by their pseudo-linguistic conversations. If the goal of those who are pro-A.B.A. is to teach normalcy in children, then the program as it is now is failing. “Normalcy” is the ideal of the manic pixie dream child -- it represents very few actual children, and yet is the standard to which we hold autistic children. We push a supercrip¹⁹ narrative through applied behavioral analysis, telling our children they must exceed normality in order to be considered average.

To understand the pedagogical world of the autistic child, we must make manifest what we’ve been discussing this whole time, and that involves verbalizing the difference between “social” and “existential” learning. Social learning is for the benefit of the society: it involves the teaching of verbal language and the instruction of normalcy. Existential learning is for the benefit of the child: it works to teach them all the things they need to know to live, without enforcing a social hierarchy of normalcy on them. A.B.A. strives to balance the manic pixie dream child expectations of the parents with the more realistic, existential learning necessary for children to function. Learning to respond to “hello” in a socially acceptable manner is not a necessary life skill, although it is treated with the same importance as one. Unlike learning to signal that you need a bathroom or being able to understand semantically what a stop sign is and what it means. There is a certain amount of semantic understanding that is necessary to function in a linguistically driven world, but beyond that, anything else is taught for the benefit of the onlooker. By letting parents dictate what autistic children learn, we are allowing them to control

¹⁹ The supercrip is defined in disability theory as “someone who overcomes their disability in ways that are often seen by the public as inspiring... Excessive praise for engaging in everyday activities is thought to reflect low expectations about what a person with a disability can do” (Martin, 2017). It works in two paradigmatic ways, by praising people with disabilities for doing the bare minimum, while simultaneously forcing them to rise above the level of what would be considered “normal” for anyone else in order to be considered a functional person.

the narrative of autism as a whole, leading us to believe that the autistic are aliens to our culture. Programs like the social learning aspect of A.B.A. actively suppress that culture by forcing autistic children to abandon the modes of communication that feel natural for them, and adopt the communication styles of the greater neurotypical society. Of course, they are not able to fully conform to the high standards of normalcy, so all we do is make them a participant in the social hierarchy without giving them the proper tools to achieve a high rank. Everyone in this system loses -- the students are not learning what they need to know to live on their own, and the parents are not able to push their child any closer to the manic pixie dream child.

If the practice of verbal communication is generally not advantageous to the autistic child, why is it so prevalent in the teaching of autistic children? I would propose that it is because it comes so close to the *feeling* of normalcy for those who have to exist around the autistic child. This idea being that if an autistic child can speak our language, then they are one step closer to being able to learn the language of normalcy that the manic pixie dream child is so fluent in. We assume that verbal communication is equivalent to cogent understanding, and yet this is not necessarily true, as is proven to us by the differences in the teaching of verbal and semantic communication. We can say to a child “you must wear a helmet to ride your bike” until they are able to say it back to us, but this in no way guarantees that the next time the child goes out to the garage to grab their bike, they will take their helmet along with them. However, if we are to show them a picture of a bike and a helmet together, it is much more likely that they will understand that the two things must go together. This is what makes alternative forms of communication, like PECs, so effective: about which the book, *Autism Spectrum Disorder 2nd Edition* says,

Your child may benefit from the picture exchange communication system ... With

guidance from a therapist, teacher, or parent, the child learns how to exchange a picture for an object and eventually learns to use pictures to express thoughts and desires.

Eventually, the child learns to create sentences using more than one picture and to answer questions. (Rosenblatt, Carbone, 84)

Here we see that PECS are considered a valuable tool when it comes to semantic communication with autistic children, and yet they are still only seen as a pathway to verbal communication. Because the majority sees verbal communication as “the norm,” alternative forms of communication are not recognized as acceptable. It is exactly what was occurring in the earlier example of those who develop telepathy -- the normal is simply what they want it to be. Until we are able to recognize things like PECs as valid forms of communication, we will not be able to truly integrate the autistic into our society. This validating must begin in the classroom with the practice of existential learning being seen as the main educational imperative. Austitic students shouldn't be forced to learn for the sake of others, they should be able to learn for themselves.

Chapter 3

Function and Pleasure Within the Context of Pedagogy

What is education *for*? In the previous chapter, we took a look *who* it is for and what education for different groups looks like. When we look at the origins of typical classrooms, we can see that the purpose of their creation was to ensure that all children started adult life *on the same page* -- with the same fundamental values of “ family, religion, and community” (American Board, 2015). The modern classroom is not dissimilar. While the specifics of the lessons have become more complex, the core idea is the same -- school exists to prepare children for adult life. Whereas children in early America might have been expected to become farmers and live somewhat self sufficiently, children now are expected to attend school and then either enter college or the workforce and have specialized knowledge in their respective fields. With this goal in mind, it seems fair to question the highly specific nature of curricula today. I still remember a time in math class my freshman year of high school when I asked my teacher “When am I going to use this?” and to my surprise, she responded with “The specifics of the lesson don’t matter. I’m teaching you how to learn.” That what we should carry with us from school to adulthood is not the specifics of 9th grade geometry, but the ability to engage with subjects even when we feel somewhat uncomfortable, is quintessential to understanding the modern American school. Education today is not necessarily about remembering specific facts, it is about preparing students for a life in which they will have to learn highly specific things in order to be able to hold a job. More pointedly, the system of education exists to mold children into “functional” adults.

But what does it mean to “function?” A car might be functioning if it takes you from place to place, or maybe it could only be considered to function when the heat and air

conditioning are working. If you talk to a man who owns a car garage, does he not have a financial incentive to tell you your car is not functioning properly? Is it possible for something to function in a context entirely separate from its intended purpose? A shovel functions when it is able to be used to clear snow from your driveway, but what if one is not available? In this scenario could you not simply nail a board to a thick dowel, push it across your driveway and achieve the same result? Is functionality a state in itself or simply a way we describe things in relation to one another? These questions, it seems, are not ones with simple answers although many have tried to understand them as such. Functionality is an ideal, one that traverses different planes of meaning, from the abstract to the human.

In medicine, the spectrum of functionality forces us to ask certain questions about what it means to be well or unwell. There is a more formal discussion happening within the field of the philosophy of medicine about functionality from the diverging perspectives of the naturalist and the normativist. Ron Amundson puts it rather well when he says:

Naturalists consider disease to be a straightforward, non-evaluative, theoretical concept within the sciences of medicine and physiology. Normativists consider disease concepts to embody evaluative judgments of the conditions designated as diseases. (Amundson, 34)

So, a naturalist views health and therefore the human body as constantly in one of two sorts of states, functional (at a range of levels) or dysfunctional, and the goal of medicine to ensure that the body is always functional. Naturalists are like scientific purists, they trust the system and medical professionals to determine what is functional and dysfunctional. As it relates to applied behavioral analysis, a naturalist believes that if a child is not thriving in their environment, we must change something within the child to suit the environment. This also includes medication --

for a naturalist, if something is “wrong,” they want to fix it. If a person has an anxiety disorder, the naturalist would prescribe them medication that would change them internally to function in their environment.

Whereas for a naturalist, functionality exists on a spectrum from functional to dysfunctional, a normativist sees dysfunction as an issue of one’s environment not meeting their needs. In this sense, there can be situations where your body or mind may not be behaving as they “should,” but you are still functional. If a person like Gabe Adams, who has no limbs, can still pull out an eyeshadow palette and whip out a flawlessly executed cut crease better than I could hope to do in three hours, could he really be considered “dysfunctional” in that situation? Or at the very least, more dysfunctional than me, who is completely able-bodied but can’t do what he does at all? Because he uses a brush held between his person and a table to apply makeup, Gabe could only be “dysfunctional” if he were to be without a table. This would be a problem of his environment and not one that has to do with him as a person. Normativists are unwilling to separate the scientific from the social -- they see the two as necessarily intertwined. To them, the dysfunction lies in the social.

Normativism is the argument that I²⁰ believe to be the most productive when it comes to pedagogy. One could argue that much of schooling is about molding children into functional adults by changing how they think and behave, but I believe it would be more appropriate to say that a good education allows a child to mold themselves into a functional adult by teaching them how to adapt their environments to suit their needs. This is not to say that naturalism is not a valid perspective. In the world of medicine, it makes sense to be a naturalist. If someone develops cancer, the answer is not to wish them the best and send them to a therapist to deal with their new reality. It is to give them radiation and operate to try and cure the condition. The

²⁰ And the majority of the Crip Theory community

discrepancy lies within what should or should not be cured. Cancer is not a social category, it is a devastating disease. Conversely, autism is not a death sentence. It isn't even necessarily a life sentence.

I don't mean to get so aggressive with this claim. We're going to go on a necessary detour here so please stick with me. I understand that for many autistic individuals, they take offense at the notion of having a "disease" or a pathology. However, there are plenty of instances of individuals with more severe autism who are profoundly disabled to the point where medical intervention is somewhat necessary. Children may exhibit violent behaviors that are concerning, but not necessarily threatening. However, those children will eventually grow into adults with the capability to seriously injure someone and the only way to ensure they do not is to give them some sort of mood stabilizer. I have no issue with this; the autonomy of autistic individuals should not come at the risk of possible harm to anyone else. Referring back to the work of Ron Amundson (Amundson, 2000) there is a common confusion amongst those who look into the "abnormal" about the distinction between level of function and mode of function. The type of autistic students I am referring to in this paper are those who experience an abnormal mode of function -- they have the ability to be functional, but they do this in ways that are considered abnormal. It is like if a student refuses to speak aloud, but is masterful at communicating with others through art. They get their points across, just in a different medium. To this, Amundson says, "The assumption that *mode* of function determined *level* of performance was falsified" (Amundson, 41). In ABA, level of function and mode of function are often confused. It is assumed that because a student might not function in a typical environment, they must have a low level of functioning. This is not necessarily the case, as the student may function well in a different environment or context. ABA does not provide room for students to explore different

modes of function and that is the issue we're addressing here, not whether autism is something pathological.

Many people live spectacularly happy lives with autism and do not see it is something that they want cured. This is the problem with those naturalist institutions like *Defeat Autism Now*, who are trying to medicalise and naturalise a social and existential condition that is inherently normativist. We wouldn't accept a nonprofit organization called *Defeat Left-Handedness Now*²¹. That's objectively ridiculous. However, to say something like *Defeat Breast Cancer Now* makes much more sense. This is because autism and left handedness are both simply aspects of being, whereas cancer is a foreign invader that destroys the body. The naturalist suggestion that autism is something to be defeated is offensive to the many individuals that feel that it is an important part of their identity. A normativist nonprofit would release a slogan more along the lines of *Respect the Autistic Now*; something that places the onus on outsiders to rethink the ways in which they interact with the autistic.

In the world of disability, these two ideas of functionality are further represented by different "models" of existence: medical and social. The idea behind the medical model is that disability is akin to dysfunction, and when a person is dysfunctional (i.e. sick with a cold, or having problems with their appendix) the goal should be to correct or cure the dysfunction. People with disabilities tend to see this model as intensely clinical, and out of touch, as it assumes a person with a disability wants a "cure." Whereas with the social model of disability, it is not the person that is dysfunctional, but the society around them. As Barnes and Mercer explain in their introductory text on disability studies, "The social model of disability reverses the causal chain to explore how socially constructed barriers have disabled people with a severe

²¹ This is ridiculous to us now, but at one point left-handedness was considered a pathology. I recall stories from my grandpa of the nuns at his school hitting him with rulers if he tried to use his left hand.

impairment” (Goodley, 11). In this sense, a person is only disabled by the context they are in. If a person in a wheelchair tries to navigate their way around a building without ramps, that person is disabled, but if there are ramps aplenty, then that person is not disabled in that situation because they are able to navigate that building as anyone else would be able to. This is, of course, allegorical to the telepathy example we looked at before.

Having established that functionality is a concept that is -- for our purposes -- inherently based in the social, what does that mean for the world of special education? In the typical classroom, functionality is a goal that can be ingrained in the minds of children at a young age, *if you want to be happy like your parents, you need to become a productive adult*. But what about those for whom the goal isn't necessarily entering the workforce? How do you motivate a student to learn for the benefit of others? In ABA, functionality is used both literally and as a more abstract goal. In the literal sense, children are grouped by their level of functionality -- you will see classrooms split by high functioning verbal students and low functioning verbal students, as well as high and low functioning groups of non-verbal students. Functionality is used as a way of categorizing students so that they can be placed in environments that can more effectively address their specific needs. Functionality is also an abstract goal in ABA, much as it is in typical education. It is more complicated in special education though, as we have a basic idea of what it means for a typical student to be a “functional adult,” but that is less clear when talking about students with disabilities.

Michel Foucault sees this sort of understanding of functionality as a place of confinement, one that he makes manifest in his usage of the concept of Bentham's panopticon. This is a type of institution²² where a single guard, shrouded in darkness, is able to control an

²² Bentham originally refers to a prison, and while Foucault does as well, he also uses the framework of the panopticon to refer to mental hospitals.

entire floor of inmates without ever making their presence known. Foucault outlines this in his work, "Psychiatric Power" saying:

The madman must not only be someone who is watched; the fact of knowing that one is always being watched, better still, the fact of knowing that one can always be watched, that one is always under the potential power of a permanent gaze, has therapeutic value in itself, since it is precisely when one knows one is being looked at, and looked at as mad, that one will not display one's madness and the principle of distraction, of dissociation, will function to the full. (Foucault, 102)

The theory is that if they believe that they are constantly under scrutiny, individuals will monitor their own behavior -- which will eventually ingrain "good" behavior into their personal habits. This is not a pleasant system, it is obviously torturous, and while I do not want to imply that ABA and prison or asylum are the same, I do want to take a moment and point out the similarities between the two.

Foucault takes Bentham's panopticon and widens it into a greater theory of how power and control are used to ensure compliance with the wills of those who hold power. For example, because of the reverence we hold for individuals like doctors, they hold an implicit authority over anyone who happens to be in a medical setting and they use this to ensure certain behaviors. I'm going to go out on a limb and suggest that the typical individual does not want to drink 64 oz of liquid laxative in an evening, but if you are going in for a colonoscopy, you will do it because a doctor told you so. You don't even have to necessarily understand why (although in the instance of the colonoscopy it isn't that hard to figure out) -- you are behaving in such a way because an authority figure has told you to do so. It is the same in applied behavioral analysis -- children don't necessarily understand why they are being compelled to stop stimming, but they

do it because it is what an authority figure demands. Let's take this even further by examining the physical layout of the ABA classroom. Students are separated by partitions into their own areas so that they are not able to see each other during general instruction. One of the more important aspects of these spaces is that the children are never supposed to be left alone. They are set up so that even if there is an emergency in another area of the classroom, and their staff member has to go assist, the student will still be visible to the head classroom teacher. In the same way that prisoners in the panopticon are constantly being watched, autistic children in applied behavioral analysis are as well. Whether that observer is watching from a desk across the room, or sitting right next to them administering lessons, behavior is constantly scrutinized in the hopes that what is "good" will become ingrained as habit.

In the world of disability studies, it is somewhat of a given that the normativist school of thought would be preferred over the naturalist. However, there are many individuals, particularly those in the medical field, that would consider themselves naturalists first. While it is not so obvious to me, I can see where they are coming from. The world can be particularly dangerous for a disabled individual and as much as we want it to change, it can be incredibly unrealistic. Take, for example, the story of Elijah McClain -- a young black man who was murdered in a confrontation with police. As far as we know, Elijah was not a person with autism. It has not been confirmed by family or news media. However, Elijah's death has become a sticking point for parents of autistic children about the way the autistic are treated by law enforcement. In the horrific video of Elijah's police encounter, he begs police to let him go saying "I am an introvert. Please respect the boundaries that I am speaking." and "I'm different." The police were called on him because he was moving erratically and wearing a ski mask. While we don't know for sure if he was neuroatypical, many people in the autistic community saw themselves and their loved

ones in Elijah McClain. I can understand the naturalistic desire to change the child when the environment is the problem because if we don't, we risk having situations like what happened to this young man. However, as we explored in the last chapter, naturalistic education does not create traditionally functional adults. The children who are products of ABA are still noticeably neurodiverse for the most part. We don't have a successful naturalist way to change children's behavior to ensure that they are safe in these situations, so it makes no sense to problematize the behavior of the children and not the police officers. A true naturalistic approach would be one that changes the officers to ensure that they don't murder disabled individuals indiscriminately, but that is not a notion that is considered viable. Why?

Additionally, the ABA classroom, like the panopticon, is a space of social isolation. Students are mostly separated from one another because ABA is seen as a program that caters to individual learning needs as opposed to group instruction. This isolation is taken further than simply instruction though, because students are almost never truly able to have genuine social interactions with one another. Even when they are all together for meal time, or perhaps sensory play time, they are still not able to interact without the intermediary of another staff member. This is more strict in lower functioning classrooms, but even in higher functioning, most of the time is spent on individual instruction and play time is still heavily monitored to make sure that it is happening "correctly." In no other context could I imagine it okay to scrutinize the behavior of children with such intensity.

The Foucauldian approach to special education is akin to the way a naturalist would approach it. Foucault's ideas of power and adoption of Bentham's panopticon suggests a world in which children are expected to adapt to their environment or face strict social consequences. When read in a normativist way, John Dewey, can be seen as providing a foil to such naturalist

theories (like the ones that Foucault himself is critiquing) of autism in the classroom. Through pedagogical theories and the push for Montessori education, Dewey encourages children to change their environments to suit their needs as opposed to adapting to them. Dewey is a key player in thinking about contemporary education. He founded a school through the University of Chicago called The Laboratory School, which was a groundbreaking space where new pedagogical theories could be studied within the context of a real classroom. Dewey was a big proponent of Montessori education, which included a significant amount of self guided activity and play. Dewey saw the classroom as a mimesis of greater society, saying “Education is not preparation for life, education is life itself.” For Dewey, it was important that the classroom was a space in which children could begin to process the things they observed in the adult world. One crucial component of this was that education was something that students found pleasurable. It engaged their curiosity and frequently involved play. Even play however, which literally allows children to exert control over their environments, is heavily regulated in the world of applied behavioral analysis.

Take, for example, the game Connect Four. In an ABA classroom, an instructor would sit with two students and prompt them to verbally address each other before each turn, saying “Tyler,²³ it’s your turn now,” to which Tyler would take his turn then be prompted to respond, “Okay Kevin, it’s your turn.” Play is highly regulated and heavily structured in the world of ABA, quite literally forcing autistic children to regulate their behaviors in order to conform to what the collective *we* deem normal. I can recall playing Monopoly with my sister in childhood. Although we would begin each game playing by the traditional rules, it would quickly devolve into what we called “bank robber” where the goal was to stuff as much money into our clothing

²³ Pseudonym, of course.

as possible and run around the house.²⁴ One summer, my neighbor, Danny got a new refrigerator and we spent probably a solid month playing in the box it came in. That box was a time machine, rollercoaster, clubhouse, and at one point something we put our little sisters in then pushed over until they cried and told our moms. All this is to say that for nondisabled children, play is a space in which the rules are completely their own. Even in school, we had an entire playground to roam, free from the watchful eye of our teacher where we could eat grass under the slide and pretend we were witches in solitude. Although I am using my stories here, I am sure that you can recall your own childhood play -- how it was a space wherein you were free to construct your own worlds, your own rules.

For children, whose lives are so heavily regulated by adults, the freedom afforded in the realm of play is essential to the development of identity. Stanley Greenspan and Serena Wieder propose that play is a way for children to process what they see in the adult world that they are typically kept separate from, saying:

Have lots of props available with which to entice your child, especially toy versions of common household objects, so he can play out dramas based on real life experiences; this is the first place imagination may express itself. (Greenspan, Wieder, 98)

This freedom afforded to non-autistic children is noticeably and detrimentally absent in the ABA classroom. Instead of using play and imagination to process what they see happening in the adult world, autistic children are instead forced to mime what adults consider “play” to be -- a turn based board game, legos played according to the rules of building, heavily monitored games of tag. It is not play because there is no joy in it, and the essential element of play is the pleasure one feels from engaging in it. Play without pleasure is simply work in disguise -- like a clown, amusing at first, but much less fun than one would expect under all that face paint. The point of

²⁴ In the process, we completely destroyed my Father’s childhood Monopoly set.

the pleasure of play is that children find joy in recreating the world around them and thus learn that that world is one where they can exercise control over their environments.

This is where we start to see the branching off of the naturalist and the normativist in education. The naturalist looks at the panopticon of ABA as a structural system that does its job effectively, and in a lot of ways, they are right. Applied behavioral analysis is excellent when it comes to adapting the behavior of a child. However, the normativist believes that the ultimate aim of education is not necessarily to change behavior for the purposes of others, but for the benefit of the child. For both the naturalist and the normativist, the goal of education is to mold children into functional adults, but functionality means something different to each group. For the naturalist, a child is a functional adult when they are able to change something within themselves in order to adapt to their environment. For a normativist, a functional adult is able to adapt their own environment to suit their needs, and this is accomplished not through surveillance, but play.

A good education prepares children for this reality. We are given time for imaginative play at recess and creativity during art -- we are expected to ask questions in class, to explore the limits of our curiosity. There is a reason that the floors of playgrounds are wood chips or soft grass instead of concrete -- because children, when given the opportunity, will explore their world to the fullest, which tends to mean that injuries are inevitable. As children age into middle and high school, they begin to experiment with choices - what level of classes will they take? Will they be more arts-focused or science-focused? They are also able to experiment with accommodations, finding that if, like me, testing makes them vomit, they can advocate for themselves and have that environment changed. A naturalist school is one that fails to present

these opportunities for students, believing instead that they will change themselves in order to make their educational experience a more valuable one.

In many ways, a severely autistic adult is functional when they are living in a copacetic way with their environment. Perhaps a person is high-functioning enough to live in an apartment on their own. Maybe they work part time at McDonalds and their rent is subsidised by their SSI checks. Perhaps the state has an aid come to their home twice a week to ensure they are healthy and safe. For another student, being a functional adult could mean living in a group home, finding joy living amongst the other residents and participating in group activities.

I consider myself a pretty functional person, and I think most would agree. However, put me in a car for an extended period of time and I am an anxious mess -- I have a panic attack on almost every long car trip I go on. In a car, I am much less functional than I am in other environments. However, over the years I've learned that if I blast the air conditioning (unfortunately even in the winter) and listen to music on my phone, I am able to calm myself down enough to get where I need to go. I have learned that I can manipulate my environment in such a way that I am able to render myself able to perform in any situation that requires it. I have seen this story frequently referred to on the internet, and as far as I can tell, it comes from a Quora answer to the question, *Has a therapist ever told you something completely unexpected?* A woman identifying as Kate Scott recalled a time her therapist asked her about a concrete thing that was bothering her and she responded:

Honestly? The dishes. It's stupid, I know, but the more I look at them the more I CAN'T do them because I'll have to scrub them before I put them in the dishwasher, because the dishwasher sucks, and I just can't stand and scrub the dishes."... He nodded in understanding and then said: "Run the dishwasher twice." I began to tell him that

you're not supposed to, but he stopped me. "Why the hell aren't you supposed to? If you don't want to scrub the dishes and your dishwasher sucks, run it twice. Run it three times, who cares?! Rules do not exist." (Scott, 2021)

I love this modern parable, and I think of it often when I find myself feeling unable to complete a task. Understanding that rules are arbitrary is a huge part of becoming a functional adult, learning that your surroundings are malleable and that you can manipulate them to suit your needs. It is the opposite of the panopticon in that it actively rejects that outside scrutiny and acknowledges the arbitrary nature of our societal compulsions.

To sum up the discussion in this chapter, the problem of ABA is not ABA itself. It is a highly effective method for controlling and curtailing problematic behavior, as we discussed in the previous chapter. Incentivising good behavior with rewards and punishing negative behaviors by removing those rewards is a very quick way to establish what behaviors are acceptable. The problem with ABA is that it is the only system used to teach autistic children. ABA is the naturalist approach that Foucault might criticize. However there are certain contexts in which it has merits, although it should not be the exclusive mode by which we teach children. In ABA, the only pleasure in learning is given by the instructor to the student through rewards like food, time on YouTube, or even just praise. By making adults the ones responsible for doling out any pleasure a student might receive we are not allowing students to find the pleasure in their own experiences through play and creativity. A more well rounded classroom might reserve the use of the techniques of applied behavioral analysis to eliminate problematic behaviors like SIB,²⁵ aggression towards others, or public displays of sexuality. However, this classroom might also forgo the use of ABA in general instruction, instead choosing to opt for a more freewheeling, Montessori approach. Students, especially lower-functioning autistic students, need to feel

²⁵ Self-Injurious Behaviors

intrinsically motivated to learn because doing so brings them pleasure. The classroom should not be a panopticon. Unlike students in typical education, special educators run the risk of not knowing what their students are comprehending. Students in typical education eventually come to understand that the less pleasurable parts of school are still important because they understand that a traditionally functional adult must learn what they are learning. This is not so easily accomplished when the very notion of typical functionality is called into question, as it is with autistic students.

Chapter 4

Loop into Fun!

Through the course of this paper, we have come to a new understanding of looping and the way it affects the p-c-a both metaphysically, and in terms of ethical decision making. While Hacking went so far as to suggest that parent's looping may affect their children, we have expanded on that to typologise the distinct ways in which loops concerning autism make up much of what our modern understanding of autism *is*. In a metaphysical sense, it tends to branch off into two distinct forms: *positive* and *negative looping*. This all depends on the way in which p-c-a perceive autism itself. Those who view it as a form of existential otherness experience positive looping, whereas those who see it as a pathology experience negative looping. In an ethical sense, we have explored the ways in which looping colors how the public, and even the autistic themselves, view Autism Spectrum Disorder. If it is explained by the p-c-a, who are essentially the mouthpieces of autism for the majority of those looking into it, then it will continue to be further pathologized by others.

We've come to define many terms and name different phenomena over the course of this project, and if we look at them now, we can see that what we were doing was simply dichotomizing the different forms of looping and exploring the ways in which they manifest. First there is negative looping. This type of looping is what causes parents to be horrified by their "autistic child." The rhetorical autistic child, in comparison to the manic pixie dream child that parents come to expect, is only made more horrifying by the existence of spaces like Autism Speaks and the various Facebook groups it spawns. In these places, parents trade horror stories and discuss methods to make their children more "normal." These are the kinds of spaces in which the negative loops fester and grow. I hesitate to criticize the parents who experience

negative looping too heavily. While I see Autism Speaks as a problematic organization, I understand the desire for parents to have a space wherein they can express themselves and their concerns about raising an existential other. Parents are going to loop in reaction to their children's diagnosis no matter what -- why not reform places like Autism Speaks from a place where that looping is negative to one where it is more positive? It is clear that Autism Speaks takes up too much rhetorical "space" in the world of autism. Perhaps instead of eliminating it all together, we could simply attempt to take away the definitive power that it has. In an ideal world, Autism Speaks would be a support system for p-c-a who are struggling to parent or connect with their autistic child. These are legitimate concerns, and as we've seen throughout this can be unimaginably distressing. Instead of creating a space where the loops are negative, we can reform by allowing the autistic into these conversations to strategize with parents.

If you will, think back to the second chapter in which we discussed the idea of the norm. Parents who experience negative looping see their autistic children as pathological, experiencing something abnormal that must have a cure. This, of course, falls into the medical model of disability, or naturalism, which believes that autism is a disease and therefore must have some sort of cure. Because they are unable to find either the cause or the cure, parents who experience negative looping attempt to "cure" their children by modifying their behavior. These "cures" range from the objectively ridiculous like camel's milk to the blatantly harmful like "Miracle Mineral Solution," or as it's known more colloquially: a bleach enema (Willingham, 2013) On the spectrum of "cures" ABA feels like a pretty sane choice, but it too can start to enter an ethical grey area if used as the sole method of educating autistic children. The intense focus on social learning based on the appearance of verbal language in ABA allows them to feel like their children are "emerging" from their autism in a sense -- hence the continued prevalence of verbal

language in applied behavior analysis. However, all of this social learning comes at the expense of existential learning -- children are essentially placed in schools to learn to appear normal, but fail to learn the things they need to know in order to live a “normal” life. Yes, they can say “Hi, how are you today,” but they are not being taught how to feed themselves in a way that nourishes their bodies, or even occupy their time when alone.

We have come to the conclusion that having this much power over the narrative of a disorder without having scientific evidence as to its boundaries is inherently unethical. As we saw in Chapter 3, the model of behavior analysis used in ABA is eerily similar to that used in Foucault’s example of the panopticon. While the panopticon is dubiously ethical itself, it is decidedly unethical when used as the primary method of education for children with autism. We established that the goal for traditional education is to create functional adults, but that for ABA it is to create “normal” adults (in quotations because they are normal in appearance alone). The idea that the standard for what education *is* changes simply because a child is an existential other is unacceptable.

By all rational thought, negative looping makes sense. I can see why parents find comfort in these patterns -- they view autism as a disease, and see ABA as a facet of curing that disease. What these parents fail to realize in this loop are the ways in which ABA functions like Bentham’s panopticon. Although their child is able to mimic normal behavior, they fail to understand why. It’s the appearance of normalcy without the semantic understanding. In a sense, it is torturous just as the panopticon is torturous. Fundamentally, children are only behaving in a way that is “normal” because they have internalized the gaze of the p-c-a. They see their own behavior, the way that it feels natural for them to be, as something wrong. The issue here is not ABA itself. As a method of changing behavior, ABA is highly effective. Certain behaviors are

simply unacceptable -- public displays of sexuality and/or violent behavior can be illegal or dangerous. These are the kinds of instances where ABA is not only appropriate, but preferred. However, we need to be careful about its *overuse*. While ABA is highly effective, it is also highly impersonal. We mistake the fact that autistic children express their love and sociality in different ways for indifference to the social altogether. Depriving them of the love and inclusion that most other children experience in school in order to completely change their patterns of behavior is problematic at best and downright unethical at worst. Truly, we don't know in what kinds of conditions these children would flourish because we don't know enough about the experience of having autism. The p-c-a control the narrative and therefore control the way that autistic children are educated.

Of course, the negative looping parent has a foil: the positive looper. These parents understand their child not as someone who is disabled or ill, but as an existential other. They may see great potential in their child but do not know how to tap into it. They recognize that neither the manic pixie dream child nor the rhetorical autistic child can exist, because they are equally ridiculous character tropes which represent a very small (if any) percentage of children. They realize both that their child does not fit into the mold of the "typical" child, and also that very few children actually do.

Such parents' ideals align more with the social model of disability -- the belief that their child is not the "problem," and any problems that they may encounter are actually results of a world that refuses to accommodate them. These parents would be considered more normativist, because they understand that their child is not ill, but is an existential other. They acknowledge that it is the social and physical landscape that is disabling to their child and do not necessarily see autism itself as a disability. As we discussed in the third chapter, functionality is inherently

subjective, and many times successfully raising an autistic child means accepting this and incorporating it into learning.

Parents who experience positive looping might struggle to find a school program for their children that feels like it values them as existential others while also ensuring that they receive a healthy balance of social and existential learning. This kind of learning would incorporate the necessary aspects of social learning in a way that is adapted to be more natural for autistic students, while simultaneously focusing on life-skills. While the general non-ABA special education classroom can be a wonderful place, parents of children with autism may find that they need a form of education that is more individualized to their child's needs.

What does ethical education look like for an autistic child? First of all, It does include some applied behavior analysis. It isn't fair to students to allow them to continue behaviors that are dangerous, lewd, or illegal. As we discussed earlier, ABA is highly effective in modifying behavior, and while the goal of education is not to change who children fundamentally are, it is true that *all* children have their behavior modified by school in some way. I see ABA as a necessary and healthy component of a functioning autistic classroom. However, it should remain just a *component*, not the main ingredient.

How do we keep students engaged if not through the tactics of ABA? The answer is that we must go out of our way to ensure that the experience of learning is pleasurable. Think back to the concept of play as a way of processing the world and Dewey's idea of schooling as "life itself." Both of these concepts illustrate the ways in which existential learning is something inherently pleasurable. Children want to learn if they are engaged in an activity that is fun, and this remains true for autistic children. The insistence on rigidity and routine in ABA means that autistic children are essentially living the same day over and over *à la Groundhog Day*. Even if it

is true that autistic children enjoy routine, there are ways to incorporate routine into education without making it so limiting. The boundaries of the classroom should be equivalent to the boundaries of the mind -- we assume autistic children do not want to explore the world around them. I believe this assumption is false. Autistic children need a safe space in which they can explore their worlds in a way that is comfortable for them, and that space should be the classroom. Play and exploration should be key aspects of learning.

The ABA classroom is one that focuses on verbal communication because its mastery suggests that one is “normal.” The autistic classroom should be a space in which all forms of semantic communication are utilized and valued equally. If verbal communication is not a medium with which students feel comfortable, they should be reached out to in other ways until one that sits well with them is identified. These alternative forms of communication might include sign language, typing, PECS, or even art as a form of communication. It should be individualized to suit the needs of each student, and instead of working to ensure the student understands us, we should be working to find a way to semantically translate the way they prefer to communicate to others.

I would like to make a quick return to the briefly discussed concept of mode of function. It’s something that we’ve been flirting with over the course of this paper, but have been hesitant to approach. This is because in terms of the theoretical, it is frequently paired with level of function, which is not something that I want to focus on in this project. All of the adaptations suggested to the classroom here play to the idea of mode of function. We have been taught to value this because the mode of function is what allows us to appear normal while simultaneously being functional. Amundson believes we place too much emphasis on appearance, saying:

Functional determinists were more concerned with the cosmetic issue of mode of

function than the pragmatic issue of level of function. If this is so, the aversion to atypical modes of function is a simple prejudice, and not an objective scientific assessment.

(Amundson, 48)

Assuming Amundson is correct in his proposal, we are educating autistic students in a way that is fundamentally unjust. Thinking way back to our discussion of Socrates and justice: in this instance, is justice really the will of the stronger? How could it truly be if the will of the stronger is based in the desire to oppress the atypical behaviors of the neurodiverse? While Thrasymachus may be objectively right, he is not morally right. Justice as a concept should be expanded to include those whom society deems weak.

With all of this in mind, I'd like to propose an Autistic Student's Bill of Rights. While standardization and autism go together like milk and vinegar, there should be certain guarantees made to any autistic child to ensure that they are being educated in a way that is ethical. I would like to lay them out for you here:

The Autistic Student's Bill of Rights

All autistic students within the classroom must:

1. Have access to a form of communication that is comfortable for them first
2. Be allowed to explore any questions they may have
3. Have time to play that is unregulated by adults
4. Not be isolated from typically-abled students
5. Be allowed to stim as much as they please, without criticism or redirection
6. Be allowed to interact with their peers without regulation from adults
7. Not be forced into any activity for the sake of those around them
8. Never experience the use of physical restraints unless they themselves or a peer is in danger of bodily harm
9. Have access to a space that is open and exciting where they *want* to learn
10. Be able to focus on their own needs before addressing parental concerns

Conclusion

I was scrolling through the internet the other day when I came across something utterly disappointing. First off, you should know something about me -- I have had many special interests over the years (this is a polite way of saying autistic obsessions). I am currently interested in the Disney Parks, the internal politics of the house and senate, and autism itself. When I was in high school, one of my first serious special interests was the stand-up comedy scene of the mid-2000s. I was a *Daily Show* fanatic -- I watched every episode, followed the internal politics of the show itself, watched every stand-up special, every interview, from anyone even tangentially related. It's safe to say that I know and love a lot of individuals who are currently somewhat big on the comedy circuit. So imagine my utter dismay when I figured out that pretty much everyone I idolized -- Colbert, Stewart, Oliver (this one hurt the most) -- as a young and dubiously autistic kid will be appearing on April 30th, 2021 on *Color the Spectrum*, a program presented by NEXT for Autism (NEXT for AUTISM, 2021).

NEXT is by no means engaging as heavily in negative looping as Autism Speaks. However, I wouldn't necessarily also hold them up as a bastion of positive looping. They have a history of making somewhat offensive choices, refuse to fully disavow ABA as a primary method of teaching, and are a neurotypical-led organization. Do I fault these celebrities for joining this organization to fundraise? Absolutely not. I was reading a Jon Stewart interview wherein he really seemed to "get" what autism is in a much more nuanced way than most. The issue isn't so much that these people are fundraising for autism organizations, it's that they don't seem to be thinking that hard about which organizations they are working with. The way Jon Stewart talks about autism actually aligns well with the ASAN mission. However, because institutions like Autism Speaks and NEXT for Autism have so much power (much of that due to

their connections to famous individuals), most people are not exposed to the smaller organizations led by and for the autistic. Having a child with autism can be isolating for parents. I am very familiar with this and sympathetic to it. Parents definitely deserve spaces in which they can laugh and commiserate and help each other, but they should not be making decisions about the future of autism as a field without having autistic individuals at the table.

Having developed the language of my displeasure through the creation of this project, I feel that I now understand why it irks me so to see these individuals doing things like *Color the Spectrum*. Expanding a bit on the idea of positive and negative looping, I see these political satirists as people who have created an echochamber for positive looping in a civic sense. John Oliver especially will explain an issue that affects us as citizens, change our view of that subject in relation to our lives, and give us something to do about it. For example: He did a piece about net neutrality where he explained the biases of its proponents (notably the former head of the FCC, Ajit Pai), and gave viewers an uncomplicated way to voice their displeasure to the FCC with the creation of the website “www.gofccyourself.com²⁶” (Last Week Tonight, 2017).

The issue here is that John Oliver and others like him are cornerstones of modern positive looping -- they care about the increase of positive effects on the communities they speak to. Rarely do we see them take a side that could be considered harmful to anyone except those with excessive power. However, from the perspective of the neurotypical, it is not seen as a problem to be a negative looper on the subject of autism. These political satirists believe that they are serving the autistic community by serving the p-c-a. However, we know from this paper that the p-c-a are not necessarily doing right by the autistic community. Discourse about the autistic that happens without them is not only unethical, it is inherently uninformed. By participating in

²⁶ A site which takes you to the formerly well-hidden page for public comments on the FCC’s website.

events like these, celebrities (whether I like it or not) are perpetuating the cycle of negative looping. As they have said for many years in the greater disabled community, and ASAN still proudly proclaims today: *Nothing about us, without us*. Power to you, fellow autistics. We will be heard.

Works Cited

Admin. (n.d.). Autistic Self Advocacy Network. <https://autisticadvocacy.org/>.

“11 Facts About the History of Education in America.” *American Board Blog*, 1 July.

2015, www.americanboard.org/blog/11-facts-about-the-history-of-education-in-america/.

Amundson, Ron. "Against Normal Function." *Studies in History and Philosophy of Science*, vol. 31, pp. 33-53.

Aristotele. *Nicomachean Ethics*. Translated by Terence Irwin, 2nd ed., Indianapolis, Hackett, 2007.

Arky, Beth. “Why Many Autistic Girls Are Overlooked.” *Child Mind Institute*, 23 Oct. 2019,

childmind.org/article/autistic-girls-overlooked-undiagnosed-autism/#:~:text=Another%20problem%3A%20misdiagnoses-,Dr.,social%20dysfunction%E2%80%9D%20caused%20by%20autism.

“Color The Spectrum.” *NEXT for AUTISM*, 1 May 2021,

www.nextforautism.org/current-events/color-the-spectrum/.

Dewey, John. *Experience and Education*. New York, Free Press, 2015.

“Diagnostic Criteria -- Autism Spectrum Disorder.” *Centers for Disease Control and Prevention*,

Centers for Disease Control and Prevention, 29 June 2020,

www.cdc.gov/ncbddd/autism/hcp-dsm.html.

Donne, John. *No Man is an Island*. Retrieved December 05, 2020, from

<https://web.cs.dal.ca/~johnston/poetry/island.html>

Foucault, Michel. *The Archaeology of Knowledge and the Discourse on Language*. New York, Vintage Books, 2010.

---. *The Birth of the Clinic: An Archaeology of Medical Perception*. Repr. ed., New York, Vintage Books, 1975.

---. *Madness and Civilization: A History of Insanity in the Age of Reason*. New York, Random House US, 2013.

Freire, Paulo. *Pedagogy of the Oppressed*. 50th ed., New York, Bloomsbury, 2018.

Garland-Thomson, Rosemarie. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. Repr. ed., New York, Columbia UP, 2008.

---. *Staring: How We Look*. Oxford, Oxford UP, 2015.

Garland-Thomson, Rosemarie. "Feminist Disability Studies." *Signs*, vol. 30, no. 2, 2005, pp. 1557–1587. *JSTOR*, www.jstor.org/stable/10.1086/423352. Accessed 3 May 2021.

Hacking, Ian. *Philosophical Issues in Psychiatry 3: The Nature and Sources of Historical Change*. Edited by Kenneth S. Kendler and Josef Parnas, Oxford, Oxford Univ. Press, 2015.

---. *The Social Construction of What?* Cambridge, Harvard UP, ©1999, 2003.

Last Week Tonight. "Net Neutrality II: Last Week Tonight with John Oliver (HBO)." *YouTube*,

[YouTube](https://www.youtube.com/watch?v=92vuuZt7wak), 7 May 2017, www.youtube.com/watch?v=92vuuZt7wak.

Luterman, Sara. "Perspective | The Biggest Autism Advocacy Group Is Still Failing Too Many

Autistic People." *The Washington Post*, WP Company, 20 Feb. 2020,

www.washingtonpost.com/outlook/2020/02/14/biggest-autism-advocacy-group-is-still-failing-too-many-autistic-people/.

Martin, Jeffrey J. "Supercrip Identity." Oxford Scholarship Online, Oxford University Press, 2017,

oxford.universitypressscholarship.com/view/10.1093/oso/9780190638054.001.0001/oso-9780190638054-chapter-15#:~:text=A%20common%20stereotype%20in%20the,by%20the%20public%20as%20inspiring.&text=Excessive%20praise%20for%20engaging%20in,with%20a%20disability%20can%20do.

"Media Coverage of Law Enforcement Use of Force and Disability." *Ruderman Family*

Foundation, 3 Oct. 2017,

rudermanfoundation.org/white_papers/media-coverage-of-law-enforcement-use-of-force-and-disability/.

Nietzsche, Friedrich Wilhelm. *On the Genealogy of Morals*. Translated by Walter Kaufmann and R. J. Hollingdale, Vintage books ed., New York, Vintage Books, 1989.

Plato. *The Republic*. Translated by Richard W. Sterling and William C. Scott, Norton pbk. ed., New York, Norton, 1996.

Scott, Kate. "Kate Scott's Answer to Has a Therapist Ever Told You Something Completely

Unexpected?" *Quora*, 2021,

www.quora.com/Has-a-therapist-ever-told-you-something-completely-unexpected/answer/Kate-Scott-6?ch=99&share=924eb0ff&srid=P2BN.

Rabin, Nathan (2007, January 25). *The Bataan Death March of Whimsy Case File #1:*

Elizabethtown. Retrieved December 05, 2020, from

<https://film.avclub.com/the-bataan-death-march-of-whimsy-case-file-1-elizabet-1798210>
595

Reber, Deborah. *Differently Wired: A Parent's Guide to Raising an Atypical Child with Confidence and Hope*. New York, Workman Publishing, 2019.

Rosenblatt, Alan I., and Paul S. Carbone. *Autism Spectrum Disorder: What Every Parent Needs to Know*. 2nd ed., Itasca, American Academy of Pediatrics, 2019.

Schloss, Patrick J., and Maureen A. Smith. *Applied Behavior Analysis in the Classroom*. Boston, Allyn and Bacon, 1994.

Simplican, Stacy Clifford. *The Capacity Contract: Intellectual Disability and the Question of Citizenship*. Minneapolis, Univ. of Minnesota Press, 2015.

Smith, Lisa. "The Do's & Don'ts after an Autism Diagnosis." *Autism Speaks*, 16 Feb. 2016,
www.autismspeaks.org/blog/dos-donts-after-autism-diagnosis.

Solomon, Andrew. *Far from the Tree: Parents, Children and the Search for Identity*. New York, Scribner, 2012.

Willingham, Emily. "The 5 Scariest Autism 'Treatments'." *Forbes*, Forbes Magazine, 29 Oct.

2013,

www.forbes.com/sites/emilywillingham/2013/10/29/the-5-scariest-autism-treatments/?sh

=682e05731953.