

## **HIDDEN TRAUMA:** A Personal Story of Living with Dyslexia

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*Jeffrey Morrison, MA, LMHC*

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This is a story about a trauma no one sees. It is a family story, an educational story, and a Focusing story. It is also about taming harsh inner judgment, holding one's deep shame tenderly, and finding one's gifts next to the wounds.

In the fall of my senior year of high school I began my search for a small liberal arts college to attend. I had not been a stellar student. In fact, school had seldom been a place where I felt good about myself. I did however have some confidence in talking about myself even though I was by nature shy and introverted.

I was interviewing with the director of admissions at a small college when he leaned forward and said to me, "I just want you to know that your SAT scores don't mean that you are mentally retarded."

Despite all my struggles with school, I knew I was not mentally retarded. Standardized tests were difficult for me, as was anything to do with reading. My high school French teacher told me to come back "once I learned English." Even my mother sent me off to college encouraging me to "date women who can spell."

### **How I realized I was dyslexic**

It wasn't until my daughter Kelsey was diagnosed with dyslexia that I read the book, *Overcoming Dyslexia*, by Sally Shaywitz, M.D., and had one of those "aha" moments in which my childhood and educational struggles began to make sense. I too, am dyslexic. I have since recognized that most adults come to this realization about themselves only when a child is struggling in school and is diagnosed by a specialist. My daughter had always been a very confident child and engaged student. When reading became the center of learning in first grade, she changed. Unable to keep up and perform with the rest of the students, she became anxious and developed stomach aches. My wife Esther, an elementary school teacher working in the same school, knew something was not right, but was told just to "Read at home with Kelsey, and she will be fine as she is so smart and capable in so many ways." For my wife, this was a bit insulting as she read to our daughter every day of her life!

I would like to emphasize the traumatic nature of what was happening for our daughter and the impact it had on our family. Teachers are not trained to recognize dyslexia, and the services needed to treat it do not exist in schools. The consequence is that schools often look the other way when a child exhibits dyslexia, because simply to suggest to a parent that a child may have a disability leaves the school legally responsible to do something about it. Fortunately, the reading specialist who was working with Kelsey spoke to my wife and

handed her the book *Overcoming Dyslexia*. Thus began a long journey of learning and seeking out the best care and interventions for our daughter — services that, unfortunately, are not available to everyone.

It took us more than a year to discern what sort of testing, evaluation, and interventions were needed. This process was incredibly frustrating, time consuming, expensive, and stressful. Eventually we found a wonderful organization, complete with educational counselors, to help us. We also discovered that Kelsey was allergic to gluten, dairy, and eggs. When bi-weekly tutoring and a new diet were in place, things began to change for the better.

### **How is dyslexia a kind of trauma?**

Trauma is an experience or experiences that overwhelm the organism. If what was implied could not occur, the organism becomes blocked and begins to shut down and or seek out new behaviors in an attempt to carry forward experiencing.

Being able to learn how to read would carry forward a life process for a child in first grade. When the implied sequences of being able to read do not occur, the organism adapts in predictable trauma responses of fight, flight, or freeze. Anxiety, depression, illness, and behavior problems begin to form as a way of coping with the blocked or stopped process. These very behaviors are attempts to solve the problem that the stopped process presents, but they don't carry forward the life process beyond the stoppage.

Imagine everyone around you being able to do something important and you cannot. In fact the harder you try the more frustrated you become and the further behind you fall. You cannot see what it is others are doing to be successful, nor is your teacher able to explain anything to you other than to encourage you to “keep up” or practice more of the activity that you are unable to do in the first place. All you can experience are your failed attempts to solve the problem. Over time, this situation generalizes into other learning experiences, the way you see yourself, and what is possible in your world.

### **Dyslexia and neuroscience: a very brief overview**

In Shaywitz's (2003) work, she found:

As virulent as any virus that courses through tissues and organs, dyslexia can infiltrate every aspect of a person's life. It is often described as a hidden disability because it was thought to lack visible signs, but dyslexia is hidden only from those who do not have to live with it and suffer its effects.... We now know exactly where and how dyslexia manifests itself in the brain.” (p. 4)

The diverse symptoms of dyslexia, such as trouble reading, panic about reading out loud, problems spelling, difficulties finding the right word, mispronouncing words, and anxiety about rote reciting from memory all stem from a single isolated flaw. At the same time,

other intellectual abilities such as thinking, reasoning, and understanding are all untouched by dyslexia. This adds to the problems of diagnosing and understanding why some smart people can't read.

Recent research has developed a model of dyslexia based on phonological processing — in short, the brain's ability to process the distinct sounds of language. According to Shaywitz (2003), dyslexia is intimately tied to: "A specific component of the language system: the phonological module. The word phonologic is derived from the Greek word phone, meaning sound." (p.40).

The phoneme is the fundamental element of the language system. A person learns to read by looking at a word and converting the letters into the distinct sounds or phonemes. For example, the word *cat* is sounded out as three phonemes: K-aaa-t = cat

Different combinations of 44 phonemes comprise the English language. Those who are dyslexic have difficulty both storing and retrieving these sounds. When they are asked a question, they often will retrieve a word that is similar to but different from the one they are attempting to say. Being unable to see a printed word as something that can be broken into smaller parts and combining different sounds — let alone retrieving them in the correct order — compromise reading ability.

Children who are dyslexic perceive a word as an amorphous blur, without an appreciation of its underlying segmental nature. They fail to appreciate the internal sound structure of words. (Shaywitz, pp. 43-44).

### **Brain wiring and functional magnetic resonance imaging (MRI) research**

Functional MRIs show that dyslexia is the result of:

A glitch having taken place during fetal life, when the brain is hard-wired for language. As a result, the tens of thousands of neurons carrying the phonologic messages necessary for language do not appropriately connect to form the resonating networks making skilled reading possible. (Shaywitz, pp.67-68).

Learning to read means being able to break words into their sounds. When normal readers do this, their brains correctly store the printed letters on the page with the corresponding sounds. When they see the word again, they are able to retrieve and link the letters and the sounds and speak or read them silently to themselves. Dyslexics need to be taught how to do this, or they must suffer through years of trial and error. Studies demonstrate dyslexic readers develop neural pathways that are different from those of normal readers. Whereas reading becomes an automatic process for more than 80 percent of the population, 20 percent of us must develop a manual process of building our neural pathways through intensive therapies and years of repetition.

My daughter's therapy began with her reaching into a bag to find a plastic letter, feeling it and letting a picture form in her brain, and then saying and hearing the sound of that letter. She had tutoring with an educational counselor twice a week for a year, and then weekly for another two years. She has maintained a high grade-point average through middle school, due in part to her determination to be seen as normal and successful. She needs a great deal more time than most kids her age to complete assignments, help from her older brother and her mother.

I remind her I never did that well in school and that she will always have to outwork others just to keep up. I also remind her that she has other talents, gifts, and creative outlets that allow her to shine; such as dance, art, creative writing, and an amazing ability to implicitly understand human interaction as well as explicitly express that awareness, sometimes to my great chagrin. Through her experience of learning to read and manage her disability I have been able to reflect on just how dyslexia interferes with being normal. Not trusting your abilities, or even the ability to know what you're missing, invites anxiety and depression. One disconnects from self as a way to manage overwhelming feelings.

### **Interaffecting family and personal history**

It may seem odd to include family history here, but there is a context in which every situation occurs. I am a mixture of biology, a constellation of family members who carry their own history, and something uniquely more. As you read the following, do keep in mind/sense the context that I grew up in, noticing particularly the intergenerational and vicarious aspects of trauma.

#### **My paternal family:**

My paternal grandmother began her career as a schoolteacher and went on to be involved in literary circles in New York as a poet. My paternal grandfather grew up on a farm in southern Illinois, taught in a one-room schoolhouse, and eventually went on to complete his Ph.D. in education at Columbia University. He became an assistant commissioner of education for the state of New York.

My father, an only child, skipped two grades, which he handled academically, but which left him at a loss socially. He went to college at 16, and graduated at 19. He began active duty in the Navy just as World War II ended, and then attended Harvard Law School where he experienced receiving a grade other than an A for the first time.

#### **My maternal family:**

My maternal grandfather was a successful contractor in Michigan. My maternal grandmother was a co-founder of a local Planned Parenthood and a homemaker. My mother was adopted and was an only child as well. My mother earned a masters degree in education and taught until I was born.

I was an only child until my brother arrived when I was four. I grew up with love, a big back yard, and a belief that I was important and of value. Perhaps more than anything else, this belief supported me through years of suffering through grade school, high school, and college. Nevertheless I felt a pressure to carry forward the family tradition of education, excellence, and teaching. However, education was an area of life in which I felt ill equipped to succeed.

### **My struggles as a student**

In my living room hangs a picture of me as a small child, painted by an artist my parents knew. I am perhaps three or four years old, wearing a suit, and looking intently at a book on my lap. It is what I was raised to be, but not who I was.

Books were overwhelming problems. I liked pictures and wandering outside exploring the world. When friends would spend lazy summer days reading and sharing comic books, I would flip through the pictures as if I were reading. I taught myself to look as if I were reading so as to not draw attention to myself.

Early on in school I struggled. Reading, writing, and spelling were a disaster. If I had a dollar for every hour I spent staring out the classroom window lost in a daydream, I could retire. I can still feel the panic of waiting my turn to read out loud in our low-level reading group. Thank goodness for math and science. I saw my first school psychologist in third grade. She asked if I liked school, and I remember thinking to myself, “Does she really think kids like school?” Perhaps some did; I preferred building tree forts.

My fifth grade teacher loved having us take dictation. It was a perfect combination of all the skills I lacked. I had to listen to what was being said, retrieve the words, try to imagine what those words looked like and figure out how to spell them. I fell behind immediately and never recovered. I began to get stomach aches and missed much of the end of the school year.

My sixth grade teacher had us write a story each week. I liked creating stories and learned I had good ideas, but I needed a great deal of help from my mother with my spelling and grammar. My teacher noticed my difficulty with spelling, writing, and reading. He referred me on for evaluation, which determined that I was rather bright, but below grade average in spelling and reading. I was just happy the test confirmed that I wasn't dumb.

Somehow high school became a bit easier. My English teacher passed me along without requiring much writing. I listened well in class to the books being discussed so it seemed as though I was reading them. I had some other successes that encouraged me. I discovered that I was an excellent baseball player, and my success on the high school baseball team improved my self-esteem as I experienced approval and even applause for something I could do well.

I went to college and thought I would study economics. My father thought I would make a good investment banker. I soon realized I was not well prepared for academic success. I did not have my mother's editorial support. I remember many unhappy nights with an old manual typewriter, correction tape and a dictionary. It is hard to look up words that you

have no idea how to spell. I felt lost, alone, and depressed. I began to fall behind, eventually failing out of school.

It was a dark time in my life. I felt like a failure and yet a kind of curiosity about myself seemed to emerge. Before I left that school, I took a psychology class and a philosophy class and enjoyed both. A kind of self-reflection and personal meaning began to develop.

After a year off and some soul searching, I found another school and my niche. I became a philosophy and religion major with minors in psychology and art. It seems funny that what saved me was a full load of reading and writing papers (often turned in late). Many dyslexics find success a bit later in life, after they have found what they are passionate about. They can learn and master the language of their specific interest and begin to thrive.

My new college was small, personal and had some of the best teachers of my life. I had a religion teacher who taught me existential philosophy, religion, and to seek the meaning of my own experiences! I had never before encountered education as an exploration of self. No one in school had ever expressed interest in what I thought or experienced. Something in me mattered? Something in me that wanted to be expressed was worth pursuing, writing about, creating through sculpture or movement? My favorite professor, Howard Johnson, saved my life. We read Heidegger in his office, had long talks, and Dr. Johnson often reaffirmed my intrinsic self worth. Tears fall as I remember him.

So much of my life that had been blocked found a way forward during this time. My philosophy professor taught me how to present an argument and write a thoughtful paper. My psychology professor became head of the counseling center and allowed me to co-lead a support group. My art teacher allowed me into the sculpture studio to create whenever I wanted. His wife taught me contact improvisational dance. It was a good time in my life. It felt good to just be me!

My transition to the “real world” after college was difficult. I did not know what I wanted to do other than hitchhike from coast to coast and explore — which I did. I had avoided all the career counseling offered at school. Eventually, I returned home to the Pittsburgh area. I read an article in the newspaper about a class taught by a graduate student at Duquesne University. It talked about existentialism, client-centered therapy and something called Focusing. I took the class, and it changed my life. I had found a practice and a process that allowed me to tap into my rich inner life. The Focusing teacher, Les Brunswick, mentioned a graduate program in psychology in Seattle. I applied and was accepted into Seattle University and their Masters program in Existential Phenomenological Therapeutic Psychology. A new chapter in my life began.

### **Learning Focusing is a different kind of education**

Although I had worked in the therapy field since 1986, it wasn't until I began my private practice in 2000 that I decided I wanted to study Focusing more deeply. I found a Focusing partner who was studying with Ann Weiser Cornell. I began regular trips to

California to study with Ann and became certified in 2006. I appreciated Ann's clearly articulated teaching and certification process. As I learned the deeper structure of Focusing, I encountered the deeper structures of my own being and how I learn. I was able to more fully trust my own experience and to be gentle with myself when I struggled. Focusing allowed me to unwind many tangles, fear, and doubt. My confidence that I could have a successful private psychotherapy practice grew slowly. I also saw the positive results my clients were experiencing as I integrated Focusing into how I worked.

In 2011, I began Shirley Turcotte's program in Aboriginal Focusing-Oriented Therapy and Complex Trauma — a land-based, indigenous, and experiential perspective of trauma. Shirley has a big personal story and uses it to teach from. As I went through the program I kept searching for my story. I was able to see bits and pieces but was still not be able to put them together. It wasn't until I was asked to take notes at a meeting that I said, "Now you'll all get to experience *my* PTSD and trauma."

Still, it took a while to really see more deeply into how I held myself back, and what I needed to turn to so I could become the warm kind of Focusing teacher I wanted to be. There it is...that word...**teacher!** It still scares me. I am more comfortable saying I'm a therapist who teaches Focusing. There was something in the process of putting myself out there as a leader in the educational process that required coming out of the shadows of my learning disability. I knew I had to be able to speak and write in order to interest students in my Focusing-Oriented Therapy Training Program. So I pressed on.

### **Speaking from my story**

Recently, I gave a talk to the Seattle Counselors Association on Focusing and Trauma. I began with my own story about how my dyslexia contributed to my disconnection from self. I used my and my daughter's stories to introduce how to work with embodied, vicarious, and intergenerational trauma. The talk was very well received and satisfying for me. I have come to realize that my experience as a dyslexic has its own trauma story. It is my story, complete with wounds and gifts and wonderful teaching examples from which others may learn.

If my wound is a disability that prevented me from being educationally successful when growing up, and twisted my own notion of self-worth, what then is the gift? A gift is what often comes from our response to our wounds. It is what got us through and allowed us to heal from and overcome our trauma.

One gift I have come to realize is my ability to sit with someone in his or her darkest moments. I will doggedly pursue them even when they want to abandon themselves. Another gift is a certain persistence and repetition I can sustain over long periods for both myself and in my work with others. I am realizing that my organism's painful response to being dyslexic has given rise to deeply enlightening connections with others. As my terror of being a pretender has diminished, my courage to pursue my goals has grown.



Shaywitz suggests (2003) that many of the most creative and successful people are dyslexic. She believes it has to do with not being able to simply memorize or do things by rote, but rather to get far underneath the concept and understand it at a fundamental level. In many ways, my dyslexic brain is wonderfully suited to the study of philosophy and the experiential process of Focusing. Where most reading brains speed along on a super highway of the left hemisphere, mine meanders on back roads and dirt pathways on the right hemisphere crossing over at times to the left. This allows for little side trips of imagination, crossing and dipping and making it my own by deeply experiencing the concepts.

### **What best-selling author John Irving and I have in common:**

We both had SAT scores under 500. Neither of us can spell. We both discovered we were dyslexic when one of our children was diagnosed with the disability. What got him through high school was a wrestling coach; for me it was my success as a baseball player.

Shaywitz quotes Irving saying that in writing, being dyslexic has become an advantage. “In writing a novel, it doesn’t hurt anybody to have to go slowly. It doesn’t hurt anyone as a writer to have to go over something again and again.” (p. 347).

The worst thing for Irving was being called lazy. As dyslexia is a hidden disability, people wrongly assume that if you are not achieving it’s because you’re lazy and your own damn fault. What they don’t see is that a dyslexic has to work several times as hard as non-dyslexics to achieve the same results. Once they develop the needed stamina and gain confidence in their abilities, this diligence pays off.

Author and shame researcher Brené Brown says that courage is the ability to face one’s shame in a way that allows you to do what you really want to do. Our shame is a placeholder for our trauma. Go there and you will find the wound and your gifts. It is not an easy journey.

Focusing has given me a way of being with and interacting with my experience, helping me to unwind my tangles, blocks, and shame. Healing is a journey of recovering bits of the fabric of our being and weaving them back together to reform the whole. Focusing has given me a way to encounter my many hurt parts and to know which ones to pick up and weave in and which to let go. Focusing has also connected me to a supportive community with many encouraging teachers. It offers me a different kind of knowing — one that comes from felt sensing and learning to listen deeply inside to what my organism gathers implicitly.

I gratefully realize that I do carry forward my family’s tradition of education in my own unique way. I can even call myself a teacher!

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**Jeffrey Morrison** is a Focusing-Oriented Psychotherapist and Focusing Coordinator with a private therapy practice in Seattle and Vashon Island, WA, where he lives with his family. He offers Focusing-Oriented Therapy Training and Certification for psychotherapists and other healing professionals at his Vashon location. He can be reached at [Jeffrey@morrisontherapy.com](mailto:Jeffrey@morrisontherapy.com) or <http://morrisontherapy.com>

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