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Hike Your Own Hike: Cosmopolitanism and Applied Behavior Analysis Explored Through SPN

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HIKE YOUR OWN HIKE: COSMOPOLITANISM AND APPLIED BEHAVIOR
ANALYSIS EXPLORED THROUGH SPN

A Thesis Presented

by

Caitlin Brianna Walsh

to

The Faculty of the Graduate College

of

The University of Vermont

In Partial Fulfillment of the Requirements
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ABSTRACT

Ever since I started working with animals, I felt an intrinsic motivation to develop relationships based on trust and mutual admiration. Working in the horse world, I became dismayed at the coercive methods used to assure progress and achieve competition goals. I moved to Burlington to pursue a career helping children. Working as a behavior interventionist I felt peace and satisfaction as I utilized my previous skills and knowledge learned from my work with animals and my undergraduate education. After about a year of work, I started to become frustrated and dismayed at the treatment of some of our children. This SPN thesis is an exploration of those challenges and who I wish to become as I move forward in my career.

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Many people supported and encouraged me throughout this process. I owe them my gratitude for listening to my stories, giving me critical pointers and advice, and helping me see the simplicity in the end. I am thankful to Robert Nash for creating the Interdisciplinary Program and encouraging his student's to explore their own narratives. Thank you Caleb for your coffee chats and ability to remind me to keep it simple over the past year. Thank you Brie for showing how "what, so what, now what" could guide the first draft of my thesis. Thank you to Molly, who reminded me of balance and peace during this difficult process.

My parents influenced a lot of this writing, through their indirect contributions of letting me hike my own hike as an animal crazy kid, but also their direct help through feedback and support during the writing process. Thank you for letting me explore my passion and interests, and for recognizing my early accomplishments. Thank you to Mister, Zoe, Isabel, Gromit, and Mara some of the best four-legged friends around.

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CHAPTER 1: INTRODUCTION

1.1 Purpose

“You will find parts of the truth (along with much error) everywhere and the whole truth nowhere. The deepest mistake, he supposed, is to think that your little shard of mirror can reflect the whole.”¹

“Here ya go honey” my mother said as she handed me a simple chain necklace with the charm letters T.V. I slipped the necklace on as we walked up the front steps of another school for an interview. I fingered the new charm necklace, meant to give me strength on the numerous upcoming teacher visits for my entry into kindergarten. After visiting so many schools, how was I to pick a favorite? I liked the school with the individual desks for kindergarteners, the school with the rocket ship in the playground, the school without uniforms, or the school that called teachers by their first names. Eventually we settled for the same school as my older sister, a K-12 secular private school.

The educational opportunities at the school were unparalleled. High quality instruction, small class sizes, PE, plenty of art supplies, a strong music program, an emphasis on outdoor experiences. My classmates were the children of doctors, professors, businessmen, famous Hollywood actors. Comparisons between me and my classmates started young, conversations about requests on Christmas and birthday lists. My father would respond to our moans and frustrations with a simple phrase, “there is

¹ Kwame Anthony Appiah, *Cosmopolitanism: Ethics in a World of Strangers* (New York: W.W. Norton & Company, Inc, 2006), 8.

always someone richer, smarter, and more beautiful than you,” and at my private school this phrase was more a statement of fact. These early experiences made me accept difference. Different abilities, different resources, different opportunities. Difference is inherent, a natural part of life. These differences unite us. Solomon concludes “to be entirely typical is the rare and lonely state.”² Yet, to survive the chaos of the world we create categories and place meaning on particular experiences and thoughts. We create cultural norms, use language to share common beliefs, and many go to great pains to fit in to society.

As residents of the universe, we all share similar origins. Every atom on the planet Earth is composed of elements from the universe. The energy of the universe is constant, chaotic, and forever changing. We exist because of the stress exerted by chaos in the universe; “the nitrogen in our DNA, the calcium in our teeth, the iron in our blood, the carbon in our apple pies were made in the interiors of collapsing stars.”³

Cosmopolitanism argues that we have two types of obligations. We are obligated to others; not just those we know, but those who also share the Earth. This obligation to others means we are obligated to learn about the practices and beliefs of individuals. By valuing other’s practices and beliefs, we value their lives.⁴ Cosmopolitanism embraces the chaos of the universe, our connection to other members of our tribe, and descendants of the “star stuff” of the universe.

² Andrew Solomon, *Far From the Tree: Parents, Children, and the Search for Identity* (New York: Scribner Publishing, 2012), 4.

³ Carl Sagan, *Cosmos* (New York: Random House, 1980).

⁴ Appiah, *Cosmopolitanism: Ethics in a World of Strangers*.

Without stress and chaos, we would still be stars. Our place in the universe is fleeting and insignificant when compared to the lifespan of the earth and stars themselves. The universe does not exist as a result of our being, but instead continues to exist despite our living; “there is no more purpose in the universe than we, as intelligent beings, put into it.”⁵ When I impose my own order and intent upon the world, I create new waves of energy that reach out and influence others. Do I create waves which radiate respect or hate? Do I prioritize one type of experience over another through my actions? At my Unitarian Universalist church we discuss how our actions have the ability to push on the arc of the moral universe towards justice. My actions determine the amount of justice in the world.

For behavioral therapists, one major source of difference between therapists and their clients is neurology. Autistic students experience the world much differently than their therapists. Experiences from my childhood, working for different horse trainers, and while hiking the Appalachian Trail have made me recognize how the practices of many Applied Behavior Analysis therapies aimed at helping autistic students instead do the opposite. ABA therapy exists in a world of difference: different behaviors, different thinking, different learning. To attempt to mold a person into a typical mold is to deny the shared ubiquity of unique difference. ABA therapists must accept differences, accept their role as leaders of justice, acknowledge the cosmopolite mindset. Instead of accepting differences, my experiences with ABA therapy placed great emphasis on minimizing differences, teaching kids skills how to “pass” in mainstream society, and

⁵ Alistair Sincliar, *The Answers Lie Within Us: Towards a Science of the Human Spirit* (Brookfield: Ashgate, 1998), 5.

ignoring the unique beliefs and values influenced by autistic neurology. As I move forward in my career, how do I bring about a more cosmopolite approach to behavioral therapy? The radical behaviorism developed by B.F. Skinner aimed to help individuals by eliminating disconnections of the mind and body. By working from a standpoint of acceptance, the goal becomes supporting and understanding an individual, a goal with no fixed end point. Instead of fixing individuals, we build awareness, knowledge, and skills of both the individual and society.

When I hiked the Appalachian Trail in 2013, I created a mantra for myself to deal with difficult days: Experience is universal, perception is individual. On the trail this mantra helped me transform a potentially depressing weather condition into an excuse to splash about and get soaked. Our perception of reality is the result of the coordination and integration of sensory information of both internal and external environmental stimuli. The skill of integration is based on past life experiences as well as underlying neurological capabilities. Perception is the result of learning and innate neurological structure.

Another common phrase shared on the Appalachian Trail is Hike Your Own Hike, *HYOH*. I first came across this phrase in the early days of the trail. For many people, hiking the Appalachian Trail is a life long dream, and so starting around early March, the trail becomes flooded with hopeful hikers. *HYOH* acknowledges the different abilities and goals of each individual hiker and the importance of recognizing these inherent differences. I would think *HYOH* when friends I had just met decided to hike late into the night, skip lunch, take a scenic detour, stop in town for a few days. *HYOH* is a phrase which depends on your perception of the world, and the goals and dreams one

decides based on that perception. After I completed the trail in late September this phrase continued to permeate my life and thinking. Each of us has own path and goals in life, and we must stay true to our own “hike” to achieve these goals and dreams.

In the fall of 2014 I decided to leave the horse farm I had been working at and move to Burlington to work as a behavioral interventionist. My entire life I have been interested in behavior, and my childhood was filled with trying to understand and connect to various dogs and horses I trained. Before I started my job I had very little experience with disabled children, the main clientele of my new job. My first day I watched my coworkers shape and teach different skills to my new student using the principles of Applied Behavior Analysis. I felt intrigue as I saw my coworkers use principles of behavior to shape and reinforce appropriate behavior. I felt shock as I watched our student become frustrated and erupt into an aggressive attack on herself and others, leading to restraint by my coworkers. The past few years as a behavior interventionist I have questioned the motives and intentions of others. As I look to my past, I see the experiences with my childhood dogs, time as a horse trainer, and lessons learned from school and the Appalachian Trail give me context to these dilemmas.

1.2 Why SPN?

Scholarly Personal Narrative as a writing style utilizes narrative storytelling, personal experiences, and scholarly perspectives. SPN is an interplay of connection to past events, connection to other writers, and connection to an audience. The Scholarly, S, represents connection to other writers and ideas. The Personal, P, is connection to past events and memories. The Narrative, N, is connection to an audience through storytelling.

Human beings are products of the universe, we all share the same composition and elemental foundations; we represent the miracle of star stuff. As the product of former stars, we are designed to resonate and come together. The connections between S, P, and N demonstrate the ability of individuals to resonate and share universal goals and dreams.

Why do I care so much about acceptance? Why can't I feel brave to share my ideas and trust that they will be accepted? Why do I feel the need to justify my beliefs with awkward references to other scholars? My own search for perfection, for acceptance influences my ability to share my own story. I only believe my own story when it is supported with endless facts and ideas of others. Until recently, I did not believe my ideas deserved to stand on their own, that my own opinion mattered. SPN writing has taught me to accept my own truths, and to share them with others. The power in my opinion does not stem from its plausibility or strong adherence to previously presented ideas, but rather due to the fact that it is my own idea. My story matters because it influences my current and future life.

Writing is a mechanism to process the raw experiences of life, to build connections and stories between past events. The raw energy of life stems from the inherent chaos of the universe. This chaos is constant, and only through writing can we impose a "narrative order on the chaos of our lives."⁶ Order is necessary to live a life of integrity; a life that is consistent, cohesive. Through narrative writing we begin to see our lives as a continuous story.

⁶ Robert Nash and Sydnee Viray, *How Stories Heal: Writing our Way to Meaning and Wholeness in the Academy* (New York: Peter Lang, 2014), 57.

Writing reinvigorates our souls by re-examination of life. Writing about my childhood is joyful, recounting the adventures with my pets, seeing my foolish and risky mistakes, smiling at the times I escaped unscathed. Writing about past challenges helps me recognize the threats to my integrity, and how those threats lead me to recoil and doubt myself. By writing about my past I create a path for the future. This trail takes me forward, up the switchbacks, to a new mountain, a new viewpoint. Without writing, I never would have learned to find the path even if I was standing at a marked trailhead. Writing is putting one foot in front of another on the trail to meaning. Scholarly Personal Narrative uses the stories of one's past to share universal themes and ideas with a larger target audience.

There is great power in putting our personal experiences into words. Several of the stories told in this thesis gave me strong feelings of anxiety, depression, and sadness to simply write about. While I could feel the history of these episodes when I worked on other parts of my thesis, I lacked true clarity and passion until I had written these events out in full. Hands shaking, I know others need to hear these stories. I believe there is a better way to help these children, and I hope to write my way into finding this truth by first finding the truth in my own beliefs.

SPN writing has taught me the importance of a community of meaning-makers, and the limitless capacity of that community to create and sustain one another. As an educator, it is my goal to create the same feelings of possibility for my students. Education needs to be holistic, meaningful and based on acceptance, flexibility and creativity. Similar to the process of SPN, individual growth requires knowledge of the self, connection to others, and connection to the world.

1.3 A Look Ahead

As a quarter-lifer, the lessons of my past have been intensely put to the test the past few years. Yet, these challenges informed me of my essential beliefs, my non-negotiable morals and beliefs. As I move forward in life, into the field of behavioral therapy, how do I stay true to these non-negotiable truths? Who do I wish to be as a professional?

I first explore stories of my childhood, my interactions with my pets, and the role of connection, empathy, and leadership. I then share stories from the past few years of my work as a behavior interventionist, and how I felt deeply troubled by these experiences. Finally, I explore positive experiences, and some values and beliefs I have learned by reading autistic narratives.

1.4 Identity-First Language

Through this paper I will discuss my interactions with autistic children and readings from adult autistics. Only recently did I recognize the importance of identity-first language. Researchers Dunn and Andrews discuss that the development of identity-first language is a more recent trend, differing from person-first language used by the American Psychological Association and medical journals. Identify-first language aims to build acceptance towards disability and allows the disabled individual to choose their identity, rather than letting others name their identity. As a result, identity-first language “promotes autonomy, agency, and indicates a decision to exercise choice over one’s disability destiny.”⁷ Identity-first language transforms a euphemism for disability,

⁷ Dana Dunn and Erin E. Andrews, “Person-First and Identity-First Language,” *American Psychologist* 70, no. 3 (2015): 257.

person-first language, into an identity. This thesis examines how neurology influences identity and therefore I will use identity-first language throughout this thesis. Most of the ABA therapists I have worked with try to suppress autistic identity, believing instead, that behavioral therapy can teach skills and mannerism associated with mainstream society. These therapists want to help their autistic students to “fit in” and “look normal”. By using identity-first language, I hope to illustrate how this conception of helping students is instead damaging to individual identity and the autistic culture. Identity-first language helps remind the therapist of the underlying neurological differences which influence an individual’s learning, concept of good and bad, and motivation.

By focusing on identity-first language, the autistic community challenges the biomedical perspective of autism, which uses a lens of disability and skill deficit and affects the values, beliefs and expected norms of the autistic community.⁸ Most behavioral programs for autistic clients focus on building social skills and skills related to cultural norms. Therefore, it seems increasingly relevant to build a sense of identity for autistic children, and to build a sense of connection to autistic communities.

1.5 Autism and Neurodiversity

For many autistic individuals, diagnosis of their condition is made at an early age by medical professionals. Only until recently, has autism been recognized as a neurological variance instead of a condition caused by “refrigerator mothers” and bad parenting choices.⁹ Autism, a neurological variation, represents differences in

⁸ Nancy Bagatell, “From Cure to Community: Transforming Notions of Autism,” *ETHOS* 38, no. 1 (2010): 33-55.

⁹ Steven Silberman, *Neurotribes: The Legacy of Autism and the Future of Neurodiversity*, (New York: Avery, 2015).

neurological interaction and processing of information. This neurological variation, as explored by neuroscientists Markram and Markram, is hyper-connective, leading to hyper-reactive and hyper-plastic neuronal circuits. This neurology leads autistic individuals' to experiencing the world with greater intensity and sense of chaos.¹⁰ On both the cognitive and sensorimotor levels, autistic brain registers more information than neuro-typical peers. The underlying neurological networks provide the foundation for discovering and interpreting new information. When the underlying network is hyper-reactive, and quickly able to form new connections, hyper-plastic, the underlying brain is constantly working, leading to a feeling of intensity in high-stimuli environments. Markram and Markram explain that because of the intensity of sensory processing, autistic learners actively avoid features of learning that are connected with past punitive experiences and instead seek out stimuli which are related to positive experiences. Autistic learners seek out secure worlds, which only allow positive stimuli and are devoid of surprises, since surprises further overload busy neuronal circuitry. As teachers, we must be aware of prior knowledge and the neuronal networks they represent.¹¹ As the teacher of an autistic learner, Markram and Markram suggest to surround a child with highly predictable routines and a calm environment free from unforeseen sensory and emotional events so that positive experiences are accumulated and punitive experiences are minimized.¹² A learner immersed in this environment will hopefully avoid

¹⁰ Kamila Markram and Henry Markram, "Intense World Theory-a unifying theory of the neurobiology of autism," *Frontiers in Human Neuroscience* 4, no. 224 (2010): 1.

¹¹ James E. Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, (Sterling: Stylus Publishing LLC, 2002), 92.

¹² Kamila Markram and Henry Markram, "Intense World Theory-a unifying theory of the neurobiology of autism," 19.

development of excessive sensory and emotionally driven brain development. For autistic learners, nature offers a calm, predictable environment suited for discovery and learning.

The portions of the brain typically associated with this hyper-reactivity are the limbic system and amygdala. The limbic system and amygdala are parts of the old brain responsible for survival response. James Zull, a brain and learning researcher, explains that the amygdala “is located in the back cortex. It helps decide meaning; it does not solve problems, create new ideas, or plan new actions.”¹³ Therefore, this neurological variation influences meaning making, not the ability to think creatively or autonomously. As such, this neurological difference in building meaning influences autistic learners through “atypical ways of thinking, moving, interaction, and sensory and cognitive processing.”¹⁴ The differences in thinking, moving, interaction, and processing are neurologically based and represent a new type of diversity: neurodiversity.

By building awareness of neurodiversity, we can understand our neurology influences meaning making which in turn influences many decision making processes. Instead of seeing autistic individuals as deficient in ability, instead autistic individuals see themselves as “a genetically-based human neurological variant.”¹⁵ Neurodiversity emphasizes the connection between all neurological variations, and that autism is just a portion of this diversity. Instead of associating autism with disorder, neurodiversity associates neurodiversity with genetic-based variations of neurology.

¹³ James E. Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 59.

¹⁴ Nick Walker, “What is Autism,” *Neurocosmopolitanism* (blog), March 1, 2014, <http://neurocosmopolitanism.com/what-is-autism>.

¹⁵ Ibid.

CHAPTER 2: BEGINNINGS

2.1 Mister

My earliest memories of horses involve sitting on the sidewalk with my older sister as we played with our toy horses. All of a sudden my sister turns and asks, “What’s your favorite animal?” I jump my toy horse over a crack in the sidewalk and reply “horsies!” Julia blocks my horse, saying “Horses are my favorite animal. Dogs can be your new favorite animal.” I felt a sense of disappointment, but knew that horses would just be my second favorite animal. This exchange between two sisters became constitutive to my identity, I now saw myself as dog person. As Johnson explains, language has the power to transform how we see ourselves in relation to others and ourselves.¹⁶ My sister became the authority of horses, and saw myself as the authority for dogs. I began to read dog books, enjoying classics such as *Lad: A dog and for my next birthday* received an encyclopedia of dog breeds. My position of authority became public, as I began pointing out dog breeds from the car, and that we soon would be getting an Australian Shepherd to replace the void left by our old Dalmatian who had died the year before. For many, dogs are simply members of the household, but for me, dogs were a way to prove my authenticity.

¹⁶ Peter H. Johnston, *Choice Words: How Our Language Affects Children’s Learning*, (Portland: Stenhouse Publishers, 2004).

My sister's words transformed my motivation toward animals. Suddenly, instead of only being motivated by internal forces, my interest in animals suddenly became associated with approval from my sister. If I loved dogs, she approved but if I loved horses, I felt guilt and fear of her disapproval. Because of my love for my sister, I acted on her proclamation and became devoted to dogs. My parents began to see me as a dog person. My friends began to see me as a dog person. I began to see myself as a dog person. My identity as a dog person was authentic, I did love dogs, but environmental stimuli influences each of us differently based on our individual experience. Facts are relative to the meaning we give them. As we navigate our environments, our brain deciphers, categorizes, and gathers information about the present world. Based on our learning history, and the innate structures of our brain, different features of the environment influence behavior.

The elementary school my sister and I attended had an annual pet and hobby show in early May. The previous summer we had gotten our first dog, and so my sister and I eagerly entered Mister, our Australian Shepherd, into the dog "show". The day before the show, a dog trainer came in and gave a free demonstration on dog training. My sister and I both attended, and afterwards at home, we picked out our favorite flavors of milkbones (taste-tested in earlier sibling adventures), and practiced sit, down, and stay with Mister eager for our upcoming performance. I prepared for the upcoming show, unaware of how my own desire for recognition and acceptance as a dog lover would lead to feelings of embarrassment and failure.

After an excruciating half day of school, it was time for the fair. I ran down to the playing field, scanning for my parents and Mister. We had arranged to meet at the doggy

kennels, where all the dogs in the “show” were kept for the day. Walking down the aisles I saw poodles, golden retrievers, Labradors, all straining at their leashes looking for their owners. I found my sister and dad waiting with Mister at the check in booth. Starting with Kindergarteners, each class got a chance to parade their dogs around the arena, and luckily I was in second grade and didn’t have to wait too long. Our turn finally came and my class entered the arena. As we walked around the perimeter of the arena, my eyes were on the judge who I wanted to impress with Mister’s obedience. All of a sudden I hear HEY! and look over to see Mister gobbling up a spectator’s taco lunch! Horrified, I pulled Mister’s leash and tried to regain control. I glance anxiously at the judge checking to see if noticed our snack break. I tightened my grip on the leash, as Mister sniffed the air, his nose exploring the possibilities at the school fair. As the judge approached us, I tensed with anticipation to show off our trick. I jiggled Mister’s leash and told him “SIT.” Mister lay down, inching toward another spectator’s lunch. I blushed, clenched my fist in frustration and accepted the judge’s attempt at positivity by complimenting Mister’s shiny coat.

Our failure was simply due to different goals and values. Mister smelled the tacos, I noticed the judge. Mister believed our purpose in the show was to find food, as any dog would believe. I believed our purpose in the show was to demonstrate our strong relationship and my authority and knowledge, as any competitive kid looking for approval would believe. Our different agendas changed the meaning we applied to different facts in our environment.

Our perception of the world creates and shapes our sense of reality, creates meaning, and influences behavior. Our sense of reality represents underlying fundamental

assumptions of truth about the world. Nash and Jang quote James David Hunter who argues that our perceptions, shaped by these truths, “act as a lens that highlights certain aspects of our moral experience as important or unimportant, relevant or irrelevant, good or bad, and right or wrong.”¹⁷ This lens grounds our view of the world. Our moral experience is unequivocally connected to our perceptual experience. Mister’s innate capability to detect scent meant that as we entered the show grounds, his nose smelled the plate of greasy, delicious tacos and characterized the showground as an important place. As a dog, a domesticated version of the wolf who evolved in packs, Mister also possessed a fundamental truth of respecting leadership. Clearly, Mister’s decision to eat tacos versus following my 2nd grade leadership skills demonstrates how reality helps guide decision-making. As I entered the show arena, my eyes focused on the position of the judge and the behavior of the other dogs in our class. Searching for indications of my success or failure led to my demise. Zull argues we “recognize how relative our facts can be and how their meaning depends on our individual experience.”¹⁸ My need to prove my canine authority meant that anything but absolute success represented failure. If instead I had viewed the dog show as a fun opportunity to show off my dog, I would have connected with the other members of my class who also struggled with their dogs. My sister’s words years before determined how I saw the facts of the dog show, and how this experience rattled my trust in Mister and my need to prove myself to others.

¹⁷ Robert Nash and Jennifer J. J. Jang, *Preparing Students for Life Beyond College: A Meaning-Centered Vision for Holistic Teaching and Learning*, (New York: Routledge, 2015), 37.

¹⁸ James E. Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 3.

Although Mister tested my sense of identity as a dog person, my failure represents a much larger issue of relationships with others who are profoundly different. I will never be a dog. I will never know what it feels like to smell a hot plate of tacos with the acuity of a dog's nose. The differences between me and a dog are significant as we experience the world in much different ways. Yet the ability to form a strong relationship exists because of the things we share, such as laying in the sun on a hot summer's day, a meal at the end of a long day. Mister and I each had a different perspective of the world based on our neurology. In order to find truth in the world, we must be willing to practice different perspectives. By learning to look for truth through different perspectives, we move closer to understanding the whole nature of truth. To look for truth is to embrace differences in perception. Just as much as one perspective on life matters, the comparison and connection between multiple perspectives brings greater truth to the world. One person's conclusions about truth based on their perceptions of the world will vary from the conclusions of others as their irrelative perceptual skills vary. Society benefits as multiple perspectives are embraced and compared for the views of truth they reveal.

2.2 Zoe

Communication is vital to relationships. Communication style determines the distribution of power, and whether members take into account others thoughts, wants, and needs (Bordas 2012). When I worked with Mister, I did not take into account his desires. Instead I communicated through his choke chain and leash, a clear one directional relationship. Our relationship failed to flourish into anything beyond reluctant obedience. When my family got a second dog, my motivation for interacting with dogs

transformed, as did my method. Our new dog taught me to be creative and flexible to the needs of the individual.

In the summer of third grade, my life changed forever. As my family returned from our annual vacation in Yosemite, we went to pick up Mister from his breeder who watched him during our absence. During the exchange, she pulled my mother and father aside and warned them of Mister's health, appalled at his recent weight gain. She suggested we consider getting Mister a companion and that we put him on a strict diet. My parents agreed, and a few months later we returned to pick up our new dog.

Our new puppy was much different than Mister. Named after the older sister in the comic "Baby Blues", Zoe, was a curious dog. The first day at our house Zoe demonstrated her curiosity and fearlessness. Zoe grew up in the high desert and had never seen anything but dusty prairie, and so when my neighbor put her feet in the pool, Zoe walked casually up beside her and hopped into the pool. Luckily swimming is instinctual, and she managed to scramble out of the pool, now aware of the different properties of water versus land. We all laughed at our new silly pup as she sprinted around the yard, rolled in the grass, and barked about the excitement of her new life. We had no idea that her curiosity would cause us endless frustration for the next few months.

Zoe, unlike Mister, came without any previous training. On walks, she would pull, choking and gagging herself on the leash, failing to grasp the concept that pulling was causing her such distress. My parents stopped taking her on walks. Without walks, she decided to create her own adventures, somehow escaping our yard through tiny holes between the garage and the fence to pestering the neighbor's dogs. When we finally were able to contain her, she started to torture poor Mister. Zoe tried so hard to get Mister to

play, but he was far too dignified and tried to ignore her into non-existence. Zoe responded by chewing off his collars hoping that Mister, laying despondent and unmoving hoping she would go away, would notice her. We gave Mister a metal dog collar, and hoped our puppy would mature into a complacent specimen like her older brother. Without training, Zoe was destined to be a mischievous unhappy dog, unable to participate in family outings. Zoe's misbehavior did not reflect a fractured, deviant inner being but rather an inability to communicate her needs and to have agency in her life. Every time she attempted to control her life, she instead encountered barriers: the end of the leash, the patched hole in the fence, a grumpy older dog who refused to play.

Ever since my early discussion with my sister, I had taken my assignment of dog lover to heart. My favorite movies included any dog related movie: Babe, AirBud , and 101 Dalmations were my favorites on movie nights. At the library I absorbed dog encyclopedia books. The page on the Australian Shepherd spoke candidly of the breed's trainability and tendency to be one person dogs. I realized that Mister was my father's dog; my dad was the rock that Mister could count on to feed him every morning. Zoe, however, existed in limbo, unattached to Mister or any family member. All of a sudden something clicked: I would train Zoe and prove her own intelligence and capacity as a great dog, and finally solidify my now authentic dog-obsessed identity.

The beginning of the school year was the same for both Zoe and me; a new year of education. For weeks I woke up early before school and took Zoe for walks. I taught her to sit instead of pull, stay instead of run, and to come when called. Very quickly she learned to listen to my instructions and respect my leadership since she trusted my ability to take her on adventures. Zoe's earlier disobedience was not her deviant personality, but

a lack of knowledge of how to communicate and listen to humans. In no time Zoe proved every previous assessment about her to be incorrect: she was smart, almost to a fault, but very willing to please and happy to finally have a job and a friend who took her on adventures. My goal with Zoe was simple: to have a friend. Instead of authority, I wanted connection. Each day we worked together we became closer and closer, and I began to see the importance of letting her make decisions about our adventures. We began to trust one another: I trusted she would eventually catch up after falling behind to sniff a bush, and she trusted that I would let her sniff and scamper if she paid attention to requests to not run off and come back when called. Soon she only listened to me, much to my sister's chagrin.

My passion for dogs became an obsession. I had discovered my ability to connect to dogs, to understand their needs and wants, and I became hungry to know more. Any trip to a bookstore required a visit to the pet section. My allowance was saved for dog books, equipment, toys. Soon I was helping out other families with their dogs, teaching them to walk nicely on a leash and some basic obedience. It was so easy, all I needed to do was first play with the dogs and make training a game. By playing with the dogs first, I communicated to them that training was fun and not simply about obedience. When I got older I joined an online chat forum for dog lovers. Through the internet I was able to connect with my "people", other dog lovers. I learned to see dog training through multiple lenses. I began to learn how nutrition, routine, and consistency influenced training. These early experiences with Zoe taught me to explore and search for new perspectives to better understand how to help Zoe thrive.

Communication with Zoe required creativity and flexibility. To find her motivation, I needed to think creatively and accept her needs and wants. was able to help her learn. Author Nancy Aronie writes that “creativity is staying very close to my heart, to my instinct, to my desire, to my truth, to my soul.”¹⁹ Creativity required acceptance of Zoe’s soul: her desires, perception, and capabilities. Acceptance requires looking for truth through multiple lenses, removing biases, and finding similarities. Acceptance is a mindset, a way of considering the world. True acceptance requires curiosity and questioning. To understand difference, one must question. Questions reveal different realities, and by learning about the practices and beliefs of others we act to find truth. When Zoe pulled, I asked myself if she was excited or maybe scared. When she stopped listening to me I questioned her trust and feelings of connection to me. These questions helped me understand Zoe, and her need for adventure and play in her training. Through questioning, I began to examine Zoe’s behavior as not simply a behavior, but rather a reflection of something internal. Her behavior communicated her needs. My success with Zoe taught me to view relationships as more than obedience but rather a history of communication and awareness.

2.3 Isabel

Communication is not only the ability to talk to others and share ideas, but also the practices, behaviors and decisions between members of a group. As Moon (2012) explains communication “involves more than speaking. It involves the constructs of the

¹⁹ Nancy Aronie, *Writing From the Heart: Tapping the Power of the Inner Voice*, (New York: Hachette Publishing, 1998), 152.

wider part of life of a person, conveying not only what they say but also who they are and what they believe” (2). After working with Zoe and a few neighbor dogs, I felt confident in my ability to communicate with dogs. The more I read about behavior, in both dogs and wolves, I realized the importance of developing a sense of cohesion between dogs and other members of the “pack”. These desires and needs, while common to many animal species, require different tactics to develop a feeling of connection. As I began working with horses, I began to learn the importance of patience, predictability, and learning the individual needs based on innate desires.

Despite my sister’s previous mandate, my secret passion continued to be horses. Horses represent the ultimate relationship of true connection and trust. As I finally got the chance to work with horses I realized they were much different than dogs. As flight animals, their interpretation of environmental stimuli is much more strongly influenced by their internal state. Fear transformed our sweet beautiful mare into an anxious, dangerous animal. With Isabel, we had to empathize with her needs, and see her communication style as a reflection of her internal state in order to keep her safe and happy. Our own communication style suddenly mattered much more. She was less forgiving to mistakes, and much more sensitive than Zoe or Mister. Building trust with Isabel required predictability, routine, and patience. Isabel taught me the limits of cerebral reasoning, and the importance of practical interactions and efforts. Only when we investigated how we interacted with her and what we did with Isabel, our actual practices, did we start seeing the changes we needed to make. Instead of comparing her to an external standard, we accepted her, and stopped treating her with apprehension and mistrust. As we began to trust Isabel, she began to trust us.

A retired former race horse, Isabel had doe eyes and a toe-flicking trot that convinced my mom, sister, and me to buy her. Isabel was very skinny, having just moved from Arizona to California. Her old owner assured us that she would gain weight once she settled. Little did we know that Isabel's condition reflected her inner turmoil and fear. We came back a week later with a friend's trailer, and the minute she arrived we realized our supposed sweet angel was instead a strong willed, anxious mare.

Isabel was a disaster when she first arrived. As our friend unloaded her from the trailer Isabel panicked: snapping her lead, and nearly splitting her head open as she scrambled backwards off the trailer. Separated from her previous horsemates, and confined to a new stall without neighbors she was frantic: calling constantly and pacing back and forth. Her former owner had reassured us that she would quickly regain the weight, but after a week of churning her stall into mess, we weren't so sure.

On the ground she was sensitive and tense, unappreciative of any brushing, and frequently breaking her lead when she was tied. We started using a chain on her halter to try to stay in control as she spooked and pranced around the barn. Although the chain made her more reactive, we were afraid to take it off and have no control over her. It seemed like each day she got worse, more likely to overreact to something and become impatient and pushy to get back to the barn. Soon we heard murmurs from our friend and our vet that we had made a mistake buying our now psycho mare. After about a month of owning Isabel my mom took her to the arena to help exercise off some of her pent-up energy. As Isabel did a few laps at the end of the lunge line around my mother, she suddenly panicked and began galloping around out of control. My mother lost her grip on the lead and Isabel's fear only increased as the line now trailed behind her. In her terror,

she leapt a four-and-a-half foot fence out of the arena and galloped towards the gate to the barn. Instead of returning to her stall, like any sane horse, she instead ran out the gate and headed up the road into the mountains, the line of the rope dragging behind her. Friends at the barn raced out after her, trying to track her down. My mother and I raced around in a stupor, not sure what to do, waiting to hear any news from those who had tracked her on horseback.

Finally, we got a call from a forest ranger saying they had caught a loose horse and had her up the road. With a sigh of relief, my mother and I drove up to see if the loose horse was Isabel. The ranger's office was only a mile away, and as we drove in we saw Isabel eating grass while being held by one of the rangers. Her rope was broken, it had snapped some time during her flight, and she was covered in road rash on one side after clearly falling on the asphalt. Relieved our horse hadn't broken a leg, we figured out a game plan. Without a trailer, our only option was to walk her back to the barn. Since I was only 14, I would walk Isabel while my mother and a friend each drove their cars, one leading and one following Isabel and me. That one-mile walk lasted an eternity. Some cars passed close enough that I could reach out and touch them, completely unaware of the perilousness of our journey. We made it back safely, without any unexpected panic from Isabel. I felt a rush of relief and pride towards Isabel for recognizing the seriousness of the situation and trusting our leadership back to the barn. The vet stayed for two hours stitching her up, and left us with a hopeful prognosis after a period of rest and recuperation.

The next few weeks Isabel transformed. Because of her injury, we were forced to re-evaluate Isabel's life, and recognize that former teachings and tips may not apply to

our special mare. TED talk author Adam Grant suggests we needed to “doubt the default,”²⁰ and stop comparing her to our friends’ horses. We stopped hoping she would become calm, and instead started treating her with more respect and consideration. She was not a placid beginner horse, but she was also not a wild maniac. We took the chain off her halter and switched to a rope halter to give us control. Isabel immediately appreciated the switch and started trusting us more as we led her around the barn. As Isabel calmed down during her rehabilitation, we realized the need to create our own expectations of Isabel and to also advocate for her needs and treat her with respect and consideration.

We now approached her care more holistically. As she recovered, we took her on multiple handwalks to help familiarize her with her new surroundings. On these walks, we would let her nibble whatever grass had survived the droughts of Los Angeles and sniff noses with other horses. These practices communicated our own relaxation and ease. We stopped treating her as a wild mare and instead as a mare who was very socially connected who needed confident owners. These walks taught us to trust Isabel. We changed her food, switching her off the supplements her old owners suggested and instead onto high fat, high fiber food. By taking into account her nutrition and its affect on her brain, we started to realize how every decision we made impacted Isabel. As Appiah writes “practices and not principles are what enable us to live together in peace.”²¹ Before her accident, we had tried to follow principles to help her succeed, but

²⁰ Adam Grant, *TED Talks: The Surprising Habits of Original Thinkers*, online video, 15:25, February 2016,

https://www.ted.com/talks/adam_grant_the_surprising_habits_of_original_thinkers.

²¹ Kwame Anthony Appiah, *Cosmopolitanism: Ethics in a World of Strangers*, 85.

these had failed. It was not the principle to love Isabel despite her flaws that made her improve, instead our observable actions which finally influenced our mare. Handing her treats over her door while she paced back and forth did not communicate tranquility, but taking her for slow, leisurely, social walks around the barn taught Isabel to relax. The change in our behavior affected Isabel immensely. Over the next few years we realized the importance of trusting our own instincts on how to handle Isabel. As we began to compete, and look for trainers to help us, I began to see how quickly people judged Isabel because she didn't fit into the standard expectation, and how this bias influenced their ability to see her talent and strengths instead of flaws.

The challenge with Isabel was communicating our acceptance. As Isabel was not a dog, her communicate style, her needs, were very different. A dog is a predator; a horse is prey. Isabel reacted with fear because we treated her fearfully. Isabel lacked a herd who would watch out for her needs and keep her safe. Once we accepted her needs, she began to trust us and relax.

2.4 The Klaus Schoneich Method

After finishing the Appalachian Trail in 2013 I moved back to California to make some money while living with my parents. While looking for a job I accompanied my mother to the ranch where she kept her horse. After connecting with some old barn friends, I was working semi-full time at the ranch riding horses and teaching lessons.

A ridden horse must trust a rider and subdue its own innate flight response. Horses are evolutionarily endowed with a sense of dread and terror when an animal clamps down on their back. Equestrians cinch on saddles and hop aboard, squeezing and

kicking their legs to communicate. Without trust, horses act instinctively from their fear. As horses react instinctually to their perceptual experience, many riders and trainers misname innate reactions as character traits. Labelled as stubborn, bull-headed, high-strung, flighty: trainers and riders then utilize harsher training methods in order to ensure their own safety when aboard. What is not understood is that riding horses is a relationship, both parties must trust one another.

My main client in California was Askell, a former high-stakes jumping horse. Her competitive past left her with stiff joints, tense muscles, and very reserved behavior towards humans. Her owner and I knew that she needed to relax and build loose, supple muscles. In early January, her owner entered her in a clinic run by a German Horsemaster, Klaus Schoneich. Little did I know that Klaus' was a rare trainer who examined the impact of neurology, instincts, and biomechanics in his training method.

Klaus started his clinic by working horses on the ground without saddles or bridles. With the horses contained in a small circular pen, he demonstrated how natural flight mechanics predisposed horses to excessive wear and tear on their bodies. As flight animals, horses moved much differently biomechanically when in a state of stress and fear. In flight mode, horses carry their heads high up to stay alert, brace with their shoulders, and use their hind legs for swift propulsion. Klaus then demonstrated his training method which taught the horse to shift from a flight state of mind to a play state of mind. In a play posture, the horse moved like a rainbow, back arched up supporting and balancing equally over the front and hind legs. In a play state of mind their balance increased, their eyes relaxed, and their biomechanics changed from stress to balance.

Klaus' clinic demonstrated the cumulative effects of stress and state of mind for a riding horse. Horses communicate through their eyes, body language, and demeanor. A rider must learn to listen to their horse. Pop culture for horse back riders frequently ignores common signs of distress and instead of providing education creates gadgets to stay in control. These gadgets include bridles with tight nosebands to keep a horse's mouth shut, reins which give riders increased leverage, and other harsh gadgets designed to increase the amount of pain a horse feels when they "disobey". Klaus' talent in understanding horses, and building a relationship based on trust, was based on his recognition of the values of a horse's first moral language, a language of survival. Zull argues that "there are two fundamental things that brains want: to be safe and happy. We use two parts of our survival machine to achieve these goals: our fear system and our pleasure system."²² Evolution equipped horses with innate startle and flee responses. Therefore, the first step of training is to create a feeling of safety in order to disconnect from the flight response. Klaus' systematic training therefore taught the horses increased balance through patience, body language, and gentleness. Through bending exercises, Klaus' horses moved in a posture of play, and this posture translated to a mental state. By focusing on honoring the fundamental truth of flight response, his horses came to work without fear of conflict. Klaus communicated to the horses through his body language, as other horses communicate. He trained them in a safe, contained environment to minimize potential stressors. Klaus practiced patience which showed "respect—a relational

²² James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 49.

property that is the lifeblood of a learning community."²³ Klaus demonstrated treating the horse as an individual, focused on their innate strengths, and established clear communication through respect as the building blocks of his training.

The horse trainers I worked for both liked Klaus' philosophy, but did not see the value of training from a standpoint of relaxation. In both Vermont and California, I was chastised for taking off the restrictive nosebands, and returning to more basic training techniques to re-develop a balanced and trusting partnership. When I worked in California, I was only able to use Klaus' teachings with two of the horses I trained. For the other horses I was paid to ride I had to train as my boss instructed. This meant ignoring the frustrated, disappointed, and conflicted voice which saw the coercive nature of many of these practices. I struggled to empathize with my boss when she would discuss "naughty" horses, as I just saw the horses fighting against forceful training. In Vermont, I had the same problem. Some of the owners who I worked with appreciated Klaus' training, other pointedly told me to ride more aggressively or denied my requests to remove some of the coercive equipment. When one of the horses I trained moved for the winter, I decided to move to Burlington and to stop training horses. Luckily, right before I left I connected with a horse friend and agreed to take his horse for the winter to either sell or buy myself in the spring.

When I moved to Burlington in the fall of 2014, I brought with me my new horse, Mara. Mara was a former camp trail horse and had never received formal training. I decided to restart her with Klaus' principles. When I first started working with Mara, she

²³ Peter H. Johnston, *Choice Words: How Our Language Affects Children's Learning*, 56.

would enter the barn with her muscles stiff, eyes tense, and spook at every tiny sound. I kept our lessons simple and made sure to never push her into a state of reactivity. Within a few short weeks, she realized that work was pleasant and aimed at helping her improve her balance. She entered the barn head lowered, muscles loose, and curious to our work. Despite taking three months to reintroduce her to riding, she quickly surpassed other horses in the barn in her training and ability to work calmly. Instead of working in a state of flight, she worked from a state of play. As I have continued to ride Mara, her resistance to training has decreased. For the first year I had to use treats to get her to open her mouth to take the bit; she now takes the bit willingly. She lets me catch her easily, instead of looking first to see if I brought a bucket of grain (which didn't always make her come to the gate either). The emotional scars of Mara's former life resurface suddenly at times, as a wind picks up across the field and she spooks and then panics at the potential repercussions. While working with Mara, not only did I have to earn her trust, but I also had to ignore the voice of self-doubt. My progress has been slow going, but constant. I stuck to my goals when training, stayed calm and focused, allowed Mara to determine our progress. After eight months I switched Mara to a hoof trimmer who I trusted and respected. I moved her to a farm where she received better care even though I am unable to ride as much in the winter.

Through my experiences with animals I developed a desire to use compassion to enrich and improve my human relationships based on knowledge of neurology and innate needs. After training several dogs, and my very reactive mare, I had become skilled at positive reinforcement and using clicker training to help develop relationships. Almost all of my work was done in private. Working with my dogs, my opinions were left mostly

unchallenged and mostly accepted by my family members. Because of my busy life, Isabel and I worked without the continual guidance of a horse trainer. As a horse trainer, my skills led trainers to trust my judgment and granted me some autonomy and independence in my training decisions.

CHAPTER 3: CHALLENGE OF A QUARTER-LIFER

3.1 Applied Behavior Analysis

When I moved to Burlington in 2014, I began working as a behavior interventionist. Our intervention plans were based on teachings of Applied Behavior Analysis. Behavior Analysis studies the principles of learning and motivation based on principles of radical behaviorism developed by B.F. Skinner. Applied Behavior Analysis, ABA, is the application of the science of radical behaviorism through procedures and technology informed by learning and motivation. ABA operates through basic tenants of science: description, prediction, and control. ABA focuses on behaviors of social significance by examining environmental variables and their relationship to behavior. Using the basic tenets of science, ABA therapists systematically evaluate variables involved in target behavior.

The main focus of ABA therapists is operant behavior. B.F. Skinner in *Science and Human Behavior* explains that operant behavior is a predictive description of a class of responses. The term operant “emphasizes the fact that the behavior operates upon the environment to generate consequences...The operant is defined by the property upon which reinforcement is contingent.”²⁴ As Skinner continues to explain, we continuously act, or use operant behavior, upon the environment throughout our lives. These actions create consequences, many of which are reinforcing. This reinforcement from the environment become conditioned with specific operants and “builds the basic repertoire

²⁴ B.F. Skinner, *Science and Human Behavior*, (New York: The Free Press, 1953), 65-66.

with which we keep our balance, walk, play games, handle instruments and tools, talk, write, sail a boat, drive a car, or fly a plane.”²⁵ While operant behavior is developed through reinforcement contingencies, operant behavior is signaled by specific stimuli, or discriminative stimuli. The operant behavior asking for the check at a restaurant is developed and maintained by receiving a check from the waitstaff. Yet this operant does not occur at random, and instead only occurs in discriminative stimulus conditions, or in a restaurant after eating a meal. Therefore, a full understanding of operant behavior requires knowledge of stimuli which reinforce the target response, and also the conditions which signal the availability of reinforcement to an individual. These are known as the antecedent and consequence conditions of operant behavior. ABA therapists design behavioral interventions to either replace, establish, or extinguish operant behaviors.

ABA relies on scientific attitudes to systematically approach the investigation of operant behavior repertoires. These attitudes include “determinism as its fundamental assumption, empiricism as its prime directive, experimentation as its basic strategy, replication as its necessary requirement for believability, parsimony as its conservative value, and philosophic doubt as its guiding conscience.”²⁶ By approaching operant behavior with these philosophical assumptions, therapists aim to improve and understand human behavior in socially significant ways free from personal, political, or economic constraints. These principles help therapists examine operant behavioral and identify existing functional relationships which maintain target operants. ABA therapists then

²⁵ Ibid, 66.

²⁶ John O. Cooper, Timothy E. Heron, and William L. Heward, *Applied Behavior Analysis*, (New Jersey: Pearson, 2007), 27.

design behavioral interventions which target a functional relationship and manipulate either antecedent and/or consequence stimulus conditions to extinguish, strengthen, or establish missing operant skill repertoires. The adherence to these fundamental scientific attitudes is critical to developing behavioral interventions which only act directly on the target operant.

3.1.1 Operant Behavior: A Three Term Contingency

Operant behavior, the focus of ABA therapists, is a three term contingency of antecedent, operant behavior, and a consequence. Many behavioral interventions focus on either emphasizing antecedent conditions, or increasing the amount of reinforcement following a target operant in order to establish or strengthen behavior. For example, when teaching my student Esme to cross the street safely, we first focused on emphasizing antecedent stimuli involved in crossing the street. We made flashcards of crosswalk symbols, the Red Hand and White Walk symbol. In the hallways of the office we would play a game of stop and go with these flashcards. As she became skilled at the game, we changed the flashcards, to instead a picture of a crosswalk sign, as seen across from the street, to more closely approximate natural conditions. Throughout this process, we heavily praised Esme when she responded appropriately to the walk and stop signs to reinforce the target operant of crossing the street safely. The last stage of teaching Esme to cross the street involved driving into town and practicing on multiple real crosswalks. At first, Esme became overwhelmed by the other people waiting to cross and the cars driving past. We brought along the flashcards to remind her of the cues she needed to find in her environment to cross the street safely. As before, we heavily praised Esme for

crossing the street only when the White Walk sign was displayed, and for waiting when during the Red Hand. Because the real world is much more chaotic, for the first few weeks we practiced crossing streets, we offered additional reinforcement, ice cream, after she had successfully crossed or waited for 7-10 instances. The success of this program was due to her ABA therapist's ability to accurately distinguish relevant antecedent stimuli, the White Walk or Red Hand, for Esme, as well as the additional reinforcement of ice cream when she had to discern these antecedent stimuli in much more chaotic conditions than the office.

For many behavioral interventions, target operants and their associated antecedent and consequences are easily distinguished. Yet, for some operants, the antecedent environment which elicit the operant response is not as easily distinguished. Skinner explains “[W]hen we say that behavior is a function of the environment, the term “environment” presumably means any event in the universe capable of affecting the organism. But part of the universe is enclosed within the organism's own skin.”²⁷ This internal and private environment influences operant behavior in the same manner as public environments, a three term contingency between antecedent conditions, behavior, and a consequence. In order to be effective, ABA therapy must target not only antecedent conditions but also the consequence to influence a target operant.

Peter, one of my past autistic students, was subjected to ineffective ABA therapy because of an unequal reliance on the consequence condition for a target operant. For Peter, his ABA therapist failed to acknowledge the antecedent conditions which elicited

²⁷ B.F. Skinner, *Science and Human Behavior*, 257.

his targeted operant: “inappropriate and bizarre comments.” When observing Peter and reading over his history, Peter’s ABA therapist jumped to the conclusion that his comments were reinforced by staff response, and therefore her suggestion to reduce this target operant was to ignore his inappropriate and bizarre comments. The simplicity of this solution demonstrated incomplete thinking, and incomplete use of science. The target operant was poorly defined and failed to address how staff could influence the target operant through antecedent environmental changes.

Some of Peter’s point-blank inappropriate comments about death or swearing were easy to ignore. Yet at other times the line of inappropriate and bizarre became much less clear. Peter would ask awkward questions such as Do you know that dogs sniff their owner’s graves? followed by a head tilt, chin jutting forward, and three long dog-like sniffs. Was this comment inappropriate? Peter would also ask about other students Why is Samson acting out? These questions were very hard to avoid answering, especially because Peter would probe us farther Why are you not answering!?. After several weeks of following his intervention, Peter’s inappropriate and bizarre comments had not abated, and his frustration at being ignored increased. The purpose of ABA therapy is to improve and understand human behavior in socially significant ways. Incomplete investigation into Peter’s behavior led to incorrect assumptions about the relationship between his behavior and the environment. After several weeks of following Peter’s behavior plan, I became frustrated and irritated at his lack of progress. Peter still drifted at school, not interested in engaging with his instructor’s comments or concerns. His only attempts at engagement were through his bizarre questions. Clearly there was some sort of internal

environmental condition which kept eliciting his questions despite a lack of reinforcement from staff.

One morning I woke up irritated and frustrated at my inability to connect to Peter. His actions throughout the school day highlighted his lack of trust or reliance on staff, and I felt that if I was able to connect to him somehow he would begin to trust me. When I biked to work I decided to respond to Peter's comments but only in ways which kept the conversation appropriate. Peter arrived at school, disconnected, pacing around his room and ahead of his instructors when we dropped off his lunch in the kitchen. I waited for my chance to respond, and as soon as he finished saying Do you know that dogs sniff their owner's graves? I asked him "What type of dog was on the grave?" Peter turned to me and exclaimed YOU RESPONDED! I repeated "What type of dog was on the grave?" and Peter quipped an Akita. This exchange was groundbreaking; Peter usually wandered the school without aim, seemingly deaf to the questions of the staff. After I answered his questions, Peter became more responsive to my requests and suggestions during the school day. Perhaps Peter's inappropriate questions were an attempt for social attention, the consequence that his ABA therapist had instructed us to prevent. Yet clearly, this social attention had larger consequences in Peter's behavior. Instead of strengthening the frequency of his inappropriate questions, responding to Peter increased his reception of teacher-directed conversation. In using science, we cannot ignore the desires of the spirit, the private environment, and its influence on operant behavior. By listening to Peter, and responding to his words I showed empathy "a signal that the listener may be

trustworthy,”²⁸ and perhaps addressed the internal event that kept eliciting his inappropriate questions. By overlooking Peter’s internal environment, Peter’s ABA therapist created a behavior intervention program which did not accurately influence a target operant. ABA therapy cannot ignore the importance of all three terms of any behavior. By only addressing the consequence condition, Peter’s behavioral intervention failed to change his operant behavior.

When I responded to Peter, I worked to increase my comfort by serving his needs. Just like when my family started seeing Isabel’s anxiety as an indication of her discomfort in her environment, I saw in Peter’s words a sign of some internal discomfort. In responding, I hoped to build trust and to increase his sense of safety and ease at school and towards staff. This required me to go against the wishes of his ABA therapist and my own hesitation at responding to his bizarre statements. My efforts paid off, and eventually his therapist revised her guidelines for interaction with Peter after more staff started responding to his comments.

3.1.2 Radical Behaviorism

The difficulty of interpreting the influence of the internal environment has perplexed scientists and influenced scientific conclusions. Skinner’s approach to behavior differed radically from previous scientific philosophies. Unlike previous forms of behaviorism, Skinner’s version aimed towards a science based on a “unified account of

²⁸Frank Levy and Richard J. Murnane, *The New Division of Labor: How Computers are Creating the Next Job Market*, (New Jersey: Princeton University Press, 2004), 85.

nature,”²⁹ which contrasts with previous models in which a “scientist humbly admits that he is describing only half the universe, and he defers to another world—a world of mind of consciousness—for which another mode of inquiry is assumed to be required.”³⁰ Believing the mind to be separate, mentalism argues that “a mental or ‘inner’ dimension exists that differs from a behavioral dimension.”³¹ One result of a mentalistic approach to thinking about behavior is the creation of explanatory fictions. Cooper, Heron, and Heward define explanatory fictions as “a fictitious or hypothetical variable that often takes the form of another name for the observe phenomenon it claims to explain and contributes nothing to a functional account or understanding of the phenomenon.”³² Explanatory fictions give a false sense of understanding of a phenomenon. An individual who has been mistreated in the past acts cautiously in the presence of their abuser. An explanatory fiction of this individual is that the individual acts carefully around abuse people because of their cautious personality. This explanation does not describe the variables responsible for developing or reinforcing cautious behavior. Therefore, in rejecting mentalisms and explanatory fictions, Skinner aimed to create a science of behavior which focused completely on searching for controlling variables in an environment as an explanation of behavior. This radical shift represents a fairly recent change in thinking about behavior. When I started studying Applied Behavior Analysis in 2015 I felt relief and connection to Skinner’s words after struggling with the effects of

²⁹ B.F. Skinner, *Science and Human Behavior*, 258.

³⁰ Ibid, 258.

³¹ John O. Cooper, Timothy E. Heron, and William L. Heward, *Applied Behavior Analysis*, 32.

³² Ibid, 7.

mentalisms, and explanatory fictions in my work as a horse trainer. Explanatory fictions are rampant in the horse world. Horses described as “hard-mouthed,” “anxious,” “difficult,” “spooky,” the list goes on. These explanatory fictions do not describe the past experiences of these horses which taught the operant behavior of rearing, kicking out, or bolting, the very behaviors which gained them their many false nicknames. Explanatory fictions represent a shortcut, a save from poor training. My work as a horse trainer was mentally and physically exhausting. I worked at a breeding farm in southern Vermont with over 20 horses. The physical exhaustion of taking care of the horses, some pregnant, some with foals by their sides, and a large portion as young horses with varying levels of education put most of my coworkers at the ends of their short fuses. Young horses are uneducated and reactive, and when handled roughly and inconsistently these horses quickly became dangerous leading farm staff to use harsh and punishing handling methods as well as sedation.

Naturally, each horse at the farm had its own explanatory fiction. The danger with explanatory fictions is they offer very little incentive to change a trainer’s behavior or attitude towards a horse and then also create inherent bias when handling a horse. I remember the first time I led one of the young colts out to his morning pasture romp. As I slipped his halter on, my coworker turned to me and told me her nickname for him “Monster” because he had reared up and struck her in the chest once when she had led him out. She suggested I wrap the rope over his nose to create greater leverage should he start to act up. While I wanted to feel confident leading him out, I knew that my coworker’s harsh handling methods maybe meant that “Monster” had learned to react intensely to his handlers. Therefore, any of my future attempts to calm him down would be

misinterpreted as correction and lead to an explosive outburst. I lead him out to the pasture, and simply ignored his rearing, bolting, and nipping and instead walked as fast as possible to get to the pasture. I quickly learned that paired with each explanatory fiction was harsh handling methods and general farm conditions. The young horses only got a few hours a day out of their stalls to romp around. Therefore, by the time staff went to lead them to the pasture, they had been sitting around in a stall for sometimes over 21 hours. Explanatory fictions ignored the antecedent conditions and the consequences that develop and maintain particular behaviors. I took all of my mental energy not to become reactive and afraid when working with a horse who was described as “psycho” and instead try to evaluate how to best help the horse not feel the need to act out and to not react in a manner which would teach the horse to react more intensely. Explanatory fictions ignore the history of behavior, the variables involved which lead to its creation.

Explanatory fictions also denied me the recognition of my efforts to improve the horses at the farm. When I arrived at the farm I was assigned to work with Dilly, a very large and sweet five-year-old warmblood. Dilly was already “broke”, and could be ridden on her own. To sell her, she needed to build strength and reliability as a riding horse. Immediately I was informed that Dilly was very difficult to bridle, she would throw her head up in the air. The current tactic was to leave her halter, used for leading around the farm, on under the bridle so that she couldn’t throw her head up. The first day I worked with Dilly I taught her to lower her head from pressure behind her ears for a treat. I had taught my childhood horse to perform this same trick to help with bridling and to help her stay calm. Dilly did great with this new skill until I got out her bridle, and she immediately threw her head up again. It took me over fifteen minutes to get her bridle on

the first day. Over the next few weeks Dilly and I kept working on lowering her head from a cue behind the ears. As she got better at this skill, her bridling went better and better. As bridling became less of a fight, and more a conversation of the head lowering cue, treats, and scratches, Dilly became easy to bridle. The minute I stopped having to fight her because she understood the head lower cue, bridling became easy. Dilly was simply afraid of the fight, not the bridle. When I was gone for Christmas, my supervisor rode Dilly. When I got back she remarked that Dilly sure had finally calmed down for bridling. It was at this moment that I began to lose respect and trust for my supervisor. Instead of realizing that I had taught Dilly a useful skill, she instead believed that Dilly had started to finally accept her job as a riding horse. I felt ignored and underappreciated. For weeks I had worked with Dilly using a gentle, patient method to help her overcome a training hurdle. Instead of recognizing my efforts, my supervisor built an explanatory fiction of “Dilly accepts her job as a riding horse.” While I can accept, and understand how a lack of recognition of my efforts, it is much harder for me to accept explanations of success or failure which disregard the influences of others. Where did Dilly learn to fight her handlers? The explanatory fiction of her accepting her job as a riding horse not only ignored my contributions, but also the detrimental contributions of others before me.

Skinner’s approach to behavior emphasizes congruency between private and public environment and behavior. Since radical behaviorism recognizes the contingencies between antecedent conditions, behavior, and consequence, behavior whether private or public is developed and maintained by contingencies which aren’t always accessible to the public. Skinner discusses how the development of self-awareness requires discrimination forced by external influences such as the community. For example, the

sensation of a tooth ache varies amongst individuals. What may be debilitating pain to one individual may be only a simple annoyance to another. Discrimination is a process of connecting specific environmental events to behavior. Therefore, the individual is only able to discriminate this sensation, an internal environmental event, through outward public behaviors such as holding their jaw or refusing to eat foods that require chewing. Without the community to elicit discrimination by the individual, discrimination of an internal state may never develop. Skinner explains, “self-observation is also the product of discriminative contingencies, and if a discrimination cannot be forced by the community, it may never arise. Strangely enough, it is the community which teaches the individual to ‘know himself’.”³³ For autistic individuals, who experience environmental stimuli differently than neuro-typical society, this discrimination is difficult to develop due to inherent differences between autistic individuals and their therapists.

One of my first experiences with ABA therapy included an instance where an ABA therapist tried to force discrimination of a feeling of pain. My coworker and I had just returned from a walk with our student. During the last half mile of the walk, she had begun walking irregularly, and in the car we slipped her shoes off and realized she had a huge blister. We both felt horrible, but the ABA therapist demonstrated that this event was a good way to introduce discrimination of a private event, pain, through questions. We then proceeded to ask our student “Does your foot hurt?” and then had her read a text prompt that said “Yes, my foot hurts.” We attempted to help our student “know [him]self.”³⁴ Yet, her ABA therapist explained that discrimination takes multiple events,

³³ B.F. Skinner, *Science and Human Behavior*, 260-261.

³⁴ *Ibid*, 261.

and that the ability of our student to build this discrimination was tricky, and for her to generalize all pain with the feelings of her blisters was unlikely.

Only when we learned of her blisters, did her unusual gait begin to make sense. Our student had a history of atypical movement patterns, which we were instructed to redirect by telling her to “walk normal”. Because I was a new staff member on the walk, we had not told our student to “walk normal” since her success with new staff was very low and my coworkers wanted us to have a good first outing together. After our discussion with her ABA therapist, and the practice trails of “Does your foot hurt?”, my coworker and I turned to each other with a look of relief. What if we had told her to walk normal, and instead of helping her we were actually ignoring the issue at hand by reducing her gait to a explanatory fiction of “abnormal”.

As I started taking online coursework to become an ABA therapist I began to constantly observe contradiction at my workplace. Behavior is very complex, and so I assured myself that most of the contradiction was due to the difficulty of coordinating behavioral services with school wishes, family wishes, and limitations of resources. Yet, now I see how my work perpetuated their own explanatory fictions of “normal” and how this lead to many interventions which ignored the history or purpose of behaviors for many of our students.

3.2 Perceptual Experience, the Learning Cycle and Influencing Change

Learning is the strengthening of neuronal connections between environmental stimuli and action. Zull's hypothesis of the cycle of learning suggests three ways to

influence neuronal connections: sensory, integration, or action pathways.³⁵ Operant behavior focuses on the antecedent and consequential stimulus conditions surrounding a behavior of interest. By manipulating the environment, ABA therapists hope to influence behavior by drawing attention to specific antecedent cues for behavior, as well as reinforcing the target behavior when it happens. Yet learning is much more than simply sensing and reinforcement, it is also about the ability to integrate information and turn it into purposeful action. The underlying structures, perception and the creation of private antecedent conditions all influence learning.

In *Eat, Pray, Love*, Elizabeth Gilbert sets out to save her life by experiencing the world in three different countries, each imbued with a different purpose. Gilbert's journey took place after a long and lengthy divorce, where her concepts of self were severely threatened, her core foundations were repeatedly broken, and she saw perpetual inconsistency in her life. Her journey toward healing closely follows the three steps of learning presented by Zull. In Italy, Gilbert focused on the first step of learning: sensing. Gilbert's choice to come to Italy was simple. To Gilbert, the Italian language gave her feelings of happiness, "every word was a singing sparrow, a magic trick, a truffle... the words made me laugh in delight."³⁶ Moving to Italy, she took a radical step in redefining herself by submersion into that which she found wonderful. Sensory experience created an immediate change for Gilbert. Elizabeth Gilbert's transformation from her experiences in Italy demonstrate the truth in Zull's representation of learning and also validate his

³⁵ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 15.

³⁶ Elizabeth Gilbert, *Eat, Pray, Love: One Woman's Search for Everything Across Italy, India and Indonesia*, (New York: Penguin Books, 2006), 24.

caution that learning does not occur through actions on individual steps of the cycle, but rather that the entire cycle must be completed. With this in mind, we must recognize the importance and limitation of sensory environment.

Changes and chaos in our environment can quickly unravel our assumed progress. After hiking for five and a half months on the Appalachian Trail, I felt assured in my desire and commitment to recognizing simple beauty and living simply. Three and half years later, however, I can see the strain of remembering those lessons when I am immersed in my work and my mental resources are devoted to keeping up with pressures from others. This past August my partner and I set out to hike Mt Hunger. As we neared the summit the smell of alpine spruce, cold air, and the sensation of open sky reminded me of my state of mind during the Appalachian Trail. As we arrived on the summit I was overcome with emotion, and cried with the sadness and joy of rediscovering the sense of accomplishment and peace that I had felt on the trail. Repeated exposure to a particular sensory experience causes physical changes in neurons, priming them to respond by increasing or decreasing their sensitivity. Yet without the correct environmental stimuli, these neurons remain in a neutral state, and the feelings they are attributed to remain disconnected from sustained change. Zull argues that in order to create lasting change, learning, these stimuli must become integrated through reflective observation and the creation of abstract hypothesis about future action. Integration is key to learning.

The second step in the cycle of learning, and sustained change, is integration. This step of learning is a process of transformation. Zull writes that transformation of

experience is when “information in the brain is changed into understanding.”³⁷ Our sensory organs gather auditory information and arrange it into patterns of language, visual stimuli quickly become an image of traffic caused by a car stuck in the snow instead of a sudden barrage of red lights. Through this integration we gather meaning about the world and plan our future behavior. The step of integration is constantly working, taking sensory information and arranging into a meaningful idea which we can plan future action around. The process of integration is critical in our ability to create lasting change in our lives. The decisions made from reflection and abstract reasoning greatly inform our actions and the strengthening of neuronal connections. As Zull explains, the active testing of our abstract hypothesis cycles right back into concrete experience. The cycle of learning can become a cycle of not-learning, if incorrect conclusions are reached and constantly performed. Influencing integration is key to creating lasting change.

Narratives from autistic individuals highlight the differences in sensory experience and how these differences influence learning. Judy Endow explains that "an autistic brain means the connections between areas of the brain are weak making it difficult for the brain to pull together information from the various brain regions."³⁸ Sensory information becomes distorted, sometimes amplified and for others it becomes quieted. Individuals can be hyper or hypo sensitive to their environments as their brains struggle to integrate information. In the video "Carly's Café" made by the

³⁷ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 33.

³⁸ Judy Endow, "Autism and Consequences," *Aspects of Autism Translated* (blog), June 18, 2016, <http://www.judyendow.com/autistic-behavior/autism-and-consequences/>.

autistic author, Carly Fleishmann, Carly conveys the autistic experience. Carly is unable to produce verbal speech, and the video starts with her father misinterpreting her drink choice. As she sits waiting in the café, the video suddenly zooms in and amplifies the sound of the espresso machine, the jingling of bells on the door, the sound of her sister sipping coffee.³⁹ Carly demonstrates how disorienting sensory input disrupts her thinking and her actions. This perceptual experience strongly informs her definition of pleasant versus unpleasant experiences, as well as demonstrates how easily her brain slips into survival mode as the chaos increases. Organizing the chaos of an environment is a skill at integration. One way to organize the environment is by replacing exogenous input with self-directed endogenous sensory input. Behaviorally, this input is described as stimming.

3.3 Self-Stimulatory Behavior aka Stimming

A few weeks ago one the kids I work with, Esme, and I headed over to Healthy Living for an adaptive cooking class for teenagers. Usually when I hang out with Esme after school, we walk my dog and work on communication skills through play, as well as adaptive living skills. Besides Esme, there was only one other kid in the class who had an aide with her. This young lady, Catherine, had just finished washing her hands and was walking over to pick a work table, her aide close behind her. Esme was calmly taking in the sights, which gave me a chance to spy on the other aide. I determined she was a Behavior Interventionist, BI, by her clipboard, box of edible reinforcers, and a clicker. These are all tools of ABA therapy, used to shape and reinforce behavior.

³⁹ Carly Fleischmann, *Carly's Café*, online video, 2:18, May 24, 2012, <https://www.youtube.com/watch?v=KMDGvquzn2k>.

The class instructor who handed out bowls and sprigs of thyme, instructing the class to pick off leaves to make focaccia bread. Esme did very well, realizing what she was supposed to do with only minimal modeling on my part. Part of my curiosity about Catherine's aide was due to my former role as a BI with Esme. I thoroughly enjoyed working with her now as a caregiver, and being able to attend activities such as this cooking class, where I wasn't beholden to external pressures about how Esme was supposed to behave or act. She was free to be herself, just as long as she stayed safe and respectful of others.

Right away Catherine was overwhelmed by the class and began asking multiple questions, concerned about the task and about finishing on time. Her BI working diligently to help facilitate her ability to get answers from the teachers, and reassured her that they would finish the bread by the end of class in one hour. The BI did excellently. She was capturing and reinforcing all the appropriate social skills needed to ask questions, and giving her indirect suggestions of how to acquire the information she needed. While I was impressed, I was also annoyed. In a class full of other mostly autistic teenagers, the behavior shaping of the BI felt awkward and unnecessary. This class was an informal setting, adapted to kids with special needs so they could feel comfortable in the space. When we introduced ourselves at the beginning of the class, one of the other kids stood at the window, counting cars, until he was comfortable enough in the space to participate. Greg, the teenage boy next to me who I also hung out with occasionally, sang and hummed during the entire class. This class was organized to allow the participants to proceed at a pace that was comfortable to them instead of being constrained by neuro-typical cultural expectations of time and productivity.

Shortly after finishing the focaccia bread, Esme decided to try to woo me into leaving so we could go play at the park. I gave her attention to help her wait patiently. Waiting is a difficult skill for all children, but especially children with unique environmental sensitivities and those who have anxiety around schedules. All the kids were doing great waiting for the bread, and Catherine was no exception. While she sat, she played with her hands, forming them into various shapes like a heart and the powerstance by Goku from Dragonball Z. I felt anxious, as my past experience with ABA therapy has focused on eliminating this sort of self-stimulatory, stimming, self-regulatory behavior and labels it as “socially inappropriate”. Her BI looked over, clipboard in hand, and redirected her behavior saying “quiet hands please”. After the BI redirect Catherine, she retorted “Why? I am just doing this my hands”. My heart plummeted, this teenager was aware of her own body and yet was being redirected as if she was acting inappropriately. In a room full of kids doing their own thing, why did Catherine have to sit quietly with her hands folded in her lap: what is the purpose of this therapy? Why couldn’t she move and hold her body in ways that increased her comfort and sense of ease in the class?

My mind raced over memories of my past student, Clara, who frequently tried to stim throughout the day and how negative these experiences were for everyone throughout the day. Clara was rarely happy, and instead was visibly stressed and anxious. Clara almost always became upset by staff redirecting her self-stimulatory behaviors, which were not dangerous to herself or others. Yet as a result of staff redirecting these behaviors, Clara would then become agitated and her behavior would escalate to the point of needing restraint, sometimes lasting hours. Her ABA therapist insisted that we

intervene on any stim behaviors to keep Clara and ourselves safe. I eventually quit because of the oppressive nature of this behavior intervention, and the lack of consideration of Clara and her right to engage in behaviors that improved her sensory experience.

Stimming has multiple functions for an autistic individual. Autistic blogger Amythest Schaber explains that autistics stim for “self regulation, to seek sensory input, and expression.”⁴⁰ Many autistics believe that ABA therapy which prevents self-stimulating behavior is oppressive, and that targeting of such behaviors is unethical. Moving and adjusting our bodies allows us to replace bad sensory input with good sensory input. Zull shares “[W]hen we reflect, we seem to do better if we shut out sensory experience....and we often begin some “mindless” activity, like pacing, knitting, scratching our head, or rubbing our chin.”⁴¹ For some, like Judy Endow an adult autistic, her neurology enabled her to see light interacting with water particles rising off the ground and in the air. This perceptual ability helped Judy Endow learn how to organize the chaos of her sensory world, through the repetitive actions of chasing and trying to catch her “sun sparkles and world tails.”⁴² Judy Endow found it pleasant to engage in these behaviors, and this feeling was completely based upon her neurobiology. The chaos of visual information became orderly as she learned a method to integrate the information

⁴⁰ Amythest Schaber, *Ask an Autistic #1-What is Stimming*, online video, 10:58, January 25, 2014, <https://www.youtube.com/watch?v=WexCWZPJE6A>.

⁴¹ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 167.

⁴² Judy Endow, “The Predictability, Pattern, and Routine of Stimming,” *Aspects of Autism Translated* (blog), March 5, 2016, <http://www.judyendow.com/advocacy/the-predictability-pattern-and-routine-of-stimming/>.

through repetitive catching motions. For autistic individuals, stimming is strongly connected to cultural identity.

For autistic individuals, stimming is not just a means to organize social information, but also a means of expression a common cultural viewpoint. Anthropologist Nancy Bagatell describes watching autistic individuals socializing through stimming: "I observed two men sitting near each other. One man was tapping his fingers in a rhythmic pattern while the other man rocked back and forth in time. At first glance, these motions appeared disconnected, but after a few minutes, I noticed how synchronized and almost balletic their motions were."⁴³ Shared experience is critical to building community. When we are able to see ourselves within a community of others, we become more aware of our own identity and place in a culture.⁴⁴ Stimming benefits autistic individuals, through sensory regulation and social expression and interaction, and yet my experiences with ABA therapy all have aimed to decrease this multipurpose behavior.

By focusing on self-stimulatory behavior, my old place of work decided how an individual should learn. They created their own explanatory fiction about learning. Instead of working to increase skills to facilitate daily challenges in their autistic clients, these ABA therapists actively focused on decreasing established skills used to help navigate the world. Because we prevented Clara from integrating information from her environment in a personally meaningful way, we also prevented her from learning. Clara

⁴³ Nancy Bagatell, "From Cure to Community: Transforming Notions of Autism," 39-40.

⁴⁴ Juana Bordas, *Salsa, Soul, and Spirit: Leadership for a Multicultural Age*, (San Francisco: Berrett-Koehler Publishers, Inc, 2012), 52.

was only able to perform certain tasks in specific environments, much like Elizabeth Gilbert was only able to relax while in Italy before she worked on her integration skills.

3.4 Stress, Environment, and Success

Beep beep beep beep. I quickly turn off the alarm on my watch. I snake my arm out of my sleeping bag, reach down to my dog curled up between my knees. Scratching Gromit behind the ears, he stiffens then stretches his body arching his back and wiggling closer to me. I maneuver my other arm out, arch my back and stretch my arms. Gromit digs his nails into my sleeping bag, pulls himself closer to me and lets out a MGM caliber yawn, softened by a puppy-like yowl at the same time. I listen for rain, thankfully it has tapered off overnight but I can see the tent is wet. Luckily for me, everything else I own is already wet as well from the endless rain and river crossings the past few days. For backpackers, the difficulty of wet gear is keeping it away from dry gear. Since most of my gear is wet, packing up won't be tricky. We pack up quickly, both in our bare-feet as I avoid putting on my still-wet shoes. Breakfasts are carefully portioned out, eaten way too quickly and we head out before we both convince the other to dip into future rations. I look up at the familiar white blazes and set off with big goals for the day, determined to out hike the rain and river crossings. Based on the guidebook, I am only 10 miles from some higher, drier terrain. Gromit totters along behind me, his leash tugging every few steps as he tries to pee on every bush from Georgia to Maine. We move briskly, getting into a rhythm which distracts me from my painfully cold shoes. We soon come to a descent, I giggle at another error of "Awol" the writer of my guidebook for failing to mention this dip so early in the day. Climbing up the other side of the ravine we come to

a river. Puzzled, I pull out my guidebook. Based on his guide, I was free from terrifying river-crossings for at least 4 miles, and this one looks eerily similar to the last river crossing the day before. I turn to Gromit who is straining to sniff a low shrub. Suddenly it dawns on me, this is the same shrub where we ate our post-river crossing snack the day before. In our haste to leave camp we turned the wrong way and had just spent the last hour walking back towards Georgia. Gromit ceremoniously pees on a bush, we do a 180 turn, and start heading North for the first time that day.

Our brains are challenged with massive amount of data to encode throughout a single day. Not only do our brains work tirelessly to decode environmental information external to our bodies, it must also integrate internal states. By the final days of the trail, my internal state was chaotic. Extreme elation, excitement, sadness at finishing the trail contrasted with the intense fear of thigh-deep river crossings, the threat of wet gear and bone chilling reality of freezing socks and shoes. These internal worries and fears greatly influenced my ability to integrate external information of the trail. I should have recognized Gromit's hesitance as I turned left instead of right, the sudden descent early on in the day. Yet, the stress of my internal environment caused my brain to take shortcuts by relying on the simplest information of white blazes and ignoring contradictory information. My error was not a simple lack of awareness, but instead the emotional core circumventing the processing of external information. Luckily my error did not cause me much further frustration as I felt connected to the other hikers I had met throughout my five-month journey also walking south inadvertently.

Sensory integration requires the coordination of small pieces of information into a larger more meaningful idea. The brain is constantly sensing information, integrating

inputs, and executing an action plan.⁴⁵ The step of integration is critical to developing future plans of action. Since learning occurs through action, integration is a critical step in the learning process. Without thorough integration, sensory information remains either meaningless or overwhelming. A learner must be able to extract meaning from sensory input through integration to plan future behavior.

For an autistic learner, even simple events such as the daily transition at drop off requires months of learning to become less chaotic and challenging. Transitions involve huge influxes of new sensory information, as well as an out flux of old sensory information. Therefore, the brain must not only adapt to new information, but completely abandon strategies used to regulate prior sensory information. As expectations and priorities change through the transition. As I worked with my various students at the behavioral firm, I started to recognize how modern society created barriers for many autistic learners.

Its early October, and recently my team has decided to make a major change for the kindergartener I work with in northern Vermont. My friendship with Giselle is still rocky, but gaining ground each day. My relationship with her mother is luckily better than many others on the team, I hope based on reports back from Giselle, but I suspect it is because I share a name with her older daughter. Today, instead of being dropped off at her small workroom down the hall, (nicknamed disparagingly “the closet” by her mother), Giselle instead will be dropped off with the rest of her class. Anxious, I assume a calm confident demeanor. I struggle not to peek my head around the corner of the

⁴⁵ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 16.

classroom to check for Giselle's mother. Finally, they arrive. Giselle enters the classroom, tightly gripping the coat-tails of her mother's jacket, looking at me apprehensively from behind her mother. Giselle remains frozen while other members in her class hang up their coats and backpacks unaware of the chaos of their talk and laughter. I remain neutral, allow her mother to lead. Her mother helps her out of her jacket, hangs her backpack up for her, and tries to make small-talk with her teacher. Its clear her mother wants to desperately believe that her daughter will soon run off and play with her classmates on their arrival. Giselle's classmates line up at the whiteboard to practice the alphabet letter of the day, and learn what they should do until morning circle time. Giselle still clings to her mother, hugging her tightly as her mom begins to pry her away. Her mother acknowledges me, and pushes Giselle out from behind her towards me. I kneel, reach my hand out towards Giselle, and tell her I love her leggings and hair. Mute, she looks back at her mom and I slip on her apron which signals we are now working together and earning tokens. Her tokens are a way of giving her tangible reinforcement throughout the day.. She cries out for one more goodbye hug before her mother goes, and clings to the door as her mother walks off.

On the drive home I think of Giselle's day. Shortly after her mother left, she tried to bolt from the classroom. Part of her transition plan is to allow her to leave the classroom, but she has to ask first. We also try to not honor her request if she asks while trying to bolt past staff or push through them to get to the door. Once we got to the hallway, she began sprinting to her classroom. I prayed that her mother had already left, and was not hanging around the office. Months before her mother, upset with Giselle for missing the field trip, came and yelled at Giselle in front of me and forced Giselle to hug

me. We missed the field trip because Giselle had refused to leave her small workspace. Luckily, her mother was not in sight and I managed to get Giselle to ask to enter the workspace in a calm voice after her bolt down the hallway. The rest of the day was a mix of running from the classroom back to the workspace, some moments of cooperation and peace in the classroom, and a lengthy task refusal to leave the playground when recess ended.

A learning environment affects learners in a multitude of ways from the present moment, to the future. An environment connects an individual, builds meaning, and can act as a safe place for growth and discovery. Yet, an environment can also have deleterious effects on learners, especially autistic learners who are challenged by sensory stimuli and need additional time to allow for integration of information. By insisting that Giselle now be dropped off at her classroom instead of her workplace, her mother unknowingly interrupted the fragile routine that Giselle had developed at school. When she started the day in the workroom, she was able to transition to working with me more readily, without the noise of her classmates and the sensory chaos of her classroom. While helping Giselle through the transition, which took several months, I couldn't help but wonder how much stress we were putting on Giselle for the sake of her mother and for the school. I would think of all the academic lessons which she missed out on, for the sake of "integrating" her into the classroom. While coping with society is a necessary skill for autistic children, the field of education must also recognize the demands it places on children as well.

Standards models of education are based on neuro-typical brains. Neurobiology impacts learning and teaching practices are targeted for learners with neurotypical

sensory integration skills. In moving to her new classroom, Giselle was faced with an immense challenge. Her classroom was large, with a multitude of stimuli challenging her. The classroom was not a comfortable space for her, and she had spent the past year learning how to escape from this noxious environment. With this challenge also came a transition in expectations of behavior and support. With her mother, Giselle was hesitant, hiding in the shadows, performing only when pushed forward. Because Giselle's learning process was interrupted by her integration challenges, and the emotional transition of school drop off, she had to "rely almost totally on their sensory and memory brain."⁴⁶ Her sensory and memory brain gave her information, but it did not lead to knowledge about how to act in her environment other than to survive. Instead of forcing Giselle into new situations, we worked to help strengthen her confidence and communication skills. Our only requirement for Giselle was that she remain safe, and use language to communicate her needs. Yet just like when I was hiking the Appalachian Trail, life stress can complicate even the simplest decisions.

Giselle would become panicked in the classroom, bolt towards the door. Her brain was in damage control, she was overwhelmed by the noisy, bright, spacious classroom and was unable to communicate with the same skill as when in her smaller workroom. For Giselle, dropoff at school developed neuronal connections of apprehension, fear, sadness and the environmental stimuli of bright lights, noisy kids, and unpredictability. Therefore, not only was Giselle hindered in her ability to make considerate choices due to

⁴⁶ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 33.

her emotional state, but each drop off strengthened neuronal connections between feelings of apprehension and her classroom.

All products of the mind come from the brain and its interactions with the body and the world.⁴⁷ When learners disengage their minds and bodies from the environment, learning cannot occur. When an individual is in survival mode, it is easy to miss obvious signs such as walking the wrong way on the trail, or the ability to engage in previously mastered tasks such as communicating needs.

When a parent learns their child is on the autism spectrum, or any other diagnosis of disability, their worlds change dramatically. They enter the world of disability and navigating IEP goals, rearranging their expectations of their lives. For many parents, marriages fail from the stress of dealing with the many challenges, and others must abandon their careers to help support their child. For many, remediating the current problem revolves around reducing “symptoms” of autism, which is frequently achieved through pharmacological intervention. In treating the “symptoms” of autism with psychotropic drugs, sedatives and other medications prescribed for other associated diagnosis, families are reliant on past ideology of “curing” autism instead of supporting this unique neurobiological perspective. Children and families associated with autism diagnosis are disabled in relation to mainstream society. They occupy their own subculture⁴⁸. Subcultures are seen as in opposition to dominant culture.

⁴⁷ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 6.

⁴⁸ Ken Browne, “Culture and Identity,” *Sociology for AS AQA*, (London: Polity Press, 2012), 32.

Many subcultures are portrayed as less worthy. Disability is a label main stream society targets as substandard. Even just recently the film “Me Before You” sensationalizes and casts a horrible cultural lens upon disability. In the film, the main plot centers around a female protagonist attempting to convince the male protagonist to not end his life because he is disabled. This movie sends the message that disability is worse than death! I believe that almost all disabled individuals do not see their disability as worse than death. This sort of film really affects the way culture sees individuals with a disability, and instead of fostering a multicultural perspective, it instead creates a separationist relationship, where disabled individuals’ culture is meaningless and without consideration. The autistic culture is not a voluntary membership; instead it is imposed by biological circumstance. Instead of possessing a cultural language which is “passed on from one generation to the next,”⁴⁹ members of this subculture must constant recreate and search for other members while navigating a world that constantly tries to “cure” them of their cultural perspective.

3.5 Behavior Support Plans

When I first started working with ABA therapists, I loved the idea of a Behavior Support Plan, BSP. BSPs are created by ABA therapists to act as a reference for staff when working with each client. The BSP’s goal to is to ensure continuity between staff members in teaching and managing challenges. I loved the concept of everyone approaching a problem with the same mindset, and the desire to minimize chaos and

⁴⁹ Ken Browne, “Culture and Identity,” *Sociology for AS AQA*, 29.

unpredictability for a student. Soon I realized that the language of a BSP strongly influenced staff members in both positive and negative ways.

The BSP for one of my clients, Clara, was focused on managing challenging behaviors, and placed great emphasis on eliminating her ability to escape unpleasant experiences. This caused her staff and ABA therapist to see only the negative in Clara. Mindset is critical to influencing ideas and perception. Solomon quotes Miguel de Unamuno, writing “[I]t is not usually our ideas that make us optimists or pessimists, but it is our optimism or pessimism that makes our ideas.”⁵⁰ Clara’s BSP created a pessimistic outlook towards her abilities in those working with her through its focus on her negative attributes and traits. When I drove to work I would dread days with Clara, her negative team, and the overall atmosphere of her team. As I began to interact with Clara, I would feel a wave of happiness and relief wash over me as I focused on her positive behaviors, and looked for opportunities to give her tokens and praise. Yet this euphoria was frequently short-lived, as my coworkers would interrupt by pointing out a negative behavior I had failed to correct, or by interjecting to correct Clara even when I was lead staff. Their actions were not due to their own distrust of my abilities, but rather the language of her BSP which stated “when in doubt, call it out”, meaning that if we thought Clara was behaving inappropriately we should immediately redirect her to behave more appropriately. The rhetoric of her BSP created a feeling of mistrust and suspicion of Clara, and the need for vigilance to keep her from acting as she wished.

⁵⁰ Andrew Solomon, *Far From the Tree: Parents, Children, and the Search for Identity*, 24.

After college when I worked at on a horse farm in Southern Vermont, I read the book “The Happiness Hypothesis” by Johnathan Haidt. This book described the history of happiness, and how research had shown that individuals who look for negativity in the world are more likely to find negative events, as compared to individuals who look for the positive. I frequently thought of the psychological exercise where participants are told to count the number of passes between a certain color team during a specified amount of time. While the participants are counting passes, a man dressed like a gorilla comes on stage, waves to the audience and walks off. Very few participants ever notice this gorilla-man because of their intense focus on another variable in the environment. Just as the gorilla went unnoticed, we will not see the good in our environment, or the people we are helping, if we are poised to see the bad.

It’s Tuesday which means it’s a doctor visit day. We arrive early at Clara’s house so we can be at the doctor’s office before they start seeing other patients. During her visit, a nurse comes and measures her height, weight, and blood pressure. We practice these skills nearly every day at the office and go to the doctor every Tuesday. Practice and exposure are key to helping Clara succeed in this basic task at the doctor. Future goals include a blood draw. As my coworker and I walk up to the front door, we hear a shriek from inside: not a good sign. We let ourselves in and head to the kitchen where we usually start Clara’s programming. Her mom comes around the corner looking frazzled and lets us know that Clara is having a bit of a rough morning, but is calm right now. Within moments Clara comes downstairs and sits in her chair ready to begin. Sometimes on rough days, Clara starts work eagerly, looking for some predictability and routine. We leave her house without an incident, my coworker and I give each other a look in the car

through the rear-view mirror. I sit next to Clara in the back of the car, standard protocol for the staff member who is working with her. We trade off every hour, switching between data recording and teaching. As we walk into the doctor's office, we find a seat in the waiting room. A nurse lets us know they are ready, and we follow her back to a room. Luckily we got the larger exam room, something we had to let the staff know a few weeks prior when they put us in a small room, a safety hazard should Clara become upset. As we walk into the room, Clara turns to my coworker and says "Back to car". We usually honor this phrase, but we look at each other unsure of what to do. The doctor is different, we aren't sure if we are allowed to honor her request for task evasion, since this an established skill. We decide to stay, but to stay alert and position ourselves in between Clara and the nurse in case something happens.

The nurse comes in and begins taking Clara's height and weight. Clara reaches over a pokes the nurse, a precursor behavior to a meltdown. My coworker and I look at each other and now know its time to leave. We tell the nurse we have to go and ask Clara to put her boots back. Clara sits down on the bench, and instead of putting her boots on she suddenly folds in half biting her knee forcefully. My coworker gets Clara onto the floor of the room, and tells Clara to "sit and be calm", the cue Clara has practiced to help her calm down. Clara continues to bite her knee on the floor, and we are obligated to put her into restraint to keep her safe. My coworker reaches around moves Clara's arms into a crisscross, and holds her wrists against her sides. She sits behind Clara, holding her in the wrap, following the procedure to release Clara: thirty seconds of calm body without screaming or struggling. Clara becomes more agitated and I jump into position, straddling Clara's legs as she now stretches out supine. I brace her legs to keep her from rolling out

of my coworker's arms and flipping herself into a prone position, to keep both of them safe. Clara's agitation intensifies, as she screams, cries and struggles for 45 minutes before we are able to release her. We head out, mostly composed, all of us very sweaty and physically tired. We all sit in the car in silence, each hoping for the day to become easier.

The next day at our team meeting we discuss the incident thoroughly. It is clear that my coworker and I made an error by not leaving the doctor's office when she requested to leave. But her ABA therapist understands why we were hesitant to leave, due to the strong emphasis on eliminating escape in her BSP. She vows to update the BSP to be more clear about the doctor, and spends the rest of the time helping us practice how to escort Clara out of the office in an agitated state should another episode occur in the future.

Working with Clara I constantly questioned the purpose of preventing her from having any control over her environment. It seemed the main lesson we were teaching was tolerance of our cultural practices and customs. These included walking in a certain manner, holding her body in a certain manner, speaking a specific way, not shrieking or laughing too loudly, not losing focus, not doing things in a particular manner. Her BSP ensured that we could have no tolerance of her way of being. We were under constant pressure to prevent her from engaging in any weird behavior. It was completely acceptable for multiple staff to instruct Clara and interrupt one another should Clara be engaging in "problem" behavior, such as sitting with feet pointed on the ground instead of with flat feet. We were instructed to end on the independent response which meant that Clara had to work until she performed the ideal manner. This meant that if we asked her a

question and she didn't respond correctly, we would text prompt the answer, and then ask the question all over again until she answered without a prompt. If she engaged in any behaviors targeted for reduction, such as sitting with pointed toes, we would have to redo any task until it was done "cleanly". The attitude towards perfection distinguished her program from many others. For many staff, they would observe her program before working with other clients, to observe how to run such a "tight" program. There was nothing clean about Clara's program, instead it was dirty and toxic. Day after day I saw how the language of her BSP changed my coworkers from friendly and outgoing into suspicious and resentful.

Working with Clara began to haunt me. I avoided watching her too closely, to prevent seeing behaviors that I was supposed to redirect. I tried desperately to allow her to be herself, and resented my coworkers when they interjected. I finally resigned from my position at the company, and prayed that I could make it through the final two weeks without having to restrain Clara. I made it up to my last day without any restraint. I stand behind Clara as she works on pronouncing tricky words with my coworker. After three repeated failed tries on a word, my coworker looks at me and says "sorry", and then tells Clara to "sit and be calm", standard procedure for task refusal. I kneel behind her, as protocol mandates, as she sits on the floor with her legs bent and hands clasped underneath her knees. I breath shallowly, trying to not upset the balance, sometimes Clara only needs a few moments in this position to regroup. She needs to sit for a minimum of ten seconds before I can release her back to work. Just as I reach the number ten in my head, she tips her chin up and bumps her head ever so lightly on the chest, a precursor behavior for aggression and a specific reason to restrain her. My last day of work and my

plan failed. Luckily the restraint is short, less than five minutes. Once she is back on task I ask for a break and go into the bathroom to cry at my defeat and the sadness I feel for Clara. Is this my inevitable future working with autistic children? How do I combat the misguided attempts to help these children? How do I come to terms with my own unavoidable mistakes in the future?

After I resigned from the behavioral firm where I worked with Clara, I felt much more at peace. As I left the negative atmosphere of Clara, I began to see the far reaching implications of Clara's toxic environment. I no longer needed to escape when I got home from the horrors of the day. By fixating on turning Clara into a "normal individual" we were destined to only see her failures instead of successes. Her failures were of course, indications that she is not normal, and instead is uniquely autistic.

I have seen growth in my own interaction, ability to deal with stress, and compassion towards other humans as I have learned to focus on the positive. Our beliefs determine our actions "when we act, we use our beliefs about the world to figure out how to get what we desire."⁵¹ Therefore, I feel distraught when I see my own friends struggling with issues of capability and belief of their own worthiness. I believe Clara's BSP should have focused on her strengths, with programs designed to help increase skills based on those strengths.

Educators must recognize how their words and actions create an atmosphere of acceptance or mistrust. By using a rhetoric of positivity and focus on flourishing we can hope to circumvent failure and uncertainty and instead make sure our actions are always

⁵¹ Kwame Anthony Appiah, *Cosmopolitanism: Ethics in a World of Strangers*, 19.

united towards a common goal. In exploring our own beliefs, we must be cautious not to get caught in one shard of glass and instead remember that in order to see the whole picture we must look through the mirror from multiple perspectives. Cynthia Kim, mother of an autistic son, explains that fixing an individual creates an end point, and that instead acceptance focuses on helping an individual thrive in the world. She writes

[L]earning new skills and building on our strengths equips us to cope with life's challenges. At the same time, it allows us to continue to be our autistic selves. Fixing often has the goal of making autistic people indistinguishable from their nonautistic peers, creating the feeling of brokenness that I struggled with. Equipping, on the other hand, promotes acceptance and builds confidence by reducing day-to-day struggles and improving our quality of life.⁵²

Her BSP tried to fix Clara, denied Clara the right to be herself. My experiences with Clara haunt me, scare me away from ABA therapy, and taught me to look to the words of adult autistics as I think about my future as an ABA therapist. Clara's perpetual struggle was for control over her life. Our perpetual focus was to minimize the control she had over her day and to instead "teach" her to accept change and differences.

The primary role of any ABA therapist is to create a behavior support plan, BSP. These documents determine how other staff interact with a client, and defines target goal. A BSP is meant to support and nurture an individual. Johnston argues that stories develop a child's sense of agency, and therefore educators need to "look at the kinds of stories we arrange for children to tell themselves."⁵³ For ABA therapists, acceptance must be the guiding light of any intervention or behavior change program. Acceptance requires

⁵² Cynthia Kim, "What Acceptance is Not," *Musings of an Aspie* (blog), Sept 17, 2014, <https://musingsofanaspie.com/2014/09/17/what-acceptance-is-not>.

⁵³ Peter H. Johnston, *Choice Words: How Our Language Affects Children's Learning*, 30.

leadership which serves the individual, values the influence of environment, and which works towards eradication of indifference and apathy of neurodiversity.

CHAPTER 4: FUTURE DREAMS

4.1 Acceptance

In the fall of 2015 I drove three hours south to New Hampshire to visit Plowshare, a residential community for developmentally disabled adults. Before I left for the trip I read about Plowshare and its mission. Plowshare follows the principles set forth by Rudolf Steiner, most notably the idea of anthroposophy. Anthroposophy is spiritual philosophy which argues that through inner development, connection to an objective spiritual world is possible. At Plowshare, the community focuses on each other's capabilities, not disabilities.

I arrived midmorning and was immediately greeted by two employees. Chris gave me a tour of his section of the farm, which included the woodshed and the art studio. In the woodshed, he described his process for teaching new workers the necessary skills. One area had a pile of birch branches, already cut and ready to be sorted. He explained that his organizational-minded workers sorted the wood, while his movement-minded, routine-based workers cut the branches. Chris showed me the saw-horse with a branch ready to be cut, he demonstrated how he might teach the skill, and how at first a new worker may only simply hold the saw handle while he did all the work. Eventually, with the passage of time and acclimation to the task, he explained that his workers could create enough charcoal in the woodshed for use in the art studio.

Chris and I then walked through a field to the art studio. He showed me the ceramics, and the template he used to teach his workers to build a specific pot, used by the garden to start seeds. He explained that while projects were drying, he also had his workers learn to draw. First he taught his workers to draw lines and gradually helped them learn how to draw intricate patterns. He then showed how they took these patterns, and transcribed the color patterns into musical notes. The entire process allowed a member at Plowshare to work on a project from start to finish without any deadlines or pressure to perform.

After my visit with Chris, I went up to a large shared community hall where we all ate lunch together. The meal was made from ingredients on the farm, cooked by Plowshare members, and enjoyed by all. I left Plowshare full of wonder at the level of acceptance and desire to connect and develop the skills of every member on the farm.

A cosmopolite view of the world reflects not only the need for acceptance of differences, but also an active interest in the values and beliefs of all humans. At Plowshare, not only did every member work together to support and nourish each other, but also they worked together to find spiritual meaning and happiness. When we see our common humanity “it reflects a spiritual understanding of the universal human connection and embodies the responsibility of leaders”⁵⁴ to protect and preserve future generations. Every single person deserves respect, even in the face of strong cultural differences and conflict. We are all part of the same existence, bound together by our humanity. When we become separated because of cultural conflict (and inherent ways of

⁵⁴ Juana Bordas, *Salsa, Soul, and Spirit: Leadership for a Multicultural Age*, 163.

viewing the world), we must be careful not to form alliances during these conflicts. Instead, we must work together and focus on building trust and animosity across our cultural differences. As a social species, our relationships with each other are a responsibility. If we face this responsibility with an open mind and heart, we are likely to stay united and learn greater ways of seeing the world.

Working with autistic children, I am constantly challenged to try to define their values and beliefs. Their personal culture is informed by their ability to integrate sensory information from the world. Because of their personal cultures, or perceptions of the world based on neurobiology, they require personalization of all services they receive. Therefore, a strong leadership tactic would be to employ individuals with autism in the field of education. Without a way of connecting to personal culture, we are unable to fully comprehend the types of leadership that benefit these children the most. Educators must stay aware of how these children perceive the world, but also must be vigilant to incorporate individuals who share this culture into the planning and education design for these students.

Autism is a genetic variation that influences integration and assembly of environmental stimuli. Autistic learners have differences in their sensory and cognitive processing, movement, interaction and thinking. These differences need acceptance. The goal of an ABA therapist is to reduce suffering and to teach necessary skills. These skills must help autistic individuals deal with life's challenges while allowing them to experience the world in an autistic manner.

Acceptance is not letting an individual just "be who they are", but rather instead argues to support and connect with that individual through their beliefs and values. To

support autistic learners, ABA therapy needs to develop greater awareness, knowledge, and skills of autistic issues and desires. Through awareness and knowledge of different values and beliefs, ABA therapists can then develop skills to enhance communication and connection. Because ABA therapists aim to bridge gaps in understanding and improve an individual's control over their environment, they must work to serve the needs of the client.

4.2 Servant Leadership

Models of servant leadership emphasize the importance of being present, of showing up as your authentic self in order to serve the group. When we are present, we are able to see clearly our own needs and the needs of others. As the author Terry Tempest Williams says in *Refuge: An Unnatural History of Time and Place*, "I believe that when we are fully present, we not only live well, we live well for others."⁵⁵ Servant leadership stresses the importance of serving the individual. Servant leadership operates on the basis of empowerment. Empowerment allows individuals to utilize their "talents, skills, and resources, and experience to make decisions to complete workloads."⁵⁶ Empowerment nurtures learning, growth and autonomy. Servant leadership recognizes the power of acceptance of a person, and the need to hold them accountable to their actions and

⁵⁵ Terry Tempest Williams, *Refuge: An Unnatural History of Time and Place*, (New York: Vintage Publishers, 1992), 116.

⁵⁶ Maureen Hannay, "The Cross-Cultural Leader: The Application of Servant Leadership Theory in the International Context," *Journal of International Business and Cultural Studies*, 1 (2009): 4.

performance. By focusing on serving others, this leadership technique is truly people-oriented.

To serve autistic learners, ABA therapists must first take care of the learners' sensory needs. A learning environment affects learners in a multitude of ways from the present moment, to the future. An environment connects an individual, builds meaning, and can act as a safe place for growth and discovery. Yet, an environment can also have deleterious affects on learners, especially autistic learners who are challenged by sensory stimuli and need additional time to allow for integration of information. Sensory differences need support and recognition of aversive environments. Learning occurs best in non-aversive environments, and utilization of natural resources provides a calming sensory experience. Conventional school systems are loud, bright, disorderly, and frequently chaotic. Working in a natural environment is therapeutic, as philosopher Marietta McCarty says in *How Philosophy Can Save Your Life: 10 Ideas that Matter Most*, "simple pleasures feed our essential selves...being outdoors...watching a flight of wild geese, running for home, breathing deeply."⁵⁷ Simplicity allows us to align our thoughts and ground ourselves. Free from chaos, we can reconnect first to ourselves and the earth. For ABA therapists, environment is extremely important. Environments which ameliorate sensory overload, and yet are still rich with sensory interaction allow an ABA therapist to be "so much as a listening other, but as a community member helping the community strategically manage is inquiry process."⁵⁸ Choosing an environment which

⁵⁷ Marietta McCarty, *How Philosophy Can Save Your Life: 10 Ideas that Matter Most*, (New York: Penguin Group, 2009), 3.

⁵⁸ Peter H. Johnston, *Choice Words: How Our Language Affects Children's Learning*, 55.

encourages inquiry facilitates communication, and demonstrates to the individual that their perception matters and influences group decisions. For one of my former students, nature radically transformed our relationship and allowed her to finally feel part of her kindergarten class.

One of my children who I worked with attended a nature walk every Friday as part of Kindergarten curriculum. Nature walks were one of her favorite activities of the week. She struggled to work in her kindergarten classroom, probably due to the increased, bright lights, visual stimuli throughout the room, and chaos of twelve additional kindergarteners. When she became overwhelmed she resorted to aggression towards others as well as materials in the room. She frequently escaped to hide in different parts of the room, usually with her face buried or her hands over her ears. Outside, however, she was much more engaged. At the beginning of the year she found it difficult to interact with her peers, but the nature walks helped facilitate relationships with class peers. Unlike recess, where everyone had their own agenda, the nature walk was a common activity where she and a buddy would work together. Walking through the woods, buddy pairs held hands. The simple human contact of holding hands as they walked through nature and explored the area helped her connect. She began to learn the names of her classmates. She looked to their faces to see what they are looking at, and connected on similar issues. One walk, we listened for birds. Her excitement at finding birds was obvious, she immediately wanted to draw a birdhouse as soon as we re-entered the classroom. Her sense of belonging to the class increased, as she requested to remain with her friends and continue the assignment. The nature walk gave her a purpose and helped her bridge academia and natural phenomena. The positive association to the

nature walk helped her build confidence to pursue work in the classroom. A change in environment changed her response from fight to curiosity.

Out in the woods, my student was able to use her strengths to connect with her classmates. Instead of being the student who hid in the closet during classtime, she became an active participant by simply observing. Nature removed the confines of cultural expectations. Brene Brown in *Daring Greatly* calls upon us to examine our own beliefs of the world, and how these beliefs are shaped by culture. She informs us that culture frequently attempts to teach us that we are not capable of achieving our goals or simply living with a sense of peace, and as a result we live in scarcity.⁵⁹ This mindset she cautions is dangerously debilitating. By deliberately filling our time with activities and the belief that we are capable and “enough” we are then able to obtain semi-spiritual standing in the world. Living “Wholeheartedly” as Brown describes, leads to a life filled with compassion, courage and connection to others. My student was able to live more “Wholeheartedly” in an environment which did not cause her inner distress, where she was able to feel capable.

Currently, many ABA therapists operate out of schools or clinical settings. Nature walks are not possible. One method of teaching in this setting is called Discrete Trial Teaching (DTT). DTT involves an instructor and the learner sitting across from each other and working together on learning goals free from unnecessary antecedents and use of controlled consequences, reinforcement. The use of DTT is for quick learning which can hopefully then be expanded to the natural environment. While DTT is helpful for

⁵⁹ Brene Brown, *Daring Greatly*, (New York: Penguin Group, 2012).

some learners, Zull argues “we cannot understand anything unless we create internal neuronal networks that reflect some set of physical relationships that accurately map the relationships in the concept.”⁶⁰ In a clinical setting, physical relationships are non-existent. Instead of the real world, ABA therapists use flashcards and shape traditional learner behavior such as sitting at table quietly.

Teaching concepts requires connections between neuronal networks. Naturalistic teaching, which is the opposite of DTT and instead involves capturing learning moments in the natural environment, seems to be more in align with Zull’s findings about the brain. Naturalistic teaching takes advantage of naturally occurring reinforcement contingencies. When a learner needs helps with certain skills, we must build upon their previous understanding. In DTT teaching, the learner’s ability to utilize previous learning is severely hindered because the contingencies of reinforcement are contrived and highly controlled. While learning may occur, old networks of learning are severely inhibited. Zull cautions any form of inhibition since the network still exists: “if we present the ‘old’ challenges to the learner, she may well rediscover the ‘old’ solutions.”⁶¹ A better solution would be to build new, stronger connections in the presence of old information. Zull questions “Do teachers create opportunities, even make demands, for students to transform the information which came from their past into their future?....Do we emphasize what is known, rather than what students think or do?”⁶² A teacher’s job, in

⁶⁰ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 128.

⁶¹ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 127.

⁶² James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 44.

my opinion, is to create the opportunity for exploration and support in a learner's journey. One way ABA therapists can serve the needs of their clients while also developing new neuronal networks is through play.

When I worked with my kindergarten student, I focused on building trust and connection. My kindergarten student was very silly, and loved when I entered her world to play with her. We played hide and seek even in a room devoid of furniture or corners. She would lay on her back, hiding her face under my clipboard as I dutifully counted to fifteen in the corner. After counting, I would sigh, wander around the room, ask out loud where my kindergarten had hidden. She would jump up, scream "boo" and I would jump into the air in fright. My kindergartener liked the routine of the game, and I would play authentically every time. When out on the playground, I would hang around waiting for her to play with me. Her favorite game that we made up together was Zombie/Freeze. She would say "Zombie" and I would throw my arms up and stagger after her as she ran around the playground screaming. Usually when I got super close, she would say "Freeze" and I would freeze with my arms up. She would then tell me to put my arms down, would run a safe distance away, and transform me back into a Zombie. Many of the other teachers would stand around and chat during recess, and the behavior interventionist who I trained with before I started working with my kindergartener saw recess as our only break of the day. While I wanted to sit or make idle chit chat, I knew that on the playground my kindergartener was free of the need for guidance, and that this precious time represented the only time I was completely at her disposal and able to connect in a truly authentic manner. She got to boss me around and play, but she had to communicate with me and teach me the rules of the game.

For young children, creativity and individuality can be developed through free play and exposure to scenarios which require critical thought and problem solving. Through these challenges, the skill of coordinating sensory input, integration and processing and resultant motor actions become synchronized to the learner's desires and needs. By creating a play environment, educators not only build environments with varied sensory information, but their own approach to education shifts from fixing to transformation. For children, development comes through play. An ideal play environment allows children to experience a range of emotions from excitement to frustration, but to also learn from the support of others and to "grow to be independent and self-reliant...where they can learn about themselves, about others, and about the world."⁶³ In play, children learn to integrate internal and external worlds, and quickly learn the ideas of autonomy and the reinforcing effects of pursuing personal interests. As Moore describes in *The Need for Nature: A Childhood Right*, children live through their senses. The natural environment is the principle source for sensory stimulation and therefore freedom to explore nature leads to maturation of neuronal connections of the public and external worlds with private, affective worlds.⁶⁴ An environment which is vivid, full of sensory experience, will present multiple methods of engagement for children. Multiple sensory experiences help strengthen and synchronize neuronal connections. As Zull states, "neuronal networks in students' brains are related to their

⁶³ Penny Wilson, *The Playwork Primer*, (College Park: Alliance for Childhood, 2010), 5.

⁶⁴ Robin C Moore, "The Need for Nature: A Childhood Right," *Social Justice* 24, no 3 (1997): 203.

own life experience.”⁶⁵ Experiences which strengthen or weaken synaptic connections between neuronal networks of sensory input, integration of information, and responding lead to learning. For all learners, nature requires learners to visualize and use all of their senses. If learning is play, ABA therapists need to be invisible yet available to support children in their learning. ABA therapists need to let children experience the world for themselves, and only intervene to reinforce particularly good behaviors that are not naturally reinforced by the environment, and to protect and prevent injury, frustration, or unnecessary fear in the student.

4.3 Increasing Knowledge and Cultural Awareness

Communication is essential to knowing how to help a partner feel in control. Control is critical to preventing a survival state of mind. A survival state of mind impedes learning and therefore, Zull argues “[O]ne important rule for helping people learn is to help the learner feel she is in control.”⁶⁶ Control develops agency or “the perception that the environment is responsive to our actions”, which many argue “is a fundamental human desire.”⁶⁷ Communication skills allow individuals to control their environments. As a leader, I want to focus on language and communication. An acceptance mindset places greater responsibility on the leader to learn the communication styles of their partner. Tasia, mother of an autistic teenager argues that the “acceptance mindset says

⁶⁵ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 102.

⁶⁶ James Zull, *The Art of Changing the Brain: Enriching the Practice of Teaching by Exploring the Biology of Learning*, 52.

⁶⁷ Peter H. Johnston, *Choice Words: How Our Language Affects Children’s Learning*, 29.

that while you encourage the child to communicate, you also 1) facilitate and celebrate communication in whatever form it occurs, and 2) actively try to learn the child's ways of communication.”⁶⁸ Communication cannot reflect only one partner's way of sharing information, but instead must embrace any and all attempts to share a private inner space.

Walking down the hall, Giselle hums next to me. Giselle is a new friend; we have only been hanging out a few weeks. My current task for Giselle is to integrate her back into her kindergarten classroom, but as of now we spend most of our time in a smaller workroom down the hall from her classroom. Giselle is a huge fan of My Little Pony. She loves to draw the ponies from the show and has about four My Little Pony t-shirts that she rotates through during the week. Her ABA therapist informed me early on how to handle her “scripting” of My Little Pony. Scripting, a form of echolalia of shows, movies, or other people, is viewed as a defective way to communicate. Therefore, the ABA therapist on the team instructed me to interrupt her whenever she started scripting, and instead ask her more relevant questions such as “What are we doing right now?” and if she keeps scripting to answer the question and ask it again until she responds. Within no time, Giselle stopped scripting from My Little Pony except for a few key phrases such as “I'm feeling dangerous”. Giselle would say this whenever she was more amped, and it made me always wonder what she was trying to tell us. I asked my supervisor if in these circumstances I should prompt her to say something more applicable such as “I'm feeling silly” or “I need to move”, but was discouraged from attempting to interpret her meaning

⁶⁸ Tasiyam, “Changing the Child vs Helping the Child,” *Life, his way* (blog), April 12, 2013, <https://lifehiswayblog.wordpress.com/2013/04/12/changing-the-child-vs-helping-the-child/>.

from these phrases. While I agree that my supervisor was right to not try to replace her words with mine, I wanted to use her attempts at communication instead of interrupting or blatantly ignoring them.

Giselle’s method of communicating her inner feelings, the language of My Little Pony, should have been embraced, not discouraged. Her choice of language demonstrates a difference in perception. Perception influences language in many ways. As Skinner explains, language many times is represented as a way to share information that is equally accessible to individuals. Yet, there are many ways to record events in our life, and even a phrase such as “sticky” is not fundamentally the same for everyone. A phrase like sticky involves the coordination of proprioceptive stimuli, or the position of our body in space, with environmental or exteroceptive stimuli. Therefore, as Skinner explains “when we run our hand over a surface and judge it to be sticky, gummy, or slippery, our response is in part to the resistance encountered in moving our hand, even though we appear to be talking about the surface as a public event. The important point here, however, is not the locus of stimulation but the degree of accessibility to the community.”⁶⁹ For autistic individuals, sensory differences sometimes make conventional language choices difficult. For Julia Bascom, an autistic woman, childhood experiences with language felt inadequate. A singer, Bascom, felt out of place and she felt “shamed for moving when I sang—music shouldn’t be physical, embodied, tactile experience.”⁷⁰ As Bascom advanced in her singing, she joined a youth choir. Because her

⁶⁹ B.F. Skinner, *Science and Human Behavior*, 262.

⁷⁰ Julia Bascom, “A Fifth is Two Sine Curves,” *Just Stimming* (blog), October 31, 2012, <https://juststimming.wordpress.com/2012/10/31/a-fifth-is-two-sine-curves/>.

perception of music was more “rich, dynamic, embodied, and visuospatial” she was unable to read sheet music. For Bascom, “none of the language used to communicate about music made any kind of sense to me. The spatial metaphors would not map.”⁷¹ Conventional methods of transforming music sound, a sensory event, were not adequate representations of the same sensory stimuli for Bascom’s unique neurobiology. As Skinner explains, language many times is represented as a way to share information that is equally accessible to individuals involved in communication. Yet, there are many ways to record events in our life, and even a phrase such as “sticky” is not fundamentally the same for everyone. A phrase like sticky involves the coordination of proprioceptive stimuli, or the position of our body in space, with environmental or exteroceptive stimuli. Therefore as Skinner explains “when we run our hand over a surface and judge it to be sticky, gummy, or slippery, our response is in part to the resistance encountered in moving our hand, even though we appear to be talking about the surface as a public event. The important point here, however, is not the locus of stimulation but the degree of accessibility to the community.”⁷²

For some autistic individuals, language involves moment and interaction with their environment. Amanda Baggs shares her native autistic language in her video “In My Language”. Baggs uses the first half of the video to demonstrate her ‘native language’ through her interaction with the world through all senses. She has recorded scenes of rocking back and forth, running her fingers in a water stream, hand flapping all accompanied by humming. In the second half of the video she explains her native

⁷¹ Ibid

⁷² B.F. Skinner, *Science and Human Behavior*, 262.

language through subtitles. She writes “my language is not about designing words or even visual symbols for people to interpret. It is about being in a constant conversation with every aspect of my environment...Far from being purposeless, the way that I move is an ongoing response to what is around me.”⁷³ She laments the decision that her native language is less meaningful than when she chooses to interact with others through the limited realm of spoken language. The irony she explains is “the way that I move when responding to everything around me is described as 'being in a world of my own' whereas if I interact with a much more limited set of responses and only react to a much more limited part of my surroundings people claim that I am 'opening up to true interaction with the world'. They judge my existence, awareness, and personhood on which of a tiny and limited part of the world I appear to be reacting to.”⁷⁴ For autistics, not using standard verbal language is seen as a deficit, and as an indicator of non-personhood. She points out the irony of being labeled as a deficit when society at large therefore has a deficit of autistic language: “We are even viewed as non-communicative if we don't speak the standard language but other people are not considered non-communicative if they are so oblivious to our own languages as to believe they don't exist.”⁷⁵ Autistic advocate Paula C. Durbin-Westby explains “[E]ducation should focus on the strengths of Autistic people, not on making us ‘indistinguishable from our peers.’ By the way, our peers are other

⁷³ Amanda Baggs, “In My Language,” online video, 8:36, January 14, 2007, <https://www.youtube.com/watch?v=JnylM1hI2jc>.

⁷⁴ Ibid

⁷⁵ Ibid

Autistic people."⁷⁶ By examining language, it is clear how important the autistic perspective is understanding not only how an individual talks, but also how and why they move through their environments. ABA therapists work in a quickly enlarging field, and must learn to advocate for their clients and advance the ethics of intervention beyond that legal and moral constraints associated with their degree. ABA therapists need to to consider the ethical and moral implications of introducing skills which greatly influence an individual's concept of self, in designing programs for an individual who experiences the world differently. ABA therapists need to become more resonant leaders who recognize and empower the neurodiversity of their clients, and help them lead more purposeful, fulfilling lives based upon a foundation of trust and acceptance of themselves and the world.

⁷⁶ Paula C. Durbin-Westby, "Autism Awareness is Not Enough," *Neurotribes* (blog), April 4, 2016, <http://blogs.plos.org/neurotribes/2016/04/04/autism-awareness-is-not-enough-heres-how-to-change-the-world/>.

CHAPTER 5: CONCLUSION

In order to teach others, we must first know ourselves. Without knowledge of our own points of view and beliefs, we remain unaware of our own biases. Life demands a multicultural approach to problem solving and relating to others. When we learn about multiple viewpoints, leaders can focus on leading from their conscious, instead of leading by their actions. As a child I was introverted and preferred my family and pets to my friends nine times out of ten. Through my interactions with animals I learned how to influence others while still respecting their autonomy and individuality. To relate to animals is to learn to communicate without words and instead develop a language based on body position, predictability, and confidence.

When I graduate from UVM I will become eligible to finish my certification to become an ABA therapist. As I begin to think about my future work prospects, I feel uncertain how to balance these past frustrations and experiences of broken trust in both my work as a horse trainer and the dilemmas I have already experienced working with ABA therapists. I ultimately left the horse world because of the lack of respect given to my ideas, and the lack of acceptance of a horse's needs, abilities, and signs of discomfort. Currently I feel stuck in the same position as a future ABA therapist as I felt as a horse trainer. I desperately want to work with children and design programs to help them navigate and understand their perceptual differences. Yet, my own anxiety about interacting in the professional world makes me feel hesitant and unhelpful. The BCBA Ethical Code states in Section 1.05 (e) "[B]ehavior analysts do not knowingly engage in behavior that is harassing or demeaning to persons with whom they interact in their work

based on factors of such as those persons' age, gender, race, culture, ethnicity, national origin, religion, sexual orientation, disability, language, or socioeconomic status, in accordance with the law."⁷⁷ Any discrimination I have witnessed and been a part of this far I believe is done out of ignorance. The need for increased knowledge and awareness of autistic needs and values is critical to avoiding discrimination and developing identity.

5.1 Autism and Culture and ABA Therapy

Autistic individuals are a minority in the population, about 1%, and the majority of ABA clients are autistic. Because minorities are compared to dominant culture, they are under constant pressure to conform to that culture. This is called systemic oppression.⁷⁸ Minorities are marginalized: they lack the power and ability to change the policies that oppose them. As Dr Jim Joseph explains, “leadership [then] must address barriers that perpetuate inequality and economic discrepancy.”⁷⁹ These barriers are frequently public institutions and values which determine dominant culture and promote discrimination. As a leader, I want to go beyond the ethical guidelines of the BCBA. Yet, as I am not autistic, my attempts at empathizing with an autistic world view are bound to fall short.

I recommend that the BCBA needs to advocate for the creation of an autistic advisory committee. This committee would create guidelines for behavioral intervention, to help ABA therapists recognize which skills are critical to navigating the world as an

⁷⁷ Behavior Analysis Certification Board, *Professional and Ethical Compliance Code for Behavior Analysts*, August 7, 2014, <https://bacb.com/wp-content/uploads/2016/03/160321-compliance-code-english.pdf>.

⁷⁸ Juana Bordas, *Salsa, Soul, and Spirit: Leadership for a Multicultural Age*, 108.

⁷⁹ *Ibid*, 100.

adult. They contain knowledge cultural norms and beliefs, as well as skills needed to deal with constraints of an able-bodied world. The main slogan of the ASAN is “Nothing About Us Without Us.” I am working towards a career with mostly autistic children, and I want to find lasting meaning in what I do. I worry about my influence on children, their families, and the autistic perception of ABA therapy. I want to create a future generation of autistic ABA therapists, demonstrate a commitment to autistic identity and culture, and to help my students find meaning and purpose.

ABA provides the principles and technologies to influence behavior change. The intent behind that behavior change is critical. As I learned from working with horses and dogs, there is much more to success than a method. Just as Klaus recognized the importance of teaching to the needs of his horses, ABA principles must acknowledge the who, what, where, and most importantly why for behavioral intervention. To what extent does an ABA therapist allow a child to *hike their own hike* of life? Does an ABA therapist work to teach skill to improve navigation of life's challenges and obstacles, or instead do they work to alleviate discomfort of differing identities, values, and beliefs? Most ABA therapists have never experienced a team of individuals working to change their behavior. ABA therapists do not see the world through an autistic perspective. To receive behavioral services, let alone understand the different perspective their students have on the world and how this influences their values and beliefs. Therefore, ABA therapists cannot simply target behaviors without regard of the human spirit, or without regard to perspectives offered by adults or other individuals who share more similarities with the student in question.

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