

APRIL 2015

TBI HOPE & INSPIRATION

Magazine

Against All Odds

A Tale of True Survival

My Constant Companions
Impulsivity and Disinhibition

**MEET
THE NOW-INATOR!**



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TBI Hope &
Inspiration
MAGAZINE

*Serving All Impacted by
Traumatic Brain Injury*

April 2015

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Welcome

Last month was National Brain Injury Awareness Month. Nationwide, it was time for so many to join in the national narrative about traumatic brain injury. At a local event here in New England, I had the opportunity to hear a nationally recognized brain injury expert proclaim, "The conversation about brain injury has reached a *fevered pitch*. A fevered pitch." Those two words brought joy to the hundreds of people in attendance at the event.

Slowly, the tide is turning. Every day, the media spotlight is shining on what has for so long been called *America's Silent Epidemic*.

Numbers by the Centers for Disease Control estimate the number of Americans who sustain a brain injury at 3.4 million yearly. But brain injury knows no borders. Last month, the premier issue of TBI Hope and Inspiration Magazine was launched. Readers from four continents participated in our launch and the response from the TBI community - at all levels - was nothing short of amazing.

Please feel free to share this publication. By doing so, you are helping to end the silence that surrounds traumatic brain injury.

For all who took the time to reach out to us, thank you. Our continued hope is to offer you hope - a real hope that there is life after brain injury.



David A. Grant
Publisher

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Against All Odds

By Laura Chagnon

My name is Laura Chagnon. I am a TBI survivor and quite lucky to be here today writing this. Actually, I'm not typing this with my own hands, I need the help of others to do any physical tasks.

I'm 51 years old and my life started off in good health. My major problem growing up as an adolescent was shyness. There was a lot of difficulty mixing in socially at school and I was bullied every day. During lunch in the cafeteria, I would be the only student sitting alone because I was like that puzzle piece that just didn't fit. It caused a lot of loneliness and frustration therefore I needed to vent all of my built-up emotion.

English was my strongest subject in school, I enjoyed writing, so I began writing poetry. Never did I realize how my situation at this stage of my life would be so important later on. Ironically, those dark days would open up new doors later down the road.

Well, I completed high school, despite all the bullying, but my self-esteem was left tormented. My life needed direction in order to become a stronger person. So, I chose to enter the military, the U.S. Army to be exact. I'm a very patriotic individual, so this venture seemed to be a perfect fit. My bags were packed and my destination was Fort Jackson, South Carolina. Basic training here I come. There was one slight problem, I always suffered from insomnia.



One day, my job was to carry a line of cable through the woods. I had gone

days without being able to sleep and was simply exhausted. So, I dropped the cable in the woods and went back to my barracks and collapsed. The drill instructor found me there and doctors realized continuing on with basic training could lead to more serious health issues. I was given a medical discharge and sent back home.

I had to decide what my next path in life would be, so college seemed to be a logical choice. Soon I was enrolled in Springfield Technical Community College. I wanted to become a medical assistant. Everything was going in a positive direction, my grades were good and I was excited. At 25-years-old, I could see myself graduating soon, getting a job and an apartment. Being independent would be a dream come true. My 26th birthday was soon approaching, November 4th, 1989 turned out to be a life-changing day.

My mom bought me a gray suede jacket and a white leather pocketbook. I always did things spontaneously, and this day was no different. I took off and went to Boston on my own, driven by excitement with this adventure. In Boston, I decided to go window shopping and see the sights. Being a college student, there really wasn't very much money to spend, but I didn't care.

“I don't remember what occurred since they fractured my skull.”

This fated November day started off sunny, but soon I was entangled by the dark shadows of that fall day in New England. It turned out to be the most traumatic nightmare in my life. I felt a tug on my new white purse that was strapped over my shoulder. Immediately, red flags went up and I envisioned being robbed. Since I didn't have very much money, it wouldn't really be

the worst thing that could happen.

I got spun around and I stared into the eyes of two men. In a matter of moments, my life was changed forever. My memory of the incident is very scarce. They brought me to a secluded area and I don't remember what occurred since they fractured my skull. The assailants left my crumpled body on the streets of Boston to die, and left the scene never to be caught. Boston police found me and thought my gift of life was stolen.

However, someone was holding my hand and not allowing me to die. That was God, I suffered terrible injuries, but He had a path for me. It's ironic how at

different stages of my life, I was trying to create a path. God intervened and set the right one before me.

My body was broken, and now I was a legally blind quadriplegic with a traumatic brain injury. Doctors gave me little chance of regaining much of my former cognitive ability. Was I going to give up on life? No way, my ever-loving God allowed me to live and my goal was to realize he was opening a new door for me, even though it would take me more than four years to even see it. I went through physical, occupational and speech therapy at numerous rehab centers. Finally, in 1992, I was able to return to live with my parents.

What would I do with my new life? I couldn't work a standard job with my physical skills being stripped. I needed caregivers 24/7. I guess I was in a predicament, or was I? Remembering back to those adolescent years, I enjoyed writing poetry. Guess what? Now I had the time to delve back into that with a vengeance. My process was dictating to my caregivers, and they would write down the words. When a poem was completed, it would be saved on my computer. I did this day after day, even submitting some of my works to local publications. A writer for the local newspaper even did an article on me in his human interest column and entitled it "In Poetry She Finds a New Spirit." I was excited and kept on writing with the goal of allowing others to read my words. Perhaps I could even publish a book. But that seemed to be quite a lofty goal.

Then in 2013, I met an angel. He was a short, stocky man who wore glasses, perhaps not your typical angel, his halo even a bit askew. His name is Todd Civin. My soul mate had purchased a book that Todd co-wrote. We contacted Todd with the idea he would be able to bring a sampling of my poems to his publishing company and have them evaluated. We met for lunch and had a nice conversation. I explained to him my story and my dreams of becoming a published poet. I gave him about 20 of my poems to bring back to his publishing company. He said he would give us a call in about a week. A week went by and we didn't receive that much-awaited phone call.

“In 2013, I met an angel. He was a short, stocky man who wore glasses.”

My life had been full of disappointments up to now, and this seemed no different. Then, two weeks later, I heard the phone ring. "Hello Laura, this is Todd Civin from Mascot Books. Well, your story is quite incredible and we

think your poetry is absolutely amazing. The public needs to know of you and read your beautiful words. We would like to publish a book of your inspiring poetry."

At last a long-awaited dream come true. In April of 2014 "*Never Touched a Pen*" the inspired poetry of Laura Chagnon was released. It was 25 years after my accident and I found out that dreams really do come true. I am proud to say that I am a traumatic brain injury survivor and I continue to strive each day with God by my side.

About the Author

Laura Chagnon is a freelance poet and brain injury survivor. Laura Chagnon continues to craft poetry each day with plans on publishing her second book of poetry. Laura's book is available on [Barnes & Noble](#).



Compensatory Corner

What Works for you?

We continue to offer strategies that help those impacted by Traumatic Brain Injury. Compensatory Corner is your place – by survivors, for survivors.

"Every bad day I've ever had has passed. When I get that hopeless feeling that I can't go on, I try to remember that I have a 100% track record of making it through every tough day so far. ~Denise D.

"Since my injury, I've not been able to work. This devastated me until I started doing volunteer work a few years ago. Getting out and helping others has made life much different for me. ~ Robert S.

"I can't do much of what I used to do. I try focus on what I can do!" ~Stephen H.

"Being alone isn't good for me. My husband tried to get me out a few times a week. It's hard for me to be in places where there is a lot of noise and distraction. Now that the weather is nicer, we go to the park at least once a week. I like being outside. It's good for my husband as well." ~Sandy T.

Life after TBI: “I Am Un-Believable”

By Jeff Sebell



Brain Injury Awareness month was last month, but the need for brain injury awareness doesn't stop when March becomes April.

We survivors tend to spend a lot of time and energy talking about improving the awareness of others, about ways to teach others about us, and about ways we would like others to relate to us. This is all important stuff, and would undoubtedly have a great and beneficial impact on our lives, but, by doing these things, we are putting the burden on others to

make us feel worthwhile and accepted.

However, in reality, the only ones we can really count on are ourselves. The result of relying on others is that we can't be overly upset when things don't work out the way we would like.

Maybe we can put some time and energy into reducing this reliance on others to make us feel worthwhile, and instead look at how increased self-awareness can benefit us.

Life after TBI is a convoluted mess of self-doubt, confusion, uncertainty and failures, and it's painful. Self-awareness is difficult for a number of reasons. We get caught up in the day-to-day struggles of just trying to get by, coupled with great worry about the future, and our inability to plan for it. These mental and physical struggles sap our energy and frustrate us to no end, while focusing us on problems.

Could an increase in self-awareness help us?

In my own case, I know that for many years I was so caught up in my own situation that I could not get past my difficulties and allow myself to really examine my place in the world. My life was so chaotic and different from the way it used to be, I didn't understand my place in the world anymore and I was always trying to find it.

I think this is absolutely normal for someone who has experienced a traumatic brain injury; for the changes needed, struggles and obstacles encountered are completely consuming. You become very ego-centric and lose awareness of yourself as a person in the world.

I also became very passive, and felt as though I was at the mercy of everyone, and was not in control of my own destiny. Somewhere along the line, I came to a realization that more of my life was in my own hands than I had thought, and I really could find a way to influence things. What I mean, is that I came to the conclusion that I had the power to effect changes in my life, simply by believing in myself and asserting myself. I just had to figure out how to make that change.

The change I made didn't have anything to do with where I was living or where I worked. In fact, it had nothing to do with "doing" or accomplishing anything, but it had everything to do with "me", and with "who I was". At the time, "who I was", was a married man with two children who worked as sales manager in a family business, and I was doing my best to forget about my brain injury despite having reminders pop up constantly.

In response to feeling awkward, slow, easily confused and having poor judgement; as well as feeling unsure of myself, not confident and frequently overwhelmed, I decided to go on the offensive by means of a simple exercise.

When I would greet someone and they would say, "Hi! How are you?"

I would respond, "*Un-believable!*"

Sometimes, if I was in the right mood, I would say, "Un-^{*}%[^]\$#-believable!" with an exclamation mark.

The truth was, I wasn't really "Un-believable", but I was determined to take the bull by the horns, and be that way.

My response forced me to smile. It forced me to interact. It was a conversation starter, and there was great power in presenting myself in a way others wished they could be. They wanted what I had, as though I owned some fabulous secret that could enrich their lives, and I was living it. Me, with the TBI.

If I said I was unbelievable, I could be unbelievable; or amazing, or any number of adjectives.

The more I told people I was, “Un-believable,” the more I not only believed it, the more I actually was.

Finding and believing in something positive can be difficult after a brain injury. It is possible, but you have to dare to think big and be stubborn. If you were to take a step back, look at all you have been through and what you have to battle every day, I don't think it's a stretch to say that alone makes you truly, "Un-believable!" Don't shy away from yourself and your capabilities, but claim success. Believe it and it will be so...

About “Un-Believable” Jeff Sebell

A long-time survivor, Jeff is the author of “*Learning to Live with Yourself after Brain Injury.*” You can read more about Jeff and his journey on his blog at www.TBISurvivor.com

Useful Links & Resources

[Brain Injury Association of America](#)

Brainline.org

[TBI Hope and Inspiration Facebook Page](#)

[CDC Brain Injury Facts & Stats](#)

[TBI Prevention Information](#)

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Living With Hope

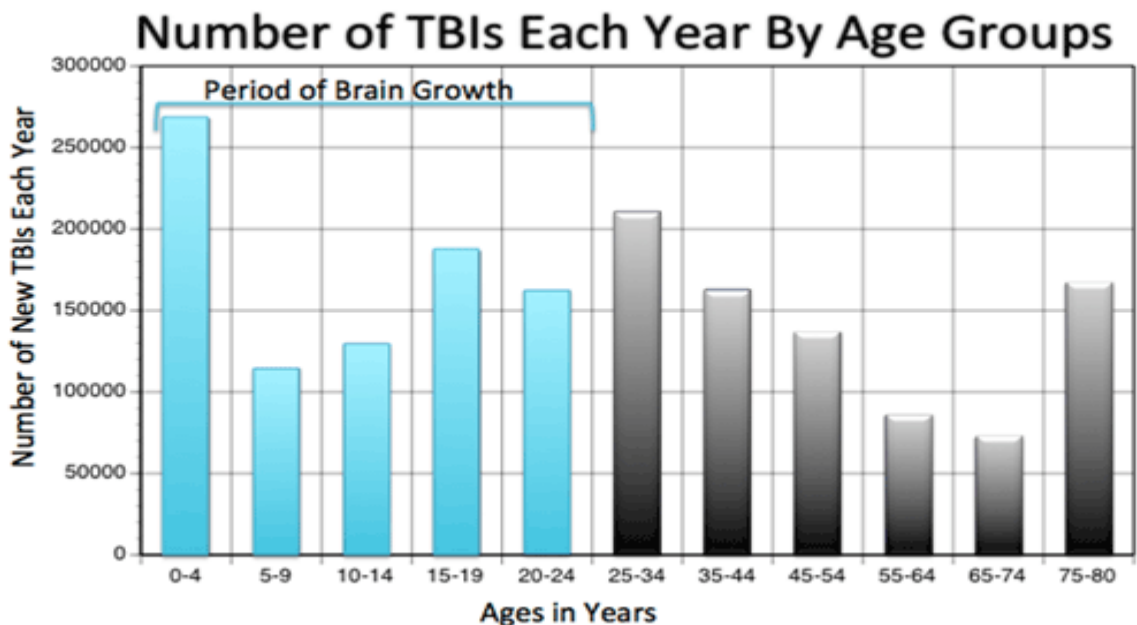
By Patrick Brigham



Welcome to the Wacky World of Patrick Brigham

Patrick Brigham is our Cartoonist in Residence for TBI Hope and Inspiration Magazine. Patrick hails from a self-described dimension of untamed nuttiness.

When we approached Patrick about adding Faith to his comic strip, his reply was spot-on. "I'm going to create Faith with glasses." When we asked why, his reply was not what we expected. "We all know that Faith is blind." As survivors and those who love them, we understand better than most how far you can go with "blind faith."



Why We Were Chosen

~anonymous

God in His wisdom selected this group of men and women to be purveyors of His goodness. In selecting them through whom to bring about this phenomenon He went not to the proud, the mighty, the famous or the brilliant. He went instead to the humble, to the wounded, to the unfortunate. He went right to those who suffer an unseen injury: those with traumatic brain injury.

Well might He have said to us...

"Unto your weak and feeble hands I have entrusted a power beyond estimate. To you has been given that which has been denied the most learned of your fellows. Not to scientists or statesmen, not to wives or mothers, not even to my priests or ministers have I given this gift of helping other traumatic brain injury sufferers which I entrust to you."

"It must be used unselfishly; it carries with it grave responsibility. No day can be too long; no demands upon your time can be too urgent; no case can be too challenging; no task too hard; no effort too great. It must be used with tolerance for I have restricted its application to no race, no creed, and no denomination. Personal criticism you must expect.

Lack of appreciation will be common; ridicule may be your lot; your motives might be misjudged. You must be prepared for adversity, for what people call adversity is the ladder you must use to ascend the rungs toward spiritual perfection, and remember, in the exercise of this power I shall not exact from you beyond your capabilities."

"You are not selected because of exceptional talents, and be careful always, if success attends your efforts not to ascribe to personal superiority that to which you can lay claim only by virtue of my gift.

If I had wanted learned people to accomplish this mission, this power would have been entrusted to the physician and scientist. If I had wanted eloquent men and women, there would have been many anxious for the assignment, for talk is the easiest used of all talents with which I have endowed mankind.

If I had wanted scholarly people, the world is filled with better qualified than you who would be available. You were selected because your unique experience with a brain injury has made humbly alert to the cries of distress that come from the inner hearts of brain injury sufferers everywhere."

Meet the Nowinator!*

By Mike Jennings

I recently discovered a new personality trait: I've become a **Nowinator!** What I mean is that I now do things right away, if I can. Let me explain.

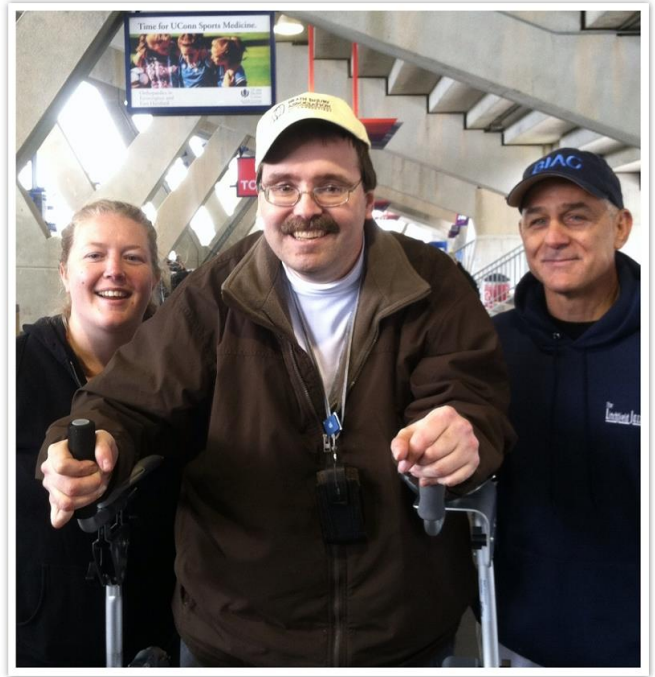
Deciding to do something later requires you to remember to do so. You may say, I'll write it down so I have a record of it. The problem is that if you write everything down, you can find yourself overwhelmed by notes. By just going ahead and doing it now, you don't have to worry about remembering it. Also, although something may seem simple at first to remember, later you may find that you forgot to do it. I know I have!

I used to be the exact opposite. I would wait until the last minute to do things. I was a classic procrastinator. Maybe it was a game to see how late I could start something and still get it done on time. Now, after my brain injury, I need to be really efficient doing everything. Here's what I do now...

Even if something can wait and I can do it later, I'll just do it now. This way, I don't have to remember later. I think less energy is required just to do it now, than remembering to do so later. An example is when I'm running low on medication and I need to have it refilled in about a week. Rather than wait until the last minute, I get it refilled right away. So I made up a new term for myself. Now, I'm a Nowinator!

Meet Mike Jennings

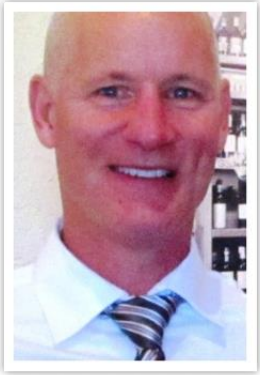
Mike Jennings is a TBI survivor and has been a Support Group Facilitator for BIAC since 2005. Previous to his injury he served as a project engineer for Hamilton Sundstrand. Mr. Jennings currently serves on the Aging & Disability Commission for the Town of Simsbury and on the Board of Directors for New Horizons Village, an assisted living complex in Unionville, CT.



**Originally published in the BIAC Newsletter*

Hope Springs Eternal with a Good Neuropsych Evaluation

By Scott LaPoint, Psy.D.



If you've sustained a traumatic brain injury (TBI), be it mild, moderate, or severe, it is likely you've also had a neuropsychological evaluation (or two or three or more). That's my hope, at least. Being evaluated by a neuropsychologist following TBI is often pivotal to understanding what has happened to you (i.e., physically, psychologically, socially, emotionally, intellectually, spiritually) and important for envisioning what the future holds.

In 20 years of working with individuals with TBI, however, I continue to be amazed by the number of people who haven't been evaluated following a suspected injury or re-evaluated on an as-needed basis. Without an updated neuropsychological evaluation, it might be impossible to understand why someone continues to experience problems or even whether the problems he or she reports are related to an injury or something else altogether. Just as important, any significant neuropsychological improvement may go unrecognized.

For starters, it might be helpful to understand what neuropsychology is and what it is not. It is not Voodoo or an exaggerated belief or system of theories erroneously presented as scientific. Neuropsychology is a subspecialty of psychology that focuses primarily on neurobehavioral functioning, which is the study of the relationships between the brain and behavior. A neuropsychologist is a licensed psychologist with specialized training (e.g., graduate coursework, experience) in neuropsychology and neuropsych assessment. In brief, a neuropsychologist is trained to

understand what parts of the brain are responsible for different aspects of cognition, personality, and behavior.

Following a TBI, a neuropsychologist attempts to measure how the brain is working through the use of cognitive and personality tests

“Typically, a neuropsychological evaluation will examine a variety of skills and abilities.”

and questionnaires, in addition to behavioral observations. After an injury, the person will be asked questions about his/her history and background, and usually someone who knows the individual will be asked to provide information, as well. By understanding

the nature of the injury, what questions to ask, and the correct assessments/tasks to administer, a neuropsychologist can arrive at an accurate diagnosis as well as treatment options.

Typically, a neuropsychological evaluation will examine a variety of skills and abilities, including but not limited to general intelligence, problem solving, self-awareness and self-appraisal, academic, abstract thinking, attention and concentration, learning and memory, language, visual and spatial perception, gross and fine motor, sensory perception, executive functioning (planning, organization, initiating, and inhibiting behaviors), emotional/behavioral functioning, and social skills.

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From my own personal experience, while the three evaluations my family member received over a four-year period were descriptive and informative, they failed to provide what I consider the most crucial part of any evaluation: functional recommendations. Much of my work today is evaluating individuals who present with cognitive deficits resulting from TBI.

“Helping someone understand his/her strengths and weaknesses can assist when decisions have to be made.”

As a psychologist, I realize that there is no point to conducting such an extensive evaluation without it resulting in a comprehensive list of recommendations. Providing a diagnosis of “Major Neurocognitive Disorder Due to Traumatic Brain Injury” (the new lingo in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition) is not sufficient to tell the individual and those who work with him/her what this person needs in order to most successfully live life post-TBI.

For me, the recommendations section provides a “road map” toward recovery. Helping someone understand his/her strengths and weaknesses can assist when decisions have to be made about returning to work, driving again, or going back to school. Also, it is important that the written report include the actual test scores (i.e., subtest scores, standard scores, T scores). These will aid the neuropsychologist and others in



understanding changes that occur over time.

So if you haven't been evaluated but believe you should be, consult a neuropsychologist. An evaluation can help to answer your questions. And remember, a follow-up evaluation may reveal progress that might otherwise go unnoticed. Hope renewed!

Meet Scott LaPoint

Scott LaPoint is a psychology resident at Lakeview NeuroRehabilitation Center in Effingham, NH, where he completed his predoctoral internship in rehabilitation psychology.

Dr. LaPoint has more than 20 years' experience in the field of brain injury, from peer advocate, job coach, and life skills specialist to certified nursing assistant, program coordinator, and Licensed Professional Counselor. He completed his doctoral education at Regent University in Virginia Beach, VA, in 2014, and received a Master's degree in counseling from Colorado Christian University in 2001.



Can You Pick Out the Brain Injury Survivor?

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Sun's Spirit

By Hilary Zayed

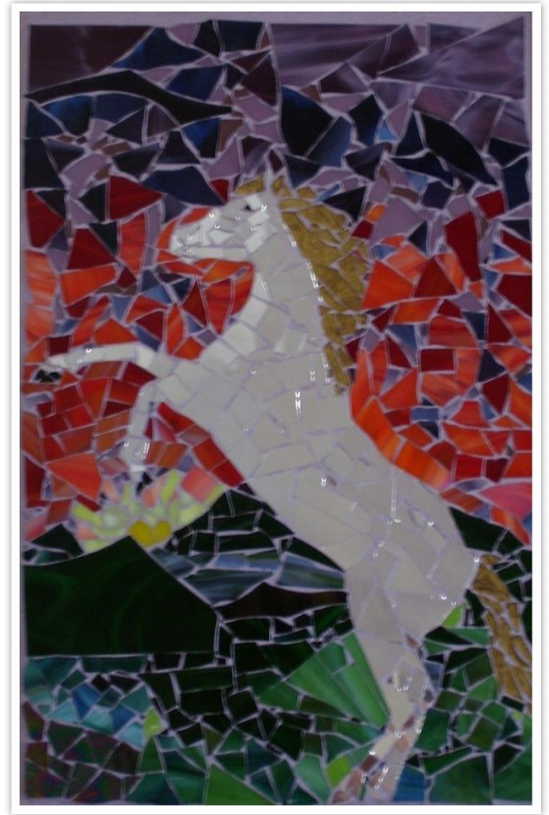
When the time comes of being well enough to start to fight what is happening, denial sets in and the battle begins: I will get better, I will get my life back, and I will have it my way.

But my way does not come and the more fight and struggle arises from within, the less healing and moving forward occurs. And at the same time, the fight precipitates the ability to create a new way of living and being, a continuing challenge to work towards health, to never give up, to work at getting better. Rear up against the dependency, and rear up to challenge what is being said about the rest of your life and find the power within to continue the fight for what you want to happen.

And later, in hindsight, you will know whether your fight was a success because you got it your way or a success because it turned out differently. Either way, it is the spirit of the earth, wind, water and fire that keeps moving you forward even though the outcome lies within the sun and moon and larger forces.

Meet Hilary Zayed

Hilary Zayed reinvented herself as an artist and writer of the brain injury experience after falling from her horse in 2006 and learning she could no longer return to being an elementary school teacher, avid flute player and passionate horseback rider. You can find more of Hilary's work at www.reinventingoneself.com

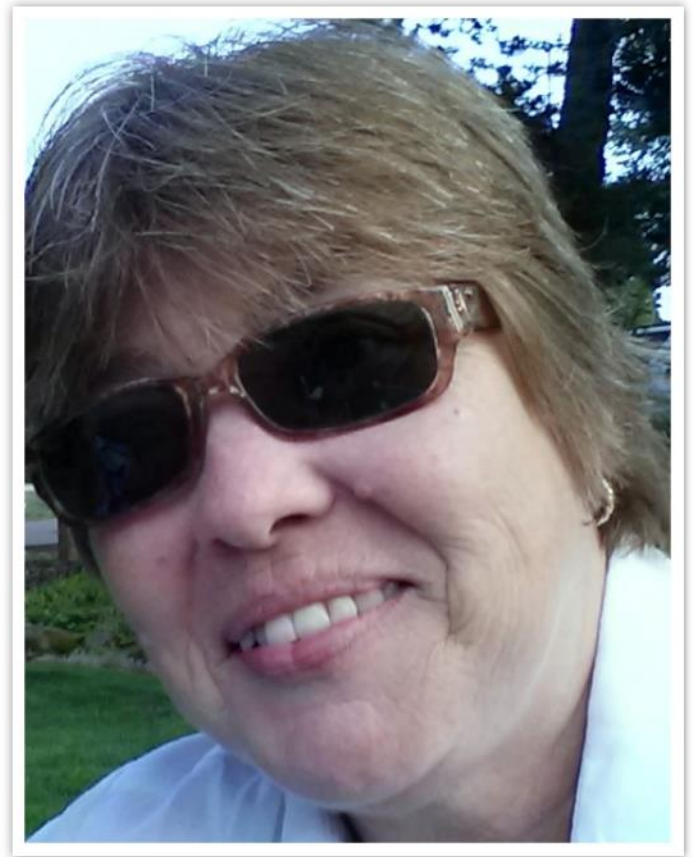


Sun's Spirit: Mirrored horse with Van Gogh glass mane and tail so the viewer can see their reflection within the horse. Mosaic background utilizing hand cut Stained Glass.

My Constant Companions: Impulsivity & Disinhibitionism

By Donna Hafner

For many of us who have had a frontal lobe brain injury, you are probably all too familiar with the two characters impulsivity and disinhibitionism. They often show up when you least expect them or want them to. For me, I've become very familiar with their antics.



My injuries were 3 years ago. I experienced very big strokes in various locations of my brain. One of them was in my frontal lobe. At first my family didn't really notice. They were just happy to have me survive the traumas that I had just gone through. A massive heart attack and a two week coma make everything else seem pale in comparison.

But it wasn't long before Impulsivity and Disinhibition reared their heads. To start with, I was swearing like a drunken sailor on shore leave. Every sentence was punctuated with a blue streak. This was completely out of character for me. I was a middle-aged professional woman who didn't typically swear in public. Truth be told, I didn't even realize that I was doing it at the time. But everyone who entered my room was met with an enthusiastic greeting filled with plenty of blippity, bleep, bleep, bleeps!

My family kind of withered, not knowing what would come out of my mouth. Maybe some of you understand this strange new experience too. I've heard from other sedate, church-going survivors who are appalled at

their newly acquired skill for swearing. It is not uncommon even amongst the most pious people. Brain injuries are mysterious things that prompt all kinds of strange and inappropriate behaviors. I'm learning to make peace with that fact.

“It was at that time that my family knew that I was not the same person that they had known before.”

They also showed up in other ways too – specifically my humor. Prior to my injuries, I was a rather serious person. Ok, I was actually a VERY serious person. Sure, I had an appreciation when something was funny...but I was NOT the person who was the life of the party with an easy laugh.

All of that changed after I woke up. In fact, I am pretty sure that somehow I grew a funny bone during my coma.

But it didn't take long for it to appear. I know that it is most typical to have survivors become more combative,

aggressive and difficult. For me, I went the other way. I'd been a difficult person before, and now I was mostly a pussy cat, I was compliant and willing to try anything that was asked of me. I had this silly grin plastered on my face. It was at that time that my family knew that I was not the same person they had known before.

So what was going on? Why was I prolifically swearing and grinning and trying to jump from my chair and dance? Oh yes, that was yet another time that I couldn't seem to stop myself. It was a couple of months later, after I had relearned to walk, and my mom and I were having a consultation with a nurse.

I was sitting in the chair, trying to follow the conversation, when suddenly she said something that reminded me of an old soft shoe song and dance routine. Before I knew it, I struggled to my feet and proceeded to wobble my way through a soft shoe shuffle. When I was done, I threw my arms open wide and said, “Ta Da!”

Needless to say, both the nurse and my mother were stunned. What the heck did I just do? I tried to explain myself, but I couldn't quite get it out. I was laughing too hard. Once I settled down, I said that I couldn't stop myself. I had felt propelled out of my chair. They looked at me like I had just lost my mind. In some ways I had. It was a prime example of what can happen when Impulsivity and Disinhibition come out to play.

That was two years ago. How are things now?

Well, it's gotten better. There is hope. I still unknowingly swear. But it happens less than it used to. My humor is still intact, but the compulsiveness to act on my thoughts is less. No more jumping up and dancing in front of strangers for me now.

I've found adaptive strategies to tame my two companions. I can often feel their mischievous presence, just below the surface. And, most times, I can contain them. Though, occasionally they do still escape and play. And when they do, they provide some of the most interesting and funny stories. I've learned that I can live with these two characters. We 3 have negotiated a truce, so to speak.

Time teaches us what our "new" selves are now. We learn to adapt. We gain insights. We grow and change. Will I still be this way in the future? I don't know. I will probably be some version of this "new" me. Hopefully a better version with a little more control over my new companions. What I know is there is Hope.

Here's wishing for continued progress for all of you too.

More about Donna Hafner

Donna is a survivor in the truest sense of the word. Coming back from near death and living life as a brain injury survivor have validated why those closest to her know her by her nickname – Resilynt.

Walking in the Dark

By Michael Strand



Living with a brain injury is feeling what it must be like to be immortal. With no memory of a past there can be no notion of a future. Forever in the present; an eternity of now. Actually, brain injury is slightly different. I have a memory, but I have no certainty that my memory is valid. At any time I can discover that what I remember is not what anyone else remembers and when this happens it is always me who is wrong. This makes using my judgment a complete joke.

Most consistently, this is an issue when I am fatigued. There are many things I have difficulty doing well or even safely when I am tired. But it is rarely as simple or obvious as being able or unable to do something. It is a matter of chance; a matter of odds. Do I feel well enough to drive? Do I feel sharp enough to handle a difficult transaction? How about when my significant other wants to discuss something with me? Am I too tired to respond rationally and responsibly? Am I more likely to lose my temper? It would be nice if in real life I could just say, “You know, those are really valid concerns, but I’m just too tired to talk about it right now.” However, in the lively chemistry of human relationships, that is rarely a response that it occurs to me to make. It is usually much later when I realize in hindsight that that is in fact what I should have said.

The problem here is that there are very few absolutes. It is rarely as obvious as, “No, I can’t fly like a bird, so I’m not jumping off this bridge.” It is

commonly something like “I really shouldn’t drive when I’m this tired, so I don’t think I can run this errand.”

The biggest problem for me now however, is not those issues as they truly are, but as they appear. They appear convenient. Although their actual convenience may be only coincidental, it seems to other people that I am only using my brain injury to get out of something I don’t want to do. Sometimes I am not even really sure if it is an actual concern or just convenience. Maybe I really would rather not go shopping for my brother’s birthday present...Or maybe it really is too late for me to be out driving.

So if even I am not sure, then I certainly can’t blame other people if they wonder, ask, or accuse me, of making an excuse out of my brain injury. It was 1989 when I had my accident and still every day I have to deal with lingering effects of my brain injury. I am pretty high functioning and most of the time I can keep my brain injury from being the most noticeable thing about me. But then my closest friends will tell me I can’t use my brain injury as an excuse anymore (mere acquaintances would never say that). When they say that I tend to want to agree with them, but then something will occur that reminds me that saying I don’t have a brain injury is denying I have a brain injury, and that can have serious repercussions when I stop using the various tactics and techniques I have cleverly devised as compensatory strategies to get through the day.

“I am pretty high functioning and most of the time I can keep my brain injury from being the most noticeable thing about me.”

Once again, the most frustrating thing is that there is no right answer and there is no wrong answer, there are only shades of might have and should have. Regrets pile up with little hope of profiting by experience because everything is relatively risky. Everything is contingent on variables that are undefinable in the present. I live caged in the NOW with no memory. There is no anticipation but what the mind imagines. In a hostile environment, that means dread. Living with a brain injury is like walking in a dark room unable to see the furniture.

Meet Michael Stand

As a survivor who has lived with brain injury since 1989, Michael shares his experience through his written work including several books and his brain injury blog. Michael is also a Chicken Soup for the Soul contributing writer.

A Legislative History: Special Education Rights for students with brain injury

By Katherine A. Kimes, Ed.D., CBIS

It is important to identify how children with disabilities, through the years, have lacked the support and services in relationship to special education services in public education. The educational rights and how they have evolved over the past decades for students with brain injury is an important legislative matter that needs to be addressed.

Appropriate educational support is vital to help improve these children's educational outcomes. We, as a society, need to understand the legislative history and understand those laws that have helped safeguard the educational rights of students with disabilities. A brief synopsis is discussed regarding the legislative acts that have been voted on to help improve the system of education for students with disabilities. From this overview, how these laws have impacted the education of children with brain injury is discussed.



Photo credit: Administration for Children and Families.

Section 504 of the Rehabilitation Act

In 1973, Section 504 of the Rehabilitation Act prohibited discrimination of students with disabilities in employment, education and all aspects of the delivery of services, to include program access. This 1973 law required schools to provide accessibility and reasonable accommodations to students with disabilities. The aim of the act was intended to ensure a discrimination free environment within the school system. This act guaranteed that students with brain injury would participate in programs provided by agencies receiving federal funding. Unfortunately, however, most schools and school districts did not follow this federal law and were not providing an appropriate education to students with disabilities.

Education for all Handicapped Children Act

Congress enacted the Education for all Handicapped Children Act, P.L. 94-142, in 1975. This act required that all public schools provide a fair and appropriate public education for all students with disabilities (FAPE) between the ages of 3-21. This law protects students with brain injury in six fundamental ways: 1. the right to be educated with other students, zero reject, 2. access to an appropriate education at taxpayers' expense, 3. the development of an Individualized Education Plan (IEP) that documents a student's unique needs, 4. being educated in the least restrictive environment (LRE), 5. the protection of student, parent, or guardian rights to a due process hearing, and 6. parent participation within the education process.

Although brain injury was not specifically categorized as a disability under this act, those students who were identified as brain injured had still access to special education services under the category of Other Health Impairments (OHI).

Americans with Disabilities Act (ADA)

The rights of individuals with disabilities were further protected in 1990 with the passage of the Americans with Disabilities Act (ADA). This was the world's first comprehensive civil rights law for people with disabilities. The ADA protects against discrimination at 4 levels: 1. education, 2. public services, 3. public accommodations, and 4. telecommunications.

The ADA resembles the 504 of the Rehabilitation Act in both language and objective, although the ADA provides global access by addressing not only non-discrimination in schools, but also non-discrimination in the work place, the community and society at large.

TBI Act

The TBI Act, P.L. 104-166 was finally passed in 1996 after several failed attempts. The purpose of the act was to amend the public service act in order to provide for the growth, development, and improvement of TBI programs. The main object was to appropriate funding for TBI studies and research.



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The act authorized funding to the US Department of Health and Human Services (HHS), Health Resources and Service Administration (HRSA) and also provided funding to the Centers for Disease Control and Prevention (CDC) for surveillance, public education, prevention and research.

The TBI act has allowed states to expand their therapeutic service capacity to include information and referral services, service coordination, and rehabilitation services, etc. Its goal is to allow individuals with brain injury to return to school, work, and home to avoid institutionalization.

While it is important to continue to fund research, prevention and education, there are also other issues that need to be addressed in the TBI Act.

A missing, but vital element relates to the funding that helps to facilitate appropriate services and supports directly to individuals with TBI. Rather than exclusively focusing and funding research, the act would benefit from funding that builds service capacity. Services and programs need to be available to the individual, community and public at large. The appropriation of funding that provides TBI services directly to the individual, to include public education, is needed. This will allow service delivery to grow, develop and improve.

Individuals Education Act (IDEA)

By 1997, the expectations for students with disabilities were still falling short. There were still too many students with disabilities dropping out of schools and unable to find jobs. A lot of these drop outs ended up in the Criminal Justice System. Additionally, young girls who dropped out were becoming unwed mothers at a higher rate than their non-disabled peers.

The Individuals with Disabilities Education Act (IDEA) was a reauthorization of the Education for the Handicapped Act and Education for All Handicapped

Children Act (P.L. 94-142). IDEA of 1997 was a triumphant step in getting TBI identified and recognized as a special education category. The signing of IDEA into law in 1997 and its reauthorization in 2004, has opened the door for students with TBI. This act has provided these children the opportunity to receive the benefits of service coordination within the public school system.

Since the act's reauthorization, students with disabilities have been provided with the opportunity to become involved in the general education curriculum. Parents have also become more involved in their child's eligibility and placement decisions. IDEA has encouraged greater expectations for these students.

Terminology Issue surrounding IDEA

Unfortunately, lawmakers did not understand the terminology associated with the different types of brain injuries: traumatic, non-traumatic and congenital (i.e. present at birth). Therefore, the language used in IDEA has disenfranchised millions of children with non-traumatic and congenital brain injuries within the special education system. While these children still receive special education support, they are being misidentified and categorized under Other Health Impairment (OHI). This causes the incident rate of brain injury to be distorted. As a result, special education still categorizes brain injury as a low incident disability. As a result, pre-service teachers do not get adequate training in this area.

Although IDEA was a groundbreaking accomplishment for children/adolescents with TBI, the act is incomplete. A greater understanding is needed. While the mechanisms of injury may be different, all brain injuries are alike in that they all alter a child's brain functioning. A TBI is similar to a non-traumatic brain injury and both types of injuries can be related to congenital brain injury. It is just the way the injury was acquired (i.e., the mechanisms of injury) that differentiates them.

Despite the differences in how the brain injury is acquired, the resulting impairments are thematically the same, but yet still uniquely different. Impairments caused by brain injury vary from individual to individual, student to student, and child to child. However, all injuries alter the functioning of the brain. This is where the commonality lies.

Summary

There are two main distinctions between the 504 of the Rehabilitation Act and IDEA (§613(f), 1997; §1400, 2004]. Section 504 is a civil rights statute that prohibits discrimination of individuals based on handicap, while IDEA is a federal grant program that authorizes federal funds to states to assist in the delivery of special education programs and service coordination.

However, even with the existence of these two federal laws, it can be difficult for children with brain injury to receive and or obtain appropriate services and supports, especially if these children are being misidentified and not accurately categorized as brain injured.

Oftentimes services and supports are not available within the school system, or are difficult to coordinate. These systemic issues stem from three underlying principles: 1. a general misunderstanding of brain injury, 2. a fragmented system of service delivery and 3. financial barriers within the school system.

Meet Dr. Katherine Kimes



Dr. Katherine Kimes has a Master's Degree in Literary and Technical Writing from DePaul University. She also has a Master's degree in Transition Special Education with an emphasis in acquired brain injury and a Doctorate in Special Education also with a concentration in acquired brain injury, both degrees confirmed by the George Washington University.

She has worked as a CSPPPD Service Coordinator and is a Certified Brain Injury Specialist. Please visit her website, www.ABI-EdServices.com, for more information.

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Word Search – Challenges We Face

S S S E N C N B V N N A A E U
S F S J M A X O A O V E Y N D
E A J E C O M T I F S W C H O
N M I C N I T S N U D O P E F
I U S N T L U I A X N M S A U
R C S I M F U N O S V N E D A
R B N H N O U F C N R A O A I
U G U O H I S I T D A S Z C S
L L C N O V O N B E M L N H E
B P X Q I U K V I E G C L E N
E V Z H S K H R F S N R V U M
J Q M N S U T I N N I T O X A
W Y E D I Z Z I N E S S K F T
O S D A J N X Z E P O T W R E
S N O I T A T N E I R O S I D

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