

ZOOM

autism through many lenses

ISSUE 7

PROTECTING
YOUR CHILD FROM
BULLYING

SOLO SPORTS &
AUTISM
A GREAT MATCH

The GAME Changer:
THE ANTHONY IANNI STORY

LINDSEY NEBEKER:

STAYING **STRONG**, **SURVIVING** AND
FINDING HER **PASSION** AGAIN

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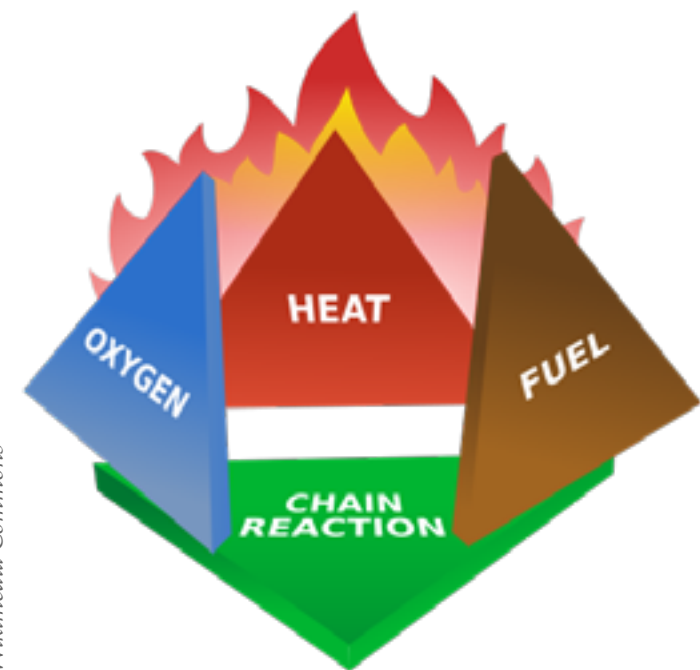
A person is sitting on a stone staircase in a dimly lit, ancient-looking setting. The person is wearing a dark, long-sleeved garment and is looking down. The background is a textured, light-colored wall or ceiling. The overall atmosphere is mysterious and contemplative.

THE DARKNESS AND SCIENCE OF PASSION

BY LINDSEY NEBEKER, B.A.

It was May 2003. I was 21. Twenty-one was too young to be lying down in my bed every night wondering if I was going to wake up the next day. Anorexia had taken hostage over my health during my junior year of college. By the end of the academic year, I decided to take a medical leave of absence from college to focus on recovery. My body and mind were frail and compromised, but I still thought it would be therapeutic to bring my Yamaha 88-key Motif Synthesizer and my Nikon 35mm SLR camera with me back home while I was participating in treatment. Music and photography were in my blood. These were the things I dreamed of pursuing in my undergraduate college studies.

But, surprisingly, during my entire course of treatment, I never touched my keyboard or picked up my camera. My soul was just too empty to care. I was convinced that the passion I once had within me was permanently



The image above is a diagram of the fire tetrahedron. The components labeled in the diagram are OXYGEN, HEAT, FUEL, and CHAIN REACTION.

dead. What was it going to take to resurrect my passion? Was it not enough to have the piano and camera there in my possession and to have the skill sets to use them?

Apparently, that's not how it works. Passion, as it turns out, is not formed out of a single substance. Passion is a science.

THE SCIENCE

One way to interpret the science of passion is by exploring the theory of fire. There are four components that are required to ignite a fire: fuel, heat, oxygen (or another oxidizing agent), and a chain reaction. "Sparking a flame" to our passion also requires our own "fuel," "heat," and "oxygen"

to create the fire. Then, in order to sustain and continue the fire that keeps our passion alive, a "chain reaction" must be present.

It took a tremendous amount of introspection, but after doing so, I was able to gain a clearer understanding of what passion actually requires and was able to figure out what made up those components to "spark" my passion, which I am happy to share with you.

THE FUEL

The "fuel" represents the subjects, topics, and instruments that are the material representations of expressing your passion. In some cases, you may have always known your fuel sources, and in other cases, you may not discover them until later. Discovering my "fuel" was the easiest part, and it involves going back to the early years of my childhood.

I was born in Tokyo, Japan, where I spent the first 11 years of my life. At age two, during a vis-



A photo of me sitting in front of our family harpsichord (circa 1984)

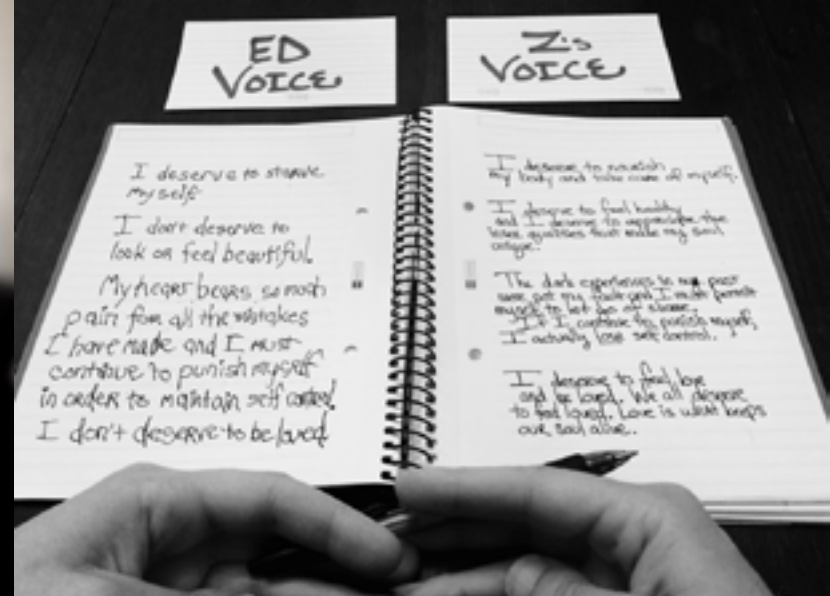
it to the United States, my parents brought me to the University of California at Los Angeles where I received an official diagnosis of autism. I began to develop speech around age four and was enrolled in a few years of speech therapy in an effort to "catch up" with the spoken and written language used by my surrounding society. At the age of 6, I began classical training on the piano. Not long afterward, I began to write and compose my own material. Before I was able to communicate with spoken or written words, I communicated through music. As an adult, I am able to communicate using speech and writing in most situations. However, I still do not consider words as my native language. I have always struggled to fit in. I tend to be shy, insecure, and still unsure of how to make or keep friends and relationships. However, when switched on "performance mode," the shyness and insecurity I once had disappears. My soul transforms into a creature of raw emotion and authenticity.

It was the black-and-white photography courses I had taken as a junior high school student that initially drew me to the camera. The idea of capturing images, developing the negatives, and printing in the dark room was a medium that I fell instantly in love with. Through music and art, I am able to communicate my emotions far more accurately than I ever could through spoken or written language.

As childhood shifted to adolescence and adulthood, sexuality and relationships (romantic and nonromantic) became my "alternative fuel" sources of passion. Those interests, along with my music and photography, were the only components required to spark my passion, or so I thought. As I would come to learn later in my life, I could not have been more wrong.

THE OXYGEN

The oxidizing agent of your passion is what



These are from the #recoverydocumented series, All photos by Lindsey Nebeker.

makes you breathe and survive. In my case, it turns out that my “oxygen” source is found in love. I am not talking about the lighter, positive aspects of love; I am talking about the devastating and heart-wrenching emotions that occur because of love. Anger, betrayal, fear, grief, heartbreak, humiliation, sorrow and trauma – these are all emotions you can experience as a result of having loved or trusted another person. That person could be your mother, your father, your significant other, your child, your friend, your neighbor, your teacher, or even an acquaintance.

The years I spent in boarding school (between the ages of 15 and 18) were the most traumatic in my life up to this point. And that three-year period happened to be when I was bitten by the composition bug. In those three years, I composed nearly 100 songs. In the sixteen years since, I have composed less than 20 songs. That does not mean, however, that my adult life

“Love is the essential non-physical ingredient for human survival. When we believe and feel like we are loved, we will be motivated to keep our passions alive.”

has been free from the darkness. While I find joy in sharing celebratory and positive experiences, I tend to be more active in capturing photographic images to describe intensely difficult experiences – either in someone else’s life or my own.

In 2015, when I revisited professional intervention for my eating disorder, I created the #recoverydocumented series on Instagram and invited the world to witness the challenges and celebrations during my own recovery. The hashtag has since been used to create mental health awareness and other facets of my journey.

THE HEAT

Identifying your “fuel” and “oxygen” is important to truly understanding your passion, but what purpose does your passion serve you? What drives you to engage in your passion?

This is where the “heat” enters into the science of passion.

My interests in music, photography and sexuality served as my “fuel,” and the darkness in my life served as my “oxygen.” But what was the message I was trying to convey and resonate? Dark experiences are hard, and I would not wish them upon anyone. But when they do arise, I feel compelled to share and convey my emotions as an effort to connect. Our primal instinct to develop some form of connection with other living beings allows us to feel less alone. While I have my own unique set of experiences, being open about them has allowed other people to feel like they do not have to endure their difficult emotions alone. Not everyone has gone through an eating disorder, but almost everyone has gone through the emotion of loneliness that coincides with having an eating disorder. Not everyone has gone through sexual abuse, but almost everyone has experienced the emotions of guilt and responsibility that can coincide with being sexually abused.

The “heat” source of my passion is to connect, be honest, be emotionally free, and survive. I have survived through bullying, rejection, sexual abuse, and two suicide attempts. I still go through discrimination, sexism, trauma, and ableism. To me, success is learning how

to rise strong and survive in my surrounding conditions.

THE CHAIN REACTION

A fire cannot sustain and continue to be alive without a chain reaction. Passion works the exact same way. Of the four components, this took the longest for me to figure out, but it turns out that my “chain reaction” source was found in love. This time I am referring to the positive aspects of love: encouragement, patience and support provided by the people who surround our lives.

It was love that saved my life back in 2003. When I finally convinced myself to accept the unconditional love and support from my family and circle of close friends, I gained the desire to heal and regained the strength to continue my music and art pursuits.

Love is the essential non-physical ingredient for human survival. When we believe and feel like we are loved, we will be motivated to keep our passions alive.

LET'S DEFINE YOUR PASSION

While I have my own discovered sources of



James and me, during a visit at his home (2015)

what makes me passionate, other people will discover their passions in different avenues. It is important to keep in mind that passion can be acquired by anyone. Only you know how to define passion. Other people do not define your passion for you.

Passion does not equate achievement and success as defined by societal standards. Many people (including myself) tend to be pulled towards the misconception that we must select something to label as a “passion” for the purpose of becoming famous, rich or successful. We must stop degrading ourselves by that unhealthy way of thinking. Passion simply relates to intense desire. Passion is the emotion or the set of emotions that drives us, excites us, and makes us determined to take action. That action may be as simple as satisfying ourselves with personal happiness, peace or pleasure. It does not require a trophy, straight A’s, a college degree, a high-paying job, fame, sex appeal, a fancy car, or a multimillion-dollar

estate. Passion is a human trait that can be expressed and felt regardless of our given abilities and conditions.

When I am asked to present or write about autism, the first thought that appears in my mind is my brother, James. Like me, James was also diagnosed with autism, but his condition is more significant and his experiences are drastically different from my own. James is 32 (as of this writing), and he does not speak, write or type. He has had wonderful caregivers and teachers, but he never received an opportunity to participate in an inclusive educational setting or an opportunity to work. It makes me feel guilty that my brother has not been able to experience the life opportunities that I have been lucky to receive.

My brother has led a very difficult and painful life. James has always tried to communicate with us, but none of us have succeeded in understanding his language. Imagine spending

32 years of your life trying to communicate your joys, frustrations, questions, sensory and health-related issues and never being understood ... and when you were not understood, you continued to feel lonely, frustrated, and aching from your health-related ailments. Imagine having dreams for your life and no one ever being able to understand or know what those dreams are. Imagine never feeling like your voice was heard.

Since James has not been able to tell me what his passions are, I tried to think back to the years when we were growing up and what activities made him smile. They are simple things, such

“Passion is a human trait that can be expressed and felt regardless of our given abilities and conditions.”

Self portrait, WORDS



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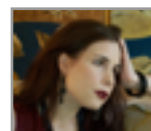
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as jumping in place, spinning nylons and shoe-laces, and listening to heavy metal music with the volume turned all the way up. It has always been difficult for me to recognize his defined talents and skill sets. I believe that the activities James engages in that make him smile provide him an outlet to release the darkness he has experienced in his life. I may never know this for sure, but it would make sense. The best thing I can do is encourage my brother to focus on the activities that makes him smile.

We must continue to extend our support to our loved ones to keep their passions alive. We must keep reminding each other of the power and presence of unconditional love.

IN CLOSING...

To live your life to your fullest potential requires a clear knowledge in the scientific formula of your defined passion. You, like many others, might still be on the quest to find your passion. You may still be trying to define your own "fire tetrahedron" and your sources of "fuel," "oxygen," "heat" and "chain reaction." You must never give up hope. Passion can exist in any form, place and time, outside in far distances and inside your soul. Listen to what your voice is saying to you and set yourself "on fire."



Lindsey Nebeker is a musician, speaker, and Development Specialist at the Autism Society of America. She also writes and contributes autism and sexuality resources for Naked Brain Ink.

She has appeared in Glamour, MTV, NPR, and the full feature documentary Autism in Love.

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