INFLUENCE: ART, ACTIVISM, AND IDENTITY AS SEEN THROUGH A NEURODIVERGENT LENS

by

Anna Matejcek

A thesis

submitted in partial fulfillment

of the requirements for the degree of

Master of Fine Arts, Visual Arts

Boise State University

May 2017

© 2017

Anna Matejcek

ALL RIGHTS RESERVED

BOISE STATE UNIVERSITY GRADUATE COLLEGE

DEFENSE COMMITTEE AND FINAL READING APPROVALS

of the thesis submitted by

Anna Matejcek

Thesis Title: Influence: Art, Activism, and Identity As Seen Through a Neurodivergent Lens

Date of Final Oral Examination: 01 March 2017

The following individuals read and discussed the thesis submitted by student Anna Matejcek, and they evaluated her presentation and response to questions during the final oral examination. They found that the student passed the final oral examination.

Jonathan Sadler, M.F.A.	Chair, Supervisory Committee
Stephanie Bacon, M.F.A.	Member, Supervisory Committee
Lily Lee, M.F.A.	Member, Supervisory Committee

The final reading approval of the thesis was granted by Jonathan Sadler, M.F.A., Chair of the Supervisory Committee. The thesis was approved by the Graduate College

DEDICATION

To my soul mate, Robert J. Matejcek, whose unconditional love and support has

influenced every aspect of my life for the better.

I see. They say I can't; I don't, I shouldn't... but somehow I do. People try to hide their colors from me; feeling safer to shut me down, shut me up, shut me out, but not you. Others dismiss my experience with closed eyes, closed minds, closed off, displaying dismay and disbelief, because if their view is limited, then mine must be too. But not you. I watched the wispy tendrils of aurora borealis reach down and embrace you, mirror your aura, shimmering green, gold and blue. I witnessed that beautiful convergence of influence, a dance of color and light, between your energy and that of the stars. But not you. Though it was invisible to you, you never doubted that it was true. I believe it because I see, whereas you believe it because it is me.

And for my baby sister Karla, you are a brilliant star in this world. Never let

anyone tell you otherwise. Never accept their ignorance as truth, never let their

misguided beliefs limit you. Be you, live your truth, believe in yourself and know you are

limitless. Shine on.

ACKNOWLEDGEMENTS

To my husband, my parents, my sisters, my friends, my family, my committee, to everyone who has supported me, believed in me, given me a chance, and never given up on me; I thank you from the bottom of my heart.

ABSTRACT

My world has no separation between art, activism, and identity. As a neurodivergent individual, I experience life through hyperactive senses. It is an intense reality; however, it is the force that drives me to create, explore, discover and learn. My mind works like a kaleidoscope, always awash in colorful abstract images, each twist or turn reveals a new perspective. For my MFA visual art thesis, I used my neurodivergent brain as the foundation of my study. The concept formed in my mind first as blurry shapes and colors, and then came into focus as I began the process of gathering and testing materials. Eventually, I was able to replicate the images in my mind, converting them into actuality with yarns, fibers, plastics, latex, and light. The physical results of this process are six lopsided, vibrant, soft sculptures based on neurons. They hang suspended and interwoven, interacting with one another in the gallery space as an installation, similar to the way neural networks connect.

By sharing my divergent artistic perspective and backing up my narrative artwork with scientific data and medical research, I hope to dispel harmful myths and foster a better understanding of the challenges that neurodivergent individuals experience. I want my art to spark productive conversations about ways we can reform our educational and societal systems to be more inclusive and open to all people. Ultimately, I would love to see my work widen the way, so that anyone who follows the divergent path after me will encounter less resistance.

vi

TABLE OF CONTENTS

DEDICATION iv
ACKNOWLEDGEMENTSv
ABSTRACT vi
LIST OF PICTURES viii
LIST OF ABBREVIATIONSx
CHAPTER ONE: A NARRATIVE OF INFLUENCE1
An Attempt to Explain that which Feels Unexplainable2
CHAPTER TWO: AN INFLUENCE ON ME10
You Can't Unchop A Tree But You Can Plant A Forest10
Going the Divergent Way13
An Introduction to Neurodiversity16
Words, Verses, Pictures
CHAPTER THREE: AN INFLUENCE OF ART
CHAPTER FOUR: OUR INFLUENCE
REFERENCES0

LIST OF PICTURES

- Picture 3. Scan two of my handwritten notes on a passage from Sara Ahmed's Sara Ahmed's book, "Introduction Find Your Way." In *Queer Phenomenology: Orientations, Objects, Others.* Durham: Duke University Press, 2006 14
- Picture 5. "Influence" Installation Gallery Corner View, Anna Matejcek, 2017 22
- Picture 6. "Influence" Detail of Dendrites and Axons, Anna Matejcek, 2017 24
- Picture 7. *"Cellular Dialogue"*, Rebecca Kamen, 2012. Article by Ellen Rolfes, "Portrait of a dyslexic artist, who transforms neurons into 'butterflies."

PBS. April 16, 2014, accessed February 1, 2017.

http://www.pbs.org/newshour/updates/neuroscience-art-brain/ 24

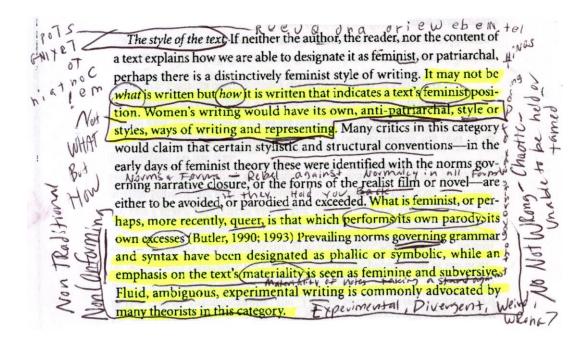
- Picture 8. "Influence" Detail of Neuron Cell Body, Anna Matejcek, 2017...... 25
- Picture 10. "Influence" Cell Body Construction Detail, Anna Matejcek, 2017 27
- Picture 11. "Influence" Cell Body Texture Detail, Anna Matejcek, 2017...... 29
- Picture 12. "Worldy Wisdom", Katherine Sherwood, 2012. "Artwork." Katherine
 Sherwood Website. Accessed February 11, 2017.
 http://www.katherinesherwood.com/sherwood/art/sherwoodart.html...... 31
- Picture 13. "Influence" Installation Gallery Front View, Anna Matejcek, 2017....... 32

LIST OF ABBREVIATIONS

ADHD	Attention Deficit Hyperactivity Disorder
PTSD	Post Traumatic Stress Disorder
LD	Learning Disability
ASD	Autism Spectrum Disorder

CHAPTER ONE: A NARRATIVE OF INFLUENCE

Deliberately, *Influence* is not a typical Masters of Fine Art thesis. *Influence* is the result of a lifetime of experiences as a neurodivergent person; therefore I wanted this paper to reflect my type of fluid, kaleidoscopic thinking.¹



Picture 1. A scan of my handwritten notes on a passage from Elizabeth Grosz's essay "Sexual Signatures: Feminism After The Death of The Author." In *Space, Time and Perversion; The politics of bodies*. New York: Allen & Unwin, 1995.

¹ "What is Neurodiversity?" National Symposium on Neurodiversity at Syracuse University. March 23, 2012. Accessed February 15, 2017. https://neurodiversitysymposium.wordpress.com/what-is-neurodiversity/. Summary: Any humans who vary from the neurotypical majority could be classified as neurodivergent. Divergent means, "tending to be different" or to "develop in different directions," while neuro- is the scientific prefix used to describe anything relating to nerves or the nervous system, which of course includes the brain. Therefore, a neurodivergent individual is someone whose nervous system and brain has developed differently from the majority of people; the way in which these individuals think and relate to the world develops in different directions from the typical individual's nervous system.

This writing is a type of performance; both excessive and subversive; breaking from the mold of convention. By sharing my divergent perspective and backing up my narrative and artwork with scientific data and research, I hope to dispel harmful myths, foster a better understanding of a variety of neurological differences, and add my voice to the many others who are questioning our society's prevailing norms.

I have discovered my identity, as an artist cannot be separated from my reality as a neurodivergent person. For this thesis, I will convert the invisible (invisible disabilities) and the abstract (abstract reality of the neurons microscopically working inside our brains) into materials that are both viewable and tangible.

Sadly, neurodivergent individuals often experience difficulties when forced into educational and societal systems that were built to support the neurotypical and, even worse, our society rarely acknowledges, or even notices, this biased discrepancy. While I do not want to divide, victimize, or assign blame; I do want to bring these issues into the spotlight. My goal for this project is to raise awareness and start productive conversations so we can work together to make our society more inclusive and open to all people.

An Attempt to Explain that which Feels Unexplainable

In an attempt to explain something that feels overwhelming and unexplainable, I am going to tell you a story. I ask that you imagine yourself as our main character, a young child of 4 or 5 years, growing up in the early 90's.

In this reality, you experienced life through hyperactive senses. Everything was brighter, sharper, bolder, louder, and more saturated and textured for you. Because of this, you reacted to the world more strongly than your peers. When you realized other people didn't see the world in the same way you did, you felt sorry that they were missing out on so much beauty and potential. Your psychedelic senses felt like a gift, and you thought of them as your secret, magical powers. You experienced everything so vividly, and with such depth and complexity. Your mind was like a kaleidoscope, and your eyes were the lenses, always turning, revealing a new perspective in the process. Your default wasn't just happy; it was joyful, inquisitive, and optimistic. You flew in every direction, like a bumblebee, buzzing with energy, and unlimited in a clear sky; soaking in everything, engrossed and amazed by it all. Your desire to explore, discover, and learn drove you forward.²

Though you had come to realize that your imaginative hands-on approach was unique, it never occurred to you that your way of learning about the world was "wrong" until your teachers told you it was. With the onset of school, everything changed. It was a shock to your system, and you became unsure of yourself for the first time.

The institutions of school and church were one and the same. The priests were scary, and their damning homilies didn't end with mass; the message of conformity followed you to the classroom. For example, you thought that being a fluid mix of both/neither/either girl and boy was how everyone felt; it seemed normal to you, but the more the priests and teachers lectured, the more you learned that you had been born wrong. Shame engulfed you; trauma built upon trauma, and fear led to more fear. Soon you couldn't sleep or think clearly.³ You started having intense episodes of unexplainable

² William Dodson, M.D., "Uncomfortable Truths About the ADHD Nervous System," ADDitude Magazine, accessed February 04, 2017, <u>http://www.additudemag.com/adhd/article/10497.html</u>. It seems odd to call a condition a disorder when the condition comes with so many positive features. People with an ADHD-style nervous system tend to be great problem-solvers. They wade into problems that have stumped everyone else and jump to the answer.

³ Jerome J. Schultz, Ph.D., "Why School Stress is Toxic for Our Kids," ADDitude Magazine, accessed

physical pain and panic. You were surprised that these attacks didn't kill you; they felt like they should. Even more surprisingly, no one noticed, you hid your pain and shame away with your true self. You became a ghost child, semi-transparent and lacking your former vibrancy and substance. You needed people to stop and *actually* see, reassure, and accept you. Instead, they looked into your now-dulled eyes and dug no deeper.⁴

During all of this, you were expected to go to school and be a normal kid. You tried your best to comply, but school was incredibly difficult. You had trouble reading body language and social cues (an example of non-verbal learning disabilities).⁵ You couldn't figure out people's intentions or motivations. You took things too literally and felt perpetually lost and vulnerable. You had no physical coordination; you were terrible at sports, and no one wanted to play with you at recess. Your multi-faceted, intense senses no longer felt like magic powers; now they felt like an overwhelming curse, an overload of sensory stimulation that physically hurt.⁶

February 04, 2017, <u>http://www.additudemag.com/adhd/article/11630-2.html</u>. It's a sad fact that many students with LD or ADHD have more failures than successful moments in school, and this affects their attitude toward learning and their behavior. A student with impediments to learning needs a developmentally appropriate level of knowledge about his own cognitive profile. Without it, he is likely to attribute his lack of success to a lack of ability or intelligence. Repeated bouts of fear, frustration, and failure in school create a toxicity that builds up over time. This state of mind is actually neurotoxic. It impairs brain function by fouling up the brain's chemistry and even shrinking critically important neural brain tissue, making problems with learning and attention worse.

⁴ RSNA, "MRI Shows Brain Disruptions in Children With PTSD," Neuroscience News, October 25, 2016, accessed February 04, 2017, <u>http://neurosciencenews.com/ptsd-brain-disruption-5353/</u>. PTSD is a mental health problem that occurs in the wake of one or more traumatic experiences. Children are particularly vulnerable to the effects of PTSD, as the multiple neurochemical and hormonal effects associated with childhood trauma can lead to lasting changes in brain structure and function.

⁵ Candace Cortiella and Sheldon H. Horowitz, The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014), PDF, New York: National Center for Learning Disabilities, 2014.

⁶ Zoë Kessler, "Hypersensitivity Is Not Imagined," ADDitude Magazine, accessed February 04, 2017, <u>http://www.additudemag.com/adhd/article/8945.html</u>. Hypersensitivity is categorized by a high level of sensitivity to physical (via sound, sight, touch, or smell) and or emotional stimuli. This causes the individual to become overwhelmed by too much information.

Everywhere you went, you were distracted, disorganized, and always seemed to be forgetting important things (an example of executive functioning deficits).⁷ You tried to keep track of your schoolwork and manage your time, but it was as if time was in on the joke; constantly speeding up when you needed more and slowing down when you needed less.

In class, you were unable to tell the difference between phonetic sounds in words, which impacted your ability to rhyme, spell, and learn new vocabulary. As a result, your ability to read suffered (an example of dyslexia, a specific learning disability in reading).⁸ Reading and writing were tedious; the way the teacher explained it didn't make sense to you. You secretly came up with your own system. It was a slow process; one you implemented every time you needed to give the appearance you had read and understood the letters like you were supposed to.

Math was even harder because it was too abstract, you could not tie it to an image in your mind. The numbers kept switching places on the page; you spent all your time chasing them around, trying to get them back in order (an example of dyscalculia, learning disabilities in math).⁹ Since numbers were intangible, you resorted to using your fingers to count, but your teacher caught you and scolded you in front of everyone. She said you should be able to do this, and that you needed to try harder. You wanted to tell her you were trying as hard as you could, but the other kids were already sneering and giggling, so you sunk lower into your seat, face flushed with shame, and tried to dissolve.

5

9 Ibid.

⁷ Candace Cortiella and Sheldon H. Horowitz, The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014), PDF, New York: National Center for Learning Disabilities, 2014.

⁸ Ibid.

In school, picking out words from all the background noises and distractions was a challenge. Sounds blended together, but if you concentrated very hard on the movement of people's lips while listening to their voice; you could sometimes piece everything together and understand what they said. However, this required a lot of extra effort, and you didn't always have enough energy left over to remember all their words, so you still ended up confused (an example of auditory processing deficit).¹⁰ If you asked a teacher to repeat something, he or she would get annoyed and tell you to pay attention the first time.

Around this time, doctors and specialists performed extensive testing and diagnosed you with a stew of learning disabilities. Your teachers were given a list of accommodations to implement in the classroom so that you would have a better chance of learning. You hoped this would help, and maybe things would start to get better, but your teachers had lots of other students to worry about, many of whom refused to sit still or stay quiet. You, on the other hand, were so skilled at hiding; they seemed to forget you were even there.¹¹

No matter the subject, you always had trouble organizing your thoughts. Even if you managed to write them down, you forgot what you said, and talked yourself in circles. Things like sentence structure and grammar were so abstract that you couldn't seem to grab onto them (examples of dysgraphia).¹² Your teachers wanted you to do

¹⁰ Ibid.

¹¹ June Silny, "The Civil War Inside My Brain," ADDitude Magazine, accessed February 13, 2017, <u>http://www.additudemag.com/slideshow/220/slide-6.html</u>. ADHD is largely invisible. We try very hard, but no one can see our internal struggle or effort. We're going through a lot but we've become good at hiding it. All we're asking for is a little compassion, patience, and non-judgmental love. If you can do that, we will try harder. We will figure out how to get through our rough spots if you promise to stand by our side, support us, cheer us on, and wait for us at the finish line.

¹² Candace Cortiella and Sheldon H. Horowitz, The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014), PDF, New York: National Center for Learning Disabilities, 2014.

everything in one very specific way, and you tried to follow the directions, but their way seemed so confusing and backward. You never got it quite right. When called up to the board, you got nervous and messed up, and the other kids laughed. The teacher didn't tell them not to, nor did she give you any reassurance. She just shook her head. You disappointed her again, but the worst part was that she wasn't surprised you screwed up; she expected it, and that made you feel like a failure. The same thing happened when you were called on unexpectedly in class. Your mind went blank as you panicked, not wanting to say the wrong thing and disappoint the teacher further, but this panic made answering correctly impossible. You couldn't think when you were so stressed.¹³

Stress followed you everywhere in school. You got a reputation amongst your teachers of not living up to your potential. Your peers ignored you until you made another mistake, then they called you names and told you the city should install a "SLOW CHILDREN" sign outside your house.¹⁴ Their words stung, but you didn't argue; at that point, you believed it, too.

The only subject you felt you could excel in was art. Art was the one bright spot in school; it eased your tension, and you were good at it. You craved that creative outlet

¹³ Jerome J. Schultz, Ph.D., "Why School Stress is Toxic for Our Kids," ADDitude Magazine, accessed February 04, 2017, <u>http://www.additudemag.com/adhd/article/11630-2.html</u>. When the fear centers of the brain are activated, the area of the cortex in the front part of the brain, called the prefrontal cortex, is de-activated. The prefrontal cortex, along with the basal ganglia and the thalamus, controls the executive functions (organizing, planning, and executing tasks efficiently) that are critical to learning. In kids who are already at risk for academic difficulty because of ADHD, the secondary impact of stress puts them in a tailspin. Just when they need this important part of the brain, it shuts down. When stress goes up, cognitive ability goes down. In fact, research shows that chronic stress is associated with a larger amygdala and a decrease in the size of the cerebral cortex, suggesting that toxic experiences actually re-form the architecture of our brain.

¹⁴ Candace Cortiella and Sheldon H. Horowitz, The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014), PDF, New York: National Center for Learning Disabilities, 2014. Nearly half of the parents of children with learning disabilities (45 percent) say that their child has been bullied in the past year. Two-thirds of respondents (66 percent) feel that children with learning disabilities are bullied more than other children.

and savored the therapeutic relief making, learning, and interacting with your hands and senses offered. Looking back now, you realize you were never deficient or lacking; if anything, you were overflowing with everything, overwhelmed by having so much forced onto you at once. You weren't lazy or dumb; you were sidetracked by your mind's attempts to escape. It was a coping mechanism, one of the only ones you had, and you used it by engrossing yourself in things others couldn't see the value in, like art.

While drawing, painting, or studying the delicate patterns of the veins in your wrist next to the veins in a leaf, you immersed yourself in the natural world, finding peace away from the hurtful, confusing demands of people. You traced your fingertips over every rock and tree trunk and embraced every feathered, scaled, and furred creature that crossed your path. Flora and fauna were your companions. Like you, they were wary of humans, and, also like you, they had good reason to be. But the more time you spent hiding amongst the trees with your sketchbook and art supplies, the more the non-humans trusted and accepted you. You spoke the same sensory-based language. You drew your observations and committed to memory every scent, every sight, every sound, savoring the realness of places still untainted and untamed by the harsh will of humanity. You took comfort in natural cycles, like the ebb and flow of the seasons, and the rebellion of nature, against mans abusive, controlling hand.

In school, the teachers shook you from your escapist daydreams, forcing you back to their unpleasant reality while pushing you onto a tight, narrow path, in line with everyone else. Even the nice ones who meant well marched you along this claustrophobic route, explaining that you had to do things this way if you were going to get anywhere in the world. Because of your overactive nervous system, your emotions were always extreme. You never just got sad; you became heartbroken. You never just got angry; you grew fierce - hissing, spitting and fighting your captors like a feral, caged animal.¹⁵ Eventually, you realized you were screaming into an empty abyss, and you returned to the study of your veins.¹⁶ For some reason, opening them up made you feel better.¹⁷ With your energy spent, you never just got tired; you collapsed in a heap of exhaustion, so weighted down that even the thought of getting back up again seemed impossible. But the poking, prodding, and demanding continued; you remained trapped for weeks, months, and years, in a system that refused to widen the path for you or anyone else who was unable to conform.

¹⁵ Jerome J. Schultz, Ph.D., "Why School Stress is Toxic for Our Kids," ADDitude Magazine, accessed February 04, 2017, <u>http://www.additudemag.com/adhd/article/11630-2.html</u>. Fear centers go on high alert, and the thinking part of the brain shuts down in the service of survival. It's a circular, self-perpetuating cycle of fear, avoidance, and escape. Thousands of kids around the world are caught up in this cycle of defeat. Hundreds of teachers are reacting in absolutely the wrong way and making the problem worse. Only when children and adults understand this, and know how to break the cycle, will things get better.

¹⁶ Yasmin Anwar, "ADHD plus childhood trauma heightens risk for self-harm, suicide," Berkeley News, July 09, 2015, accessed February 06, 2017, <u>http://news.berkeley.edu/2015/03/03/adhd-plus-childhood-trauma/</u>. Young women with ADHD who have been exposed to abuse, neglect or other traumas in childhood and adolescence are at greater risk for self-injury, eating disorders and suicide than those with ADHD who were not mistreated in early youth, according to new research from UC Berkeley. The findings, just reported in the journal Development and Psychopathology, add to a growing body of evidence that environmental factors, including maltreatment in childhood, can have a significant bearing on the negative psychosocial outcomes of attention-deficit hyperactivity disorder.

¹⁷ Sian Ferguson, "4 Myths About Self-Harm We Urgently Need to Unlearn," Everyday Feminism, January 31, 2017, accessed February 04, 2017, <u>http://everydayfeminism.com/2017/02/self-harm-myths-urgently-unlearn/</u>. Whenever mental health issues are thrust into public spaces by sufferers, ... when we write about it, ... when we discuss it in public, ... when there's physical evidence that we've been self-harming, we're told we're seeking attention. Of course, this all feeds into mental health stigma. We're taught by society that mental health is something we need to be ashamed of, something that's inappropriate to discuss with others. Shaming people as attention-seeking when they discuss mental health is an integral tool of ableism.

CHAPTER TWO: AN INFLUENCE ON ME

You Can't Unchop A Tree... But You Can Plant A Forest

My world has no separation between art, activism, and identity. It is all one in the same: an extension of who I am, what I believe in, what I fight for, what I love, and what I need. I find it impossible to separate myself from my art because with a neurodivergent, hyperactive, highly sensitive nervous system like mine; you are what you feel (and you feel everything all the time without the ability to separate yourself or compartmentalize your emotions); it is always an intense reality.¹⁸ However, I feel that the intensity in which I sense and interact with the world is one of my strengths. Without it, I do not think I would have developed two of my best characteristics: my astonishing resilience in the face of adversity and my steadfast belief that I can (and eventually will) have a positive influence on this world if I continue to push forward in stubborn determination.

I have not shared my story with you to pull at your heartstrings; I do not desire sympathy or pity because these reactions are not helpful or productive. What I want is to be heard and understood. We can't go back in time and change what went wrong, but we can make a conscious effort to make better choices now and work on improving the future.

¹⁸ William Dodson, M.D., "Uncomfortable Truths About the ADHD Nervous System," ADDitude Magazine, accessed February 04, 2017, <u>http://www.additudemag.com/adhd/article/10497.html</u>. People in the ADHD world experience life more intensely, more passionately than neurotypicals. They have a low threshold for outside sensory experience because the day-to-day experience of their five senses and their thoughts is always on high volume. The ADHD nervous system is overwhelmed by life experiences because its intensity is so high.

My particular type of divergent thinking comes from a mix of neurological differences, including two I was born with - attention deficit hyperactivity disorder (ADHD) and learning disabilities (LD), and one I acquired after surviving brain-damaging trauma - post-traumatic stress disorder (PTSD). Researchers believe that as many as one-third of those with LD also have ADHD. Neurochemical differences in the brain cause some aspects of ADHD.¹⁹ Linked to heredity (genetics) and physical brain structure (which impacts brain function) both LD and ADHD are medically verifiable biological conditions.

I was finally diagnosed with ADHD as an adult, and my first reaction was relief. I had actual, tangible proof that my lifelong struggle was real; I wasn't exaggerating or making things up, and it wasn't a flaw in my character. Then came grief; not knowing the extent of my neurological differences caused irreparable damage.²⁰ Next, flooded with frustration towards all the systems and constructs that had hindered my progress, I lamented the lack of awareness and proper support. While most of my trauma was caused by the actions of others, a significant part resulted from people's ignorance and inaction. How many other people had this happened to, and how many more people would get lost in this broken system? I realized I needed to do something to bring awareness to this problem, which led me to the creation of this thesis.

¹⁹ Candace Cortiella and Sheldon H. Horowitz. The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014). PDF. New York: National Center for Learning Disabilities, 2014.

²⁰ Sian Ferguson, "4 Myths About Self-Harm We Urgently Need to Unlearn," Everyday Feminism, January 31, 2017, accessed February 04, 2017, <u>http://everydayfeminism.com/2017/02/self-harm-myths-urgently-unlearn/</u>. Learning more about mental health issues is a valuable tool in fighting stigma. For that reason, it's incredibly important that we unlearn harmful myths about issues like self-harm. By spreading awareness, instead of lies, we can equip people to help themselves and others.

I started digging deeper, researching ADHD and LD as well as their links and long-term implications. I found the work of Dr. Russell Barkley, a Clinical Professor of Psychiatry at the Medical University of South Carolina in Charleston and a leading researcher in ADHD. Dr. Barkley and his colleagues have compiled data from two extensive studies of adults with ADHD. This work evaluates the functioning abilities of participants in numerous major life activities. These were their conclusions:

Across all of our results, one thing seems abundantly clear – ADHD in adults is a significantly impairing disorder. It is associated with numerous difficulties in virtually every domain of major life activity....Whether one studies functioning in education, occupation, social relationships, sexual activities, dating and marriage, parenting and offspring psychological morbidity, crime and drug abuse, health and related lifestyles, financial management, or driving, ADHD can be found to produce diverse and serious impairments.²¹

Despite these conclusions, the many stigmas and myths surrounding ADHD persist. The

public lacks awareness about the reality of ADHD. Very few realize that it is an all-

encompassing, lifelong challenge. Sadly, testing, medication, and other helpful resources

are expensive and not always accessible. The lack of understanding and affordable

resources has far-reaching, negative consequences. Dr. Barkley continues:

Statements to the effect that ADHD is not a valid disorder but rather a myth created by pharmaceutical companies or mental health professionals for shear mercenary commercial gain, or that it is indistinct from the other disorders with which it may be associated are not only wrong; they are egregiously so.... To continue to make such statements in the face of such overwhelming evidence to the contrary is to either show a stunning scientific illiteracy or planned religious or political propaganda intended to deceive the uninformed or unsuspecting general public.²²

²¹ Russell A. Barkley, Ph.D. "ADHD in Adults: History, Diagnosis, and Impairments - by Russell A. Barkley, Ph.D. Accessed February 04, 2017.

²² Ibid.

According to *The State of Learning Disabilities: Facts, Trends and Emerging Issues*, those with learning disabilities do not fair much better:

There remains widespread confusion and misinformation about the nature and impact of LD. Lack of accurate information about LD increases the risk of stigmatization as well as the possibility of lowered expectations and missed opportunities in school, the workplace, and the community.²³

As I said earlier, all I want is to be heard and understood, not because my situation is special or unique but because it is *neither special nor unique*. The experiences I described are commonplace for many individuals who do not fit into the typical mold. Nevertheless, our society continues to force people into a broken system, ignoring the substantial pile of evidence that proves this method isn't working (and will never work). It is time to try a divergent approach. Let's remove the stigmas, offer supports, and make the invisible struggles tangible.

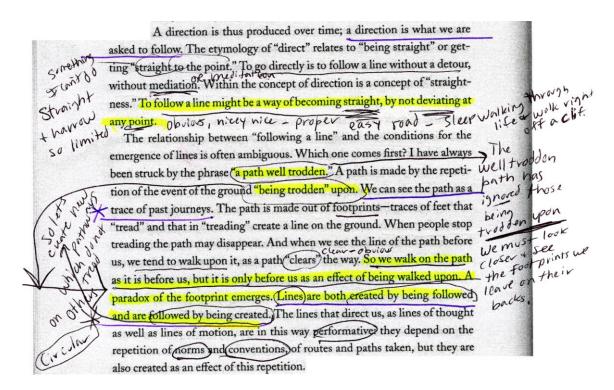
Going the Divergent Way

Over the last few years, I have strengthened my resolve to nurture hope and make a positive impact with my art, words, and actions. Since my ADHD diagnosis, I have been learning everything I can about neurodivergent ways of thinking. By deciphering how my brain works, I hope to translate my experience and this information into something visual to help neurotypical people understand the neurodivergent mind.

This process of researching, making, and reflecting led me to a place I had not anticipated; I ended up going full circle – back to my original way of looking at the world through the vast, kaleidoscopic lens of my former 4 or 5 year-old self. I realized the issues associated with divergence have one thing in common: an inability of those

²³ Candace Cortiella and Sheldon H. Horowitz. The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014). PDF. New York: National Center for Learning Disabilities, 2014.

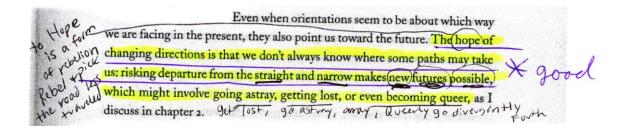
individuals to learn and thrive in a system made without taking their uniqueness into account.



Picture 2. Scan one of my handwritten notes on a passage from Sara Ahmed's Sara Ahmed's book, "Introduction Find Your Way." In *Queer Phenomenology: Orientations, Objects, Others.* Durham: Duke University Press, 2006.

It isn't that learning and thriving are impossible for people with ADHD, LD, or

any other thing our society sees as disabled, disordered, or deficit. If people are nurtured and allowed to go their own way, neurodivergence can be a gift or, at the very least, not a detriment.



Picture 3. Scan two of my handwritten notes on a passage from Sara Ahmed's book, "Introduction Find Your Way." In *Queer Phenomenology: Orientations, Objects, Others.* Durham: Duke University Press, 2006.

My younger self had loved learning in my own, tangible way, but being indoctrinated into the narrow confines of our so-called 'normative' institutions and constructs (i.e. typically organized schools, religions, genders, etc.) made learning and thriving impossible. I strongly believe that divergence (neuro- or otherwise) does not cause a deficiency, nor does it cause debilitating problems on its own; however, when forced into societal conformity problems arise. Aren't we all divergent in one way or another? Shouldn't this be the point, not the problem?

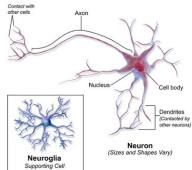
Going down a divergent path does not equate going down the wrong path. The divergent path is not the typical path; it is not the straight and narrow path, it weaves and meanders along the scenic route, but this is not a bad thing. Yes, it takes longer, but what is the rush to get to the end? I want to savor the journey and create new roads. Our current path of normative convention continues to cause harm and while this may not be our intention, it is the reality. Instead of continuing down this oppressive, well-trodden path, let's rethink our ways and make a new, better path forward.

An Introduction to Neurodiversity

Neurology is the study of the nervous system²⁴ and neurons (nerve cells).²⁵ As one might suspect, "neurodiversity" is a term used to promote neurological equality. The concept is simple; all humans exist on a spectrum of natural neurological variation, and all variations should be accepted, celebrated, and supported instead of treated as disorders or deficits.

Most people land somewhere in the middle of the neurodiversity spectrum; these people are the majority, and are, therefore, "typical," "neurotypical," or "typically minded." Anyone with more pronounced neurological differences (ASD, LD, ADHD,

²⁵ Bruce Blausen, Neural Tissue, 2013, Blausen gallery 2014, Wikiversity Journal of Medicine.



Neural Tissue

²⁴ IQWiG, "How does the nervous system work?", National Center for Biotechnology Information, August 19, 2016, accessed February 13, 2017, https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0072574/. The nervous system is made up of all the nerve cells in your body. It is through the nervous system that we communicate with the outside world and, at the same time, many mechanisms inside our body are controlled. The nervous system takes in information through our senses, processes the information and triggers reactions, such as making your muscles move or causing you to feel pain. For example, if you touch a hot plate, you reflexively pull back your hand, and your nerves simultaneously send pain signals to your brain. Metabolic processes are also controlled by the nervous system. There are many billions of nerve cells, also called neurons, in the nervous system. The brain alone has about 100 billion neurons in it. Each neuron has a cell body and various extensions. The shorter extensions (called dendrites) act like antennae: they receive signals from, for example, other neurons and pass them on to the cell body. The signals are then passed on via a long extension (the axon), which can be up to a meter long. The nervous system has two parts, called the central nervous system and the peripheral nervous system due to their location in the body. The central nervous system (CNS) includes the nerves in the brain and spinal cord. It is safely contained within the skull and vertebral canal of the spine. All of the other nerves in the body are part of the peripheral nervous system (PNS).

anyone usually labeled with words like disordered, deficit, disabled, etc.) fall into the outer edges of the spectrum of human variation, however, these individuals are as important, equal, and valuable as anyone else.

The term Neurodiversity originated in the late 1990s as activists for neuroequality (many of which were themselves divergent-minded) started this social activist movement. It promotes the idea that neurological differences should be recognized and respected as a social category on par with gender, ethnicity, sexual orientation, or other disability status.²⁶ Because neurological differences are largely invisible, it has been difficult to convince the typical population that these conditions are real. Neurodiversity advocates challenge outdated educational and societal systems that hold individuals back and instead seek to add more inclusion-focused services, accommodations, communication and assistive technologies, occupational training, and independent living support for those individuals who fall outside the neuro-typical realm.²⁷

Neurodiversity activists want typical society to understand that being neurotypical means they benefit from the privileges of being in the majority; one of these privileges being that social systems and norms were built around the way they think and see the world; which puts anyone who thinks or sees differently at an automatic disadvantage, simply by being in the minority. Neurodivergent people deserve a chance to be accepted

²⁶ Pier Jaarsma and Stellan Welin, "Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement," Health Care Analysis 20, no. 1 (2011): , doi:10.1007/s10728-011-0169-9.

²⁷ Autistic Self Advocacy Network, "Position Statements," Autistic Self Advocacy Network, accessed February 04, 2017, <u>http://autisticadvocacy.org/home/about-asan/position-statements/</u>

and supported, to live life as they are, rather than being coerced or forced to adopt the typically formed and accepted ideas of normality or to conform to a clinical ideal.²⁸

Thankfully, recent technological breakthroughs have started to make otherwise invisible, un-seeable differences in brain structure and function visible. Neurologists are now able to use brain-imaging scans to pinpoint these physical, biological differences. Hopefully, as this technology develops, more doctors will be able to see these internal differences, make better diagnoses, increase understanding that these are biological conditions, and reduce the stigmas and myths.

Words, Verses, Pictures...

Hypothetically, most neurotypical people think in words, and this helps them organize their thoughts. I, however, do not think in words; my thoughts are always vibrant, organic, chaotic pictures: pure imagery bursting with color, texture, light, shape, intensity, and experience. My emotions and my feelings produce images in my mind as I experience them. I create visual art because it is the natural way for me to express and communicate; it is my default setting.

Dr. Temple Grandin describes this entirely visual way of thinking best: "Words are like a second language to me. I translate both spoken and written words into full-color movies, complete with sound, which run like a VCR tape in my head." She explains, "When somebody speaks to me, his words are instantly translated into pictures."²⁹ Dr.

²⁸ National Symposium on Neurodiversity, "What is Neurodiversity?", National Symposium on Neurodiversity at Syracuse University, March 23, 2012, accessed February 15, 2017, <u>https://neurodiversitysymposium.wordpress.com/what-is-neurodiversity/</u>.

²⁹ Temple Grandin, Dr., "THINKING IN PICTURES: Autism and Visual Thought," THINKING IN PICTURES: Autism and Visual Thought, 2006, accessed February 06, 2017, http://www.grandin.com/inc/visual.thinking.html.

Temple Grandin's explanation of her image-centered mind perfectly encapsulates my experience, as well.³⁰

After a lifetime of wrestling with words (those obnoxious little beasts), I remain surprised by the strange sort of power they hold over us. A single word can say so much, especially when there is intent or agenda behind it.³¹ For example, take the word "disability." The slang term "to dis" means "to insult." The prefix *"dis-"* means the opposite or absence of, so when you put "dis-" in front of "ability," it is easy to understand how this structure is problematic. So many other words associated with neurological diversity such as "dysfunction," "deficit," and "disorder" have similar issues. These words have negative implications.

When trying to decide what to name this thesis, I knew the title had to be expansive like the image and feeling it invoked in my mind, but it was difficult to find a suitable written word that accurately translated my mental vision. In my head, it looks like a nebula of new stars - bursting, glowing, burning, pulsing, flowing - full of fluorescence and energy yet surrounded by velvet and comforting darkness - fluid and

³⁰ Dr. Temple Grandin has a diagnosis of autism (now called autism spectrum disorder or ADS), and I have a diagnosis of ADHD+. However, neurologists are now starting to question if ADHD is actually a part of the autism spectrum. There are many similarities and much overlap between these so-called disorders and new studies, and scientific research is pointing more and more to their connections.

³¹ Carolyn Zaikowski, "6 Ways Your Social Justice Activism Might Be Ableist," Everyday Feminist, September 20, 2016, accessed January 13, 2017, http://everydayfeminism.com/2016/09/social-justiceactivism-ableist/. Are academic terms and concepts important? Yes! Is a purist use of them more important than inclusivity and compassion? Never. Ensuring spaces which center the least privileged experience must come first – always. It's not that academic, "intellectual" English has no place; it's that academics need to recognize it as a dialect of privilege and measure this against their goals.... It's the height of so many "isms" – ableism included – to presume that one's own intellectual or academic achievement is the neutral standard against which all should measure themselves, and to call out people on that basis. Just because someone doesn't completely understand your words, doesn't mean they aren't as oppressed or revolutionary as you.

warm like a womb, buoyant, contemplative, and knowing. "Influence" was the closest word I could find.

As we use it today, influence is "the capacity or faculty of providing effects by insensible or invisible means" without "employment of material force" or an "excess of formal authority."³² Influence is ascendance: sway, pull, but not overtly forced. All of this fits with my mental image, but the best part of influence is its original meaning, which was used in the 1300s to describe an ethereal fluid believed to flow and stream "from the stars or heavens" that affected "subliminal things generally" but also acted on "the character or destiny" of humans.³³ Influence is exactly right.

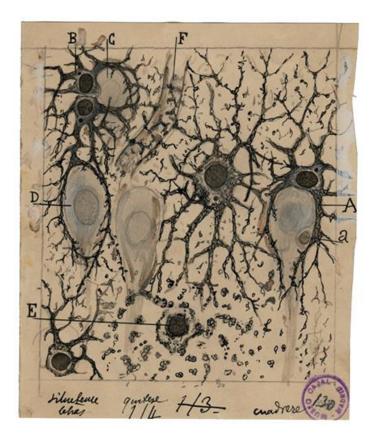
It is difficult to describe all the things that go on inside my head with words, but please believe that this is my reality, unexplainable as it might be. It is exhausting, confusing, strange, and overwhelming, but it is frequently wondrous, beautiful, exhilarating, and illuminating, and I want to share it with you. My thesis installation, titled *Influence*, is the manifestation of this desire.

³² E. S. C. Weiner and J. A. Simpson, "Influence," in The Oxford English dictionary (Oxford: Clarendon Press, 1989).

³³ Ibid.

CHAPTER THREE: AN INFLUENCE OF ART

Widely regarded as the father of modern neuroscience, Santiago Ramón Cajal, was also an artist. His neurological drawings were the starting point for my visual thesis artwork. I based my neurons on the shapes and structures he observed through his microscope lens.³⁴



Picture 4. "*Neurological Drawing*," Santiago Ramón y Cajal. Article by Darren Orf, and Avery Thompson. "When Neurologists Were Also Artists." Popular

³⁴ Alva Noë, "The Art Of The Brain, On Exhibit," NPR, January 20, 2017, accessed February 13, 2017, http://www.npr.org/sections/13.7/2017/01/20/510528975/the-art-of-the-brain-on-exhibit?

Mechanics. January 17, 2017. Accessed February 15, 2017. http://www.popularmechanics.com/science/health/g2923/brain-scan-cajal/?slide=4.

I enjoy the unruly way Cajal's biological based drawings push at the boundaries of the clinical page. His drawings (which imply the chaos of life cannot be contained by the paper) gave me the idea to fill a space with large, neural structures that couldn't quite be held by the sterile gallery walls.



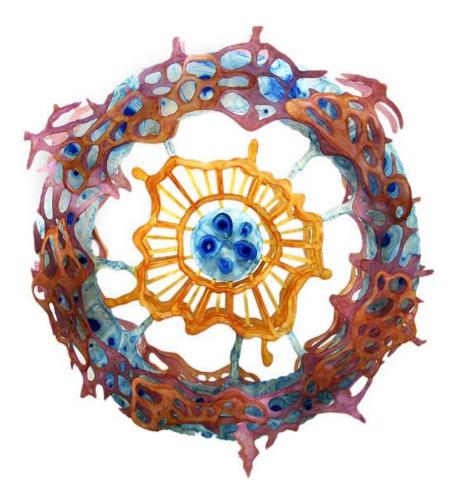
Picture 5. "Influence" - Installation Gallery Corner View, Anna Matejcek, 2017

The concept for my visual thesis formed in my mind, first, as a blur of shapes and colors that came into focus as I began the process of gathering and testing the materials. Eventually, I replicated my internal vision into the tangible with the use of fibers, plastics, latex, and light. The physical results of this process are five, bright, bold sculptures representing healthy, active neuron cells of my ADHD and LD mind and a sixth, dark, limp sculpture representing a neuron damaged by PTSD. Arranged in the gallery space my soft sculptures function as an installation. They are interwoven and entwined, interacting with one another, similar to the neurons in the brain. They hang, suspended in the air at varying heights, connected to each other by their dendrite tendrils. Cajal's biologically based diagrams were a good starting place because, as Alva Noë, author of "The Art Of The Brain, On Exhibit," explains,

These creations of Cajal's were realizations not so much of what Cajal saw — a messy arrangement under the glass — but of what he understood he was seeing... there's something mysterious and astonishing and implausible and imaginary about these drawings. With their captions, they are tamed. But remove the captions, or ignore them, and you are confronted with an intense and, even, I want to say, intensely personal construction of line pattern and shape.³⁵

Similarly, my flexible neuron sculptures confront the viewer with their intensity of color, texture, line, pattern, shape, and scale. They are my bold interpretation of how I imagine the neurons in my brain look; they are the concept of neural networks, but not necessarily the reality.





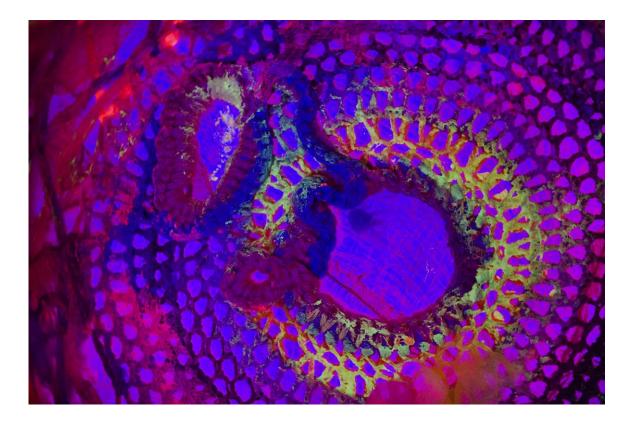
Picture 7. "Cellular Dialogue", Rebecca Kamen, 2012. Article by Ellen Rolfes, "Portrait of a dyslexic artist, who transforms neurons into 'butterflies." PBS. April 16, 2014, accessed February 1, 2017. http://www.pbs.org/newshour/updates/neuroscience-art-brain/.

Another artist of influence is Rebecca Kamen. Kamen has dyslexia, and her experiences and interests sound similar to my own. "I learned about things by taking things apart, examining them," Kamen says. "I think that enabled me to develop the skills of working with my hands more than just processing things in a more linear way."³⁶ Likewise, I learn best through the tactile process of working with materials, through trial,

³⁶ Ellen Rolfes, "Portrait of a dyslexic artist, who transforms neurons into 'butterflies." PBS. April 16, 2014, accessed February 1, 2017. <u>http://www.pbs.org/newshour/updates/neuroscience-art-brain/</u>.

error, and sensory experimentation.

Science has been a muse for Kamen as well. She believes that the artist and the scientist have similar missions, as both search for meaningful patterns and deal with invisible worlds. Her sculptures reflect these similarities. For example, Kamen makes sculptures out of mylar, which she stains rather than paints. She wants to mimic the processes scientists use to make tissue more visible and observable. "They will cut a very thin slice of brain matter, in the case of a neuroscientist, and then they will introduce a stain to it," Kamen says, "in order to see finer details under a microscope."³⁷



Picture 8. ''Influence'' - Detail of Neuron Cell Body, Anna Matejcek, 2017

Like Kaman, my material choices were driven by my concept. While physical flexibility was crucial for the way I planned to hang and display my neuron sculptures, I

³⁷ Ibid.

also wanted their flexibility to be a metaphor of the plasticity and adaptability of the human brain. Neurons form networks that physically connect, web, and flash with light as electrical impulses travel between them relaying information, linking our ideas and thoughts. The act of learning creates new physical connections inside of our brains.

I began the process of making by crocheting and macraméing the neuron cell body exteriors, connecting them at their edges, and crocheted yarn around the exterior, for strength and visual continuity. I used chunky and bulky types of heavy worsted weight yarn for the majority of the project because these yarns are flexible, durable, and come in a wide range of vibrant colors.



Picture 9. "Influence" - Dendrite Yarn Detail, Anna Matejcek, 2017

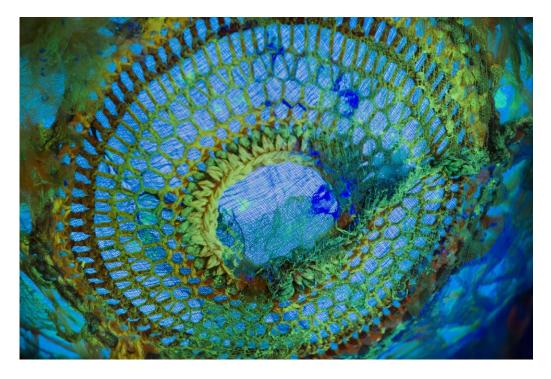
To create the neuron cell bodies, I inflated the beach ball spheres to their full capacity, covered them with hand-dyed cheesecloth, and adhered the materials with a mixture of liquid latex and acrylic paint. Physically, liquid latex is very versatile, and its ability to stretch, flex, and bounce back worked conceptually for my project. Once dried and cured, I deflated the spheres and inserted them inside the neuron cell body exteriors. After re-inflating the spheres, I cut strips of fleece, braided them, and attached them around the exterior edge of the cell body.



Picture 10. "Influence" - Cell Body Construction Detail, Anna Matejcek, 2017

Next, I crocheted around the fleece braids to add texture, length and varied branches of dendrite tendrils. Fleece is a synthetic fabric frequently used to make children's blankets and many craft projects. Technically speaking, I used fleece for this project because of its durability, range of vivid colors, flexibility, and for the fact it does not fray. It easily stretches, cuts, and braids yet it has the strength that I needed for the interior of my tendrils. Conceptually, fleece was an obvious choice because it has a reputation as a cheap, low status, poor quality material. Like neurodivergence, fleece is easily discounted and dismissed, but it has value. Fleece is so soft and warm it is difficult not to find it inviting and comforting. I embrace this contradiction between form, function, and materiality.

To represent the process of neuron axons relaying information, I selected 16-foot, color-changing LED strips. I chose these because of the way their varying flashes of light mimic electrical connections in the brain. I inserted the LED strips into clear, plastic tubes for protection, then covered these tubes with tulle, paint, latex, and dyed cheesecloth. I cut hollow foam pool noodles, shaped them into ovals, added color and texture using the same process as the axon construction, and fitted them into place over the axon tubes to represent myelin sheaths. Lastly, I added more dyed cheesecloth, latex, and paint to the entire neuron exterior which melded the piece together, created continuity, and fused with the yarn and cloth fibers as it dried, leaving a colorful, slimy, sticky texture.



Picture 11. "Influence" - Cell Body Texture Detail, Anna Matejcek, 2017

My latex and paint mixture protects and cushions what it surrounds, creating a barrier, just like cerebrospinal fluid. The gooey, dripping, physical properties of this material seem biologically reminiscent of cerebrospinal fluid (the watery substance found around the brain and spine) as well. Like Kamen, I used material choices to emphasize my subject matter.

Neurodivergent artists are helping researchers understand the ways that biology produces creativity through traits like inhibition and obsession. Anjan Chatterjee, a neurologist at the University of Pennsylvania in Philadelphia, says, "There are virtually no situations where brain damage makes things better," however, he goes on to say, "but art is one of the few complex aspects of human cognition that doesn't necessarily get worse."³⁸ For example, at 44 years old, artist Katherine Sherwood, experienced a

³⁸ Katherine Sherwood, "Artwork," Katherine Sherwood Website, Sherwood Section Katherine's Artwork, accessed February 11, 2017, <u>http://www.katherinesherwood.com/sherwood/art/sherwoodart.html</u>.

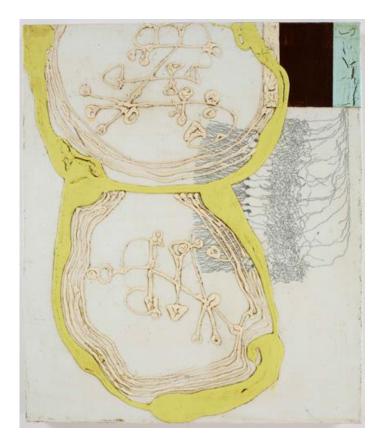
hemorrhage in her brain's left hemisphere that paralyzed the right side of her body.³⁹ You would expect such an event to be a major setback, but Sherwood persisted and figured out new ways to create. In the article, *"After Brain Damage, the Creative Juices Flow,"* Emily Sohn describes Sherwood's artistic practice after the stroke.

She could no longer paint on canvases mounted vertically, so she laid them flat, moving around them in a chair with wheels. She learned how to work with her left hand; it had less fine motor control but was more free and natural in its movements... And she began to more deeply explore the beauty of blood vessels in the brain after seeing some of her own brain scans.⁴⁰

Katherine Sherwood's work changed after her brain hemorrhage, but not for the worse. She used her experience of becoming divergently minded as a jumping-off place for her work. You can see this connection to her life-changing experience and newfound interest in neurology in her piece *"Worldy Wisdom"* where she incorporates intricate neuron webs into the background. I interpret the foreground shapes, colors, and textures as a nod to the biological as well.

³⁹ Ibid.

⁴⁰ Emily Sohn, "After brain damage, the creative juices flow for some." Los Angeles Times. May 20, 2011, accessed February 11, 2017. <u>http://www.latimes.com/health/la-he-diseases-art-20110516-story.html</u>.



Picture 12. "Worldy Wisdom", Katherine Sherwood, 2012. "Artwork." Katherine Sherwood Website. Accessed February 11, 2017. http://www.katherinesherwood.com/sherwood/art/sherwoodart.html.

Similarly, my sculptural installation, *Influence*, was based on my experience of being divergent minded. To show the vibrant side of my way of approaching the world with ADHD, I created five, healthy, ADHD powered neurons. While their colors and lights lure you in, they can become overwhelming and make you want to step away. This is how it feels to live with ADHD: you are in a constant state of being pulled towards stimuli, your attention grabbed by anything and everything, however, there is also an element of overstimulation where you get bogged down by too much information. With ADHD, the same stimuli can cause different reactions, sometimes appealing and sometimes appalling, depending on what else has been going on and your overall mood. These differing reactions are not something that people with ADHD have control over; therefore, when you have ADHD, you never know when you're going to be compelled or repelled.



Picture 13. "Influence" - Installation Gallery Front View, Anna Matejcek, 2017

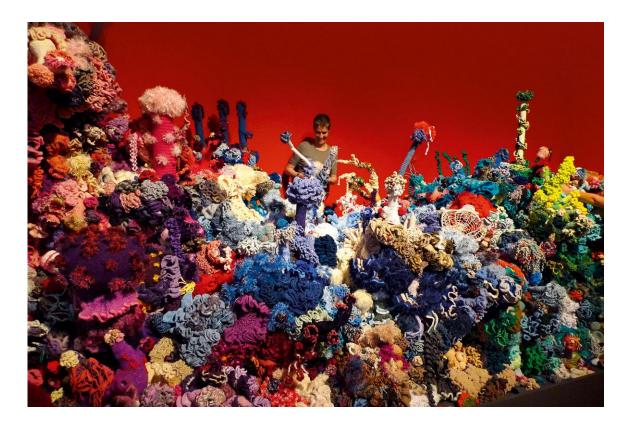
My sixth neuron is smaller, flatter, and darker, representing a brain cell damaged by trauma. A mixture of nearly black and maroon, accented with dark green, violet and soft baby pink, it was made to look bruised, gnarled, and unhealthy. It does not have the vibrant hues, light or energy of the other five. Instead, it looks withered and sad; it lies on the ground, in the corner, taking up less space and reaching up to the healthy neuron above. This otherwise healthy supporting neuron flashes faster and more sporadically than the others; as if in distress from the burden of holding up this clinging damaged cell. This is what it feels like to have PTSD; it is a constant weight, which exhausts your resources. It is unclear to the viewer as to whether the PTSD cell is draining energy from the healthy cell above, or if the healthy cell is working harder, trying to revive its neighbor, but, either way, the extra stress caused by the damage is observable in the work.



Picture 14. ''Influence'' - PTSD Neuron and Stressed Neighbor Neuron Detail, Anna Matejcek, 2017

Fiber art is rooted in the history of women's handicraft. Gender is imbedded in fibers, and *Influence*, as a fiber art work, is, therefore, inevitably gendered by history and my hand, as a woman. Author Jeanne Vaccaro states, "coded in feminine and feminist ways: handicraft is characterized as 'women's work,' and the collective labor of the artwork bridges' public and private spheres in a gesture to the consciousness-raising ethos of the feminist slogan 'the personal is political."⁴¹

⁴¹ J. Vaccaro, "Feelings and Fractals: Woolly Ecologies of Transgender Matter," GLQ: A Journal of Lesbian and Gay Studies 21, no. 2-3 (2015), doi: 10.1215/10642684-2843347.



Picture 15. "*Föhr Reef (Crochet Coral Reef Project)*", Margaret Wertheim, Museum Kunst der Westküste, Föhr, Germany, 2012. Crochet Coral Reef Gallery | Crochet Coral Reef. Accessed January 11, 2017. http://crochetcoralreef.org/coralreef-gallery.php.

An example of this type of consciousness raising handicraft is the *Crochet Coral Reef Project*, created and curated by sisters Christine Wertheim and Margaret Wertheim. The *Crochet Coral Reef Project* is a fusion of art, science, mathematics, handicraft, and community practice, and it is one of the largest community art projects in the world.⁴² The Wertheim sisters were inspired to make crochet reef forms after the technique of hyperbolic crochet was discovered in 1997 by Cornell University mathematician, Dr. Daina Taimina. The Wertheim sisters adopted Dr. Taimina's techniques and elaborated

⁴² Margaret Wertheim, "About the Project," Crochet Coral Reef, accessed January 11, 2017, <u>http://crochetcoralreef.org/about/index.php</u>.

upon them to develop a whole taxonomy of reef life forms.⁴³

In *GLQ: A Journal of Lesbian and Gay Studies*. Jeanne Vaccaro, author of "Feelings and Fractals: Woolly Ecologies of Transgender Matter," writes about this project,

... Making things with the hands intervenes in hierarchies of sensory knowledge to value the work of sensation and touch and make a potentially difficult idea tactile and intimate. Figuring a calculation is a labor shared by our motor, optic, and cognitive capacities. In crochet and handicraft, figuring yields a felt dimensionality and augments our limited ability to know a thing as impossible and imaginary as hyperbolic space. Reef makers take yarn and repurposed plastic trash in a hopeful occupation of a different perspective, abundant, infinite, and spiraling outward, proliferating an excess of surfaces, points of parallel, curvature, and intersecting lines.

Jeanne Vaccaro believes that the action of stitching (crocheting) "is attached to a hopeful idea—it points to the potential of small and private alterations," and, "over time, these small alterations add up to something monumental and inspire institutional and public dialogue."⁴⁴ My thesis artwork has a similar goal (enticing dialogue) and works towards this goal in a similar way (small, private alterations add up over time) as the *Crochet Coral Reef*.

While I made my installation with the Hemingway Gallery in mind, I built the neuron sculptures so that they could be changed and manipulated into many different configurations depending on the exhibition space that was available. Like real neurons and neurodivergent thinking, my concept was to create sculptures that were adaptable and capable of filling many different spaces. My intention was to remind us that there is

⁴³ Ibid.

⁴⁴ J. Vaccaro, "Feelings and Fractals: Woolly Ecologies of Transgender Matter," GLQ: A Journal of Lesbian and Gay Studies 21, no. 2-3 (2015), doi: 10.1215/10642684-2843347.

rarely only one correct answer; usually, there are many different ways to solve a problem. My neuron sculptures are lopsided and imperfect, which again fits with my concept of accepting and embracing imperfection and difference.⁴⁵ The installation has no specific focal point. It is a complex system that feels busy but is also organized; it bounces between order and chaos.

The materials used in my neuron sculptures include: reactive, fluorescent pigment, inflatable beach balls, LED strip lights, cotton cheesecloth, dye, UV lights, yarn, fleece, latex, and tulle. Colors are full-spectrum, bright, fluorescent neon, glowing, hyper, and reactive. All of the materials that I chose tend to lean more towards kitsch and craft than traditional fine art materials. I wanted to utilize materials that are usually ignored in the fine art world as a way to challenge the status quo and create a spectacle.

In "Feelings and Fractals: Woolly Ecologies of Transgender Matter," Jeanne Vaccaro explains how fiber, labor, process, and materials of handiwork can be used to illuminate the biological and cultural constructions of sex, gender, and the role of craft.

...the elastic materials of fiber arts build a dimensional record of bodily experience.... As a felt method, the intervention that the handmade offers is to reexamine method as the ordering — its patterns, repeats, echoes (as waves of the sonic, oceanic thumps, and women's and feminist politics and studies) — of bodily knowledge. In other words, hand making is a mode of knowing and doing objects and bodies. The handmade is an operating system or guide, a fleshy science to untangle ordinary shapes and feelings of embodied life and its intersections with vibrant matter and toxicity.⁴⁶

⁴⁵ J. Vaccaro, Ibid. My investment in method for transgender studies is in parsing the tasks of mimetic responsibility and process and untangling the associations of method with novelty, discovery, and invention to make count the ordinary feelings of identity. The demand to feel wrong, to perform a wrong body and a broken feeling, and not, for example, the pain of a discrimination, forecloses the dimensionality of feeling and the fissures, seams, and textures of experience, those things impossible to encapsulate in diagnostic language. The history of the clinic, to the way gender "deviant" and nonconforming bodies are made objects of scientific practice, sexological and psychiatric diagnosis.

In the essay, "*Put Your Thing Down, Flip It, and Reverse It*", Lacy Jane Roberts' writing expands upon the role of gender in craft, "Craft can gain from the methods and tools that queer theory has deployed to reclaim and reconfigure its own marginal position into a place of empowerment."⁴⁷ Similarly, I believe neurodivergence can reclaim and reconfigure its place beside gender with the help and use of craft.

⁴⁷ Lacey Jane Roberts, "Put Your Thing Down, Flip It, and Reverse It: Reimagining Craft Identities Using Tactics of Queer Theory," in Extra/Ordinary: Craft and Contemporary Art (Durham and London: Duke University Press, 2011).

CHAPTER FOUR: OUR INFLUENCE

As humans, we frequently say that we want to be different, but what we usually mean is that we want the autonomy to define ourselves; we don't want others to label us. Imposed labels can be painfully oppressive; eventually, you might be able to reclaim your label and use it in a positive and productive way, but this does not remove it; it never goes away. In the article, "6 Ways Your Social Justice Activism Might Be Ableist," Carolyn Zaikowski, discusses the way that imposed labels and assumptions impact disabled people.

Folks with relatively visible disabilities, such as those requiring wheelchairs or braces, come up against innumerable social obstacles. From implications that they must be completely helpless and depressed, to assumptions that they are asexual or not fully adult, to the idea that they exist to be inspirational, these folks encounter seemingly bottomless ignorance. People with "invisible disabilities" struggle in unique ways, too. Loved ones, doctors, co-workers, allies, and strangers regularly imply that our symptoms are exaggerated or made-up and that we aren't trying hard enough in our various social roles. We don't "look sick," after all. Stereotypes around gender, sex, race, age, class, and culture can exacerbate these assumptions. But countless disabilities and illnesses are not accompanied by an external signifier.⁴⁸

Zaikowski goes on to explain that ableism, like any oppression, doesn't only take the form of 'obvious' violence. She points out that disabled people frequently experience institutional discrimination in their jobs and education, they lack representation in politics, art, and media and suffer, "extremely high rates of abuse and neglect; and

⁴⁸ Carolyn Zaikowski, "6 Ways Your Social Justice Activism Might Be Ableist," Everyday Feminism, September 20, 2016, accessed February 03, 2017. <u>http://everydayfeminism.com/2016/09/social-justice-activism-ableist/</u>.

dangerous stereotyping"⁴⁹ Ableism, she argues, should be a part of any conversation

regarding intersectionality, yet it is frequently forgotten, even in social justice spaces.⁵⁰

Unfortunately, harmful stereotypes abound when it comes to disability, and

unfortunately, people like doctors, educators, and counselors (even some of which are

disabled themselves) frequently uphold the status quo.

Author Wilma Fellman, M.Ed., LPC., a career counselor specializing in ADHD,

is widely regarded as an expert. However, when her clients ask if they should tell their

boss about their ADHD, her answer is almost always "No." She goes on to explain,

Many ADHD adults who have just received their diagnosis are so relieved and elated to know—finally—the source of their symptoms that sharing the news of their diagnosis with the world seems like a natural, liberating thing to do. They tell family, friends, and the boss, often believing that the big guy will tolerate their tardiness or missed deadlines now that he knows what's causing them. The problem is, the boss might not. Not everyone is positive or knowledgeable about ADHD, and you don't want your boss thinking you are making excuses. Even if he does know about the condition, he may not have the time, resources, or inclination to help you overcome workplace shortcomings. The better option is to take steps to improve your performance without telling the company that you have the condition.⁵¹

I can understand this argument, and I do agree that we should always take steps towards self-improvement. However, telling people to hide their diagnosis only perpetuates the negative association of a diagnosis in that individuals mind and validates their shame and fear. "Telling us to suck it up and try harder is like telling a visually impaired person to see harder," says ADHDer and author June Silny. "You can't see what he sees; you trust him when he tells you the world is a blur, and you let his glasses do their job." ADHD,

⁴⁹ Ibid.

⁵⁰ Ibid.

⁵¹ Wilma Fellman, M.Ed., LPC, "Should You Tell Your Boss About Your ADHD?," ADDitude Magazine, accessed February 15, 2017, http://www.additudemag.com/adhd/article/816-2.html.

she points out, is no different. "Trust us that we would fix our symptoms if we could, and we're doing our best with the tools we have."⁵²

When you think about Wilma Fellman's advice in that context, it points out the double standard of invisible disabilities much more clearly. You would never tell a visually impaired person to try and hide the fact that they cannot see; the idea is ludicrous. And even if they tried to follow that advice, how long would they be able to keep up the farce? By telling them to try to be typical, what kind of message is that sending to them? The answer is obvious: it is telling them to conform and pretend to be like everyone else because that is the only way to be. It is reinforcing the incorrect idea that they are broken and should be ashamed.

Dr. William Dodson, a board-certified adult psychiatrist who has specialized in adults with ADHD for the last 23 years, explains that shame originally meant to 'hide or cover up,' and therefore, shame is hard to deal with because it tends to be hidden and is rarely addressed. He explains, "Feeling shame is different than feeling guilt. Guilt focuses on what one has done. Shame focuses on who one is."⁵³ In his experience, Dr. Dodson says many ADHDers feel separate and unequal, and that their repeated failure to meet others' expectations fosters shame. He says, "it is estimated that those with ADHD receive 20,000 more negative messages by age 12 than those without the condition. They view themselves as fundamentally different and flawed."⁵⁴

That means, on average, a child with ADHD will hear 4.5 more negative

⁵² June Silny, "The Civil War Inside My Brain," ADDitude Magazine. Accessed February 13, 2017, http://www.additudemag.com/slideshow/220/slide-6.html.

⁵³ William Dodson, M.D., "Feeling Bad About Oneself with ADHD," ADDitude Magazine, accessed February 15, 2017, <u>http://www.additudemag.com/slideshow/83/slide-3.html</u>.

⁴⁰

messages about their character per day than a typical child. Those negative messages leave deep marks on a child's developing mind. That child then grows into an adult, and the negative messages persist. Yet Wilma Fellman insists disclosure should be carefully thought through.

... avoid the "perceived threat," which puts a company's executives and human resources on the defensive. If a boss hears the words "disability" and the "American Disabilities Act" in the same sentence, he or she will suspect that you'll be filing a lawsuit. To succeed on the job, you want your company working with you, not against you.⁵⁵

The words "accommodations," "disability," or even the "Americans with Disabilities Act" should not invoke a threat. The legal system can be abused, but the vast majority of people living under some type of oppression are not trying to cheat, steal, or threaten. The fact that this is not blatantly obvious points to the much larger problem that we are facing as a society. We cannot afford to continue to reinforce these negative stereotypes; it is dehumanizing, damaging, and how crimes against humanity begin.

If I have learned anything from all my experiences, it is that neither changing our circumstances nor our behaviors comes easily. I have to constantly remind myself of the changes that I want to see in the world and to make a conscious decision to keep moving in that direction. In the article, "Intent vs. Impact: Why Your Intentions Don't Really Matter", Jamie Utt states,

What we need to realize is that when it comes to people's lives and identities, the impact of our actions can be profound and wide-reaching. And that's far more important than the question of our intent. We need to ask ourselves what might be or might have been the impact of our actions or words. And we need to step back and listen when we are being told that the impact of our actions is out of step with

⁵⁵ Wilma Fellman, M.Ed., LPC, "Should You Tell Your Boss About Your ADHD?," ADDitude Magazine, accessed February 15, 2017, <u>http://www.additudemag.com/adhd/article/816-2.html</u>.

our intents or our perceptions of self.56

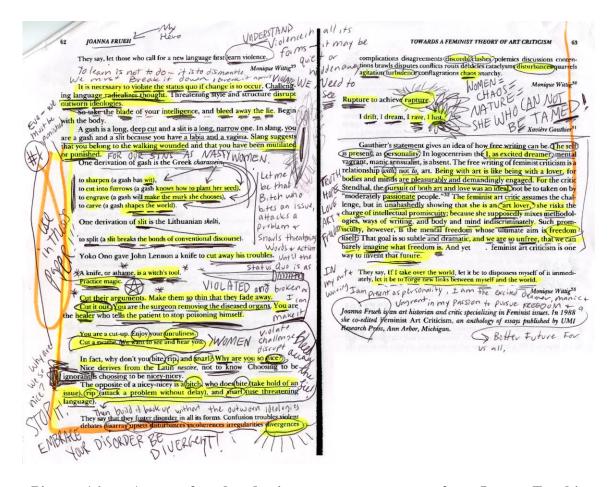
As hard as it is to accept, this advice is sound. The impact of our actions and words can harm, regardless of our intentions, and when this happens, we should acknowledge the harm and change our behavior accordingly. When the harmed party speaks up, we should listen to their concerns and attempt to empathize and make the situation better.

It is scary to open yourself to the world, especially when you know how cruel it can be. By writing this thesis, disclosing my diagnosis, and laying bare all my weaknesses and insecurities, am I making a mistake that will haunt me and ruin my chances of finding employment in the future? Perhaps, but I have decided it is a risk worth taking. A piece of me will probably always want to run and hide, but I would rather be vulnerable and courageous than safe and a coward. It may sound naive and optimistic, but I would rather keep my naivety and march on with a purpose than give up in despair. I have learned that having enough hope not to give up on yourself, on others, and on your situation is its own powerful type of a rebellion and resistance.

In her essay, Joanna Frueh reminds us, "It is necessary to violate the status quo if change is to occur."⁵⁷ Frueh encourages us to 'cut away' the standard arguments and 'cut out' the poisoned parts from our society. She insists we must 'cut up' and 'rupture to achieve rapture' ... and she is right.

⁵⁶ Jamie Utt, "Intent vs. Impact: Why Your Intentions Don't Really Matter," Everyday Feminism, May 08, 2016, accessed February 15, 2017, <u>http://everydayfeminism.com/2013/07/intentions-dont-really-matter/</u>.

⁵⁷ Joanna Frueh, "Towards a Feminist Theory of Art Criticism." In *Feminist Art Criticism: An Anthology*, 62-63. New York, NY: IconEditions, 1991.



Picture 16. A scan of my handwritten notes on a passage from Joanna Frueh's essay, "Towards a Feminist Theory of Art Criticism." In *Feminist Art Criticism: An Anthology*, 62-63. New York, NY: IconEditions, 1991.

These days I wake up every morning and ask myself, 'what can I do?' and the only answer that I can live with is to take the more difficult route, resist the temptation to give up, and continue to fight my way forward. I will use everything I have – art, images, words, ideas, feelings, senses, and everything I am – to slash through the obstacles and clear the path, open the way, and widen the road. Art is my tool to instigate change and hopefully, anyone who follows the divergent path after me will encounter less resistance due to my efforts. I will continue my creative quest to make the invisible visible and fight for everyone's right to embrace their divergence. As an artist, I will enjoy my unruliness, and as a viewer of my work, I encourage you to join me.

REFERENCES

- Ahmed, Sara. "Introduction Find Your Way." In *Queer Phenomenology: Orientations, Objects, Others.* Durham: Duke University Press, 2006.
- Anwar, Yasmin. "ADHD plus childhood trauma heightens risk for self-harm, suicide." Berkeley News. July 09, 2015. Accessed February 06, 2017. http://news.berkeley.edu/2015/03/03/adhd-plus-childhood-trauma/.
- Autistic Self-Advocacy Network. "Position Statements." Autistic Self-Advocacy Network. Accessed February 04, 2017. http://autisticadvocacy.org/home/aboutasan/position-statements/.
- Barkley, Russell A., Ph.D. "ADHD in Adults: History, Diagnosis, and Impairments by Russell A. Barkley, Ph.D." Accessed February 04, 2017. http://www.continuingedcourses.net/active/courses/course034.php.
- Blausen, Bruce. Neural Tissue. 2013. Blausen gallery 2014, Wikiversity Journal of Medicine.
- Cortiella, Candace, and Sheldon H. Horowitz. *The State of Learning Disabilities Facts, Trends and Emerging Issues (Third Edition, 2014).* PDF. New York: National Center for Learning Disabilities, 2014.
- Dodson, William, M.D. "Uncomfortable Truths About the ADHD Nervous System." ADDitude Magazine. Accessed February 04, 2017. http://www.additudemag.com/adhd/article/10497.html.
- Dodson, William, M.D. "Feeling Bad About Oneself with ADHD." ADDitude Magazine. Accessed February 15, 2017. http://www.additudemag.com/slideshow/83/slide-3.html.

- Fellman, Wilma, M.Ed., LPC. "Should You Tell Your Boss About Your ADHD?" ADDitude Magazine. Accessed February 15, 2017. http://www.additudemag.com/adhd/article/816-2.html.
- Ferguson, Sian. "4 Myths About Self-Harm We Urgently Need to Unlearn." Everyday Feminism. January 31, 2017. Accessed February 04, 2017. http://everydayfeminism.com/2017/02/self-harm-myths-urgently-unlearn/.
- Frueh, Joanna. "Towards a Feminist Theory of Art Criticism." In *Feminist Art Criticism:* An Anthology, 62-63. New York, NY: IconEditions, 1991.
- Grandin, Temple, Dr. "THINKING IN PICTURES: Autism and Visual Thought." THINKING IN PICTURES: Autism and Visual Thought. 2006. Accessed February 06, 2017. http://www.grandin.com/inc/visual.thinking.html.
- Grosz, Elizabeth. "Sexual Signatures: Feminism After The Death of The Author." In Space, Time and Perversion; The politics of bodies. New York: Allen & Unwin, 1995.
- IQWiG. "How does the nervous system work?" National Center for Biotechnology Information. August 19, 2016. Accessed February 13, 2017. https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0072574/.
- Jaarsma, Pier, and Stellan Welin. "Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement." *Health Care Analysis* 20, no. 1 (2011): 20-30. doi:10.1007/s10728-011-0169-9.
- Kessler, Zoë. "Hypersensitivity Is Not Imagined." ADDitude Magazine. Accessed February 04, 2017. http://www.additudemag.com/adhd/article/8945.html.
- National Symposium on Neurodiversity. "What is Neurodiversity?" National Symposium on Neurodiversity at Syracuse University. March 23, 2012. Accessed February 15, 2017. https://neurodiversitysymposium.wordpress.com/what-isneurodiversity/.
- Noë, Alva. "The Art Of The Brain, On Exhibit." NPR. January 20, 2017. Accessed February 13, 2017. http://www.npr.org/sections/13.7/2017/01/20/510528975/theart-of-the-brain-on-

exhibit?utm_source=facebook.com&utm_medium=social&utm_campaign=npr&u tm_term=nprnews&utm_content=20170120.

- Orf, Darren, and Avery Thompson. "When Neurologists Were Also Artists." Popular Mechanics. January 17, 2017. Accessed February 15, 2017. http://www.popularmechanics.com/science/health/g2923/brain-scancajal/?slide=4.
- Roberts, Lacey Jane. "Put Your Thing Down, Flip It, and Reverse It: Reimagining Craft Identities Using Tactics of Queer Theory." In Extra/Ordinary: Craft and Contemporary Art, 243-59. Durham and London: Duke University Press, 2011.
- Rolfes, Ellen. "Portrait of a dyslexic artist, who transforms neurons into 'butterflies'." PBS. April 16, 2014. Accessed February 1, 2017. http://www.pbs.org/newshour/updates/neuroscience-art-brain/.
- RSNA. "MRI Shows Brain Disruptions in Children With PTSD." Neuroscience News. October 25, 2016. Accessed February 04, 2017. http://neurosciencenews.com/ptsd-brain-disruption-5353/.
- Schultz, Jerome J., Ph.D. "Why School Stress is Toxic for Our Kids." ADDitude Magazine. Accessed February 04, 2017. http://www.additudemag.com/adhd/article/11630-2.html.
- Sherwood, Katherine. "Artwork." Katherine Sherwood's Website. Accessed February 11, 2017. http://www.katherinesherwood.com/sherwood/art/sherwoodart.html.
- Silny, June. "The Civil War Inside My Brain." ADDitude Magazine. Accessed February 13, 2017. http://www.additudemag.com/slideshow/220/slide-6.html.
- Sohn, Emily. "After brain damage, the creative juices flow for some." Los Angeles Times. May 20, 2011. Accessed February 11, 2017. http://www.latimes.com/health/la-he-diseases-art-20110516-story.html.
- Utt, Jamie. "Intent vs. Impact: Why Your Intentions Don't Really Matter." Everyday Feminism. May 08, 2016. Accessed February 15, 2017. http://everydayfeminism.com/2013/07/intentions-dont-really-matter/.

- Vaccaro, J. "Feelings and Fractals: Woolly Ecologies of Transgender Matter." GLQ: A Journal of Lesbian and Gay Studies 21, no. 2-3 (2015): 273-93. doi:10.1215/10642684-2843347.
- Weiner, E. S. C., and J. A. Simpson. "Influence." In *The Oxford English dictionary*. Oxford: Clarendon Press, 1989.
- Wertheim, Margaret. "Crochet Coral Reef Gallery." Crochet Coral Reef Gallery | Crochet Coral Reef. Accessed January 11, 2017. http://crochetcoralreef.org/coral-reefgallery.php.
- Wertheim, Margaret. "About the Project." Crochet Coral Reef. Accessed January 11, 2017. http://crochetcoralreef.org/about/index.php.
- "What is Neurodiversity?" National Symposium on Neurodiversity at Syracuse University. March 23, 2012. Accessed February 04, 2017. https://neurodiversitysymposium.wordpress.com/what-is-neurodiversity/.
- Zaikowski, Carolyn. "6 Ways Your Social Justice Activism Might Be Ableist." Everyday Feminism. September 20, 2016. Accessed January 13, 2017. http://everydayfeminism.com/2016/09/social-justice-activism-ableist/.