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**Embodiment, Autoethnography, Performance Poetry:
Living with Severe Traumatic Brain Injury**

**Incarnation, autoethnographie, poésie performance :
Vivre avec un traumatisme crânien grave**

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Abstract

This presentation offers neurodivergence embodied, autoethnography, and performance poetry. The confluence of acquiring severe traumatic brain injury combined with exposure to concepts and paradigms while pursuing a graduate degree in Disability Studies, catalyzed emergence and triggered development of my disabled identity. The brain damage acquired causes issues of decoding/deciphering/processing, which in turn triggers and/or produces episodes of temporal dissonance. When these shifts in timing occur, they have tremendous impact on rational thought processes and emotional stability. The salient aspects of my new life – emotional sensitivity and volatility – may on the surface seem detrimental and undesirable; however, I celebrate these qualities as they greatly enhance my identification with and empathy for others, which in turn drive my artistic, social, cultural, political expression, quest for community and belonging. While temporal dissonance is unlikely to occur during this planned short presentation, I will relate and provide the audience with windows on largely hidden and little understood forms of impairment.

Note: To hear recitation of some of these poems, check out fellow VIBE presenter Cheryl Green's podcast: <http://whoamitostopit.com/pigeonhole-podcast-17-autoethnographic-poetry/>

The original presentation at VIBE was accompanied by music from Miles Davis and Marcus Miller's 1987 album *Music from Siesta*. Readers are encouraged to listen to this album via their music platform of choice while reading the following poetry. Youtube link to the album:

https://www.youtube.com/watch?v=ZuvtNL_jyeQ

Résumé

Cette représentation réunit une incarnation de la neurodivergence, l'autoethnographie et la poésie performance. La convergence de l'acquisition d'un traumatisme crânien grave et de l'exposition

à des concepts et à des paradigmes tout en poursuivant un diplôme d'études supérieures en études sur le handicap a catalysé l'émergence de mon identité de personne handicapée et déclenché son développement. L'acquisition de lésions cérébrales provoque des enjeux de décodage/déchiffrement/traitement, qui à leur tour déclenchent et/ou produisent des épisodes de dissonance temporelle. Lorsque ces changements temporels se produisent, leur impact sur les processus de pensée rationnelle et sur la stabilité émotionnelle est énorme. Les aspects proéminents de ma nouvelle vie (sensibilité émotionnelle et volatilité) peuvent sembler négatifs et indésirables en surface. Cependant, je célèbre ces qualités, car elles améliorent considérablement ma capacité à m'identifier aux autres et mon empathie pour elles et eux, ce qui motive mon expression artistique, sociale, culturelle, politique ainsi que ma quête de communauté et d'appartenance. Bien qu'il soit peu probable qu'une dissonance temporelle se produise au cours de cette courte représentation prévue à l'avance, j'ouvrirai des brèches pour relater au public les formes de déficience largement cachées et peu comprises.

Remarque : Pour entendre la récitation de certains de ces poèmes, consultez le balado de Cheryl Green, une autre présentatrice de VIBE : <http://whoamitostopit.com/pigeonhole-podcast-17-autoethnographic-poetry/>

La représentation originale à VIBE était accompagnée de la musique de l'album Music from Siesta de Miles Davis et Marcus Miller sorti en 1987. Les lecteurs sont encouragés à écouter l'album via la plateforme musicale de leur choix tout en lisant la poésie suivante. Lien YouTube vers l'album : https://www.youtube.com/watch?v=ZuvtNL_jyeQ

Key Words: Traumatic Brain Injury, Acquired Disability, Identity, Poetry

In December 2018, I delivered this presentation, *Embodiment, Autoethnography, Performance Poetry: Living with Severe Traumatic Brain Injury to VIBE: Challenging Ableism and Audism Through the Arts* in Montreal, Quebec, Canada. I examined the lives of my brother Richard Stuart Kidd and me as severe traumatic brain injury (TBI) survivors. While Richard's accident occurred nearly 31 years ago, at this writing, I am in the 14th year of my recovery.

Congratulations and great thanks to *Vibe* participants, fellow presenters, and organizers. Hello. My name is Douglas E. Kidd. I live in Toledo, Ohio, United States of America. I use pronouns: he/him/his. For those who access the world differently, I have faded red hair, green eyes, wear a neon-yellow shirt, black pants. From an ancient past, I have *Neanderthal* genes; my last ancestor from North Africa lived to 1780; in the last three centuries, Scottish, English, Irish, German, French, Scandinavian, East European descent. Trigger warning: descriptions/images of catastrophic car accident, coma-amnesia, physical, emotional trauma/injury; expression/presentation of severe TBI. I dedicate this to Richard, my mother, Mary, and neurodivergent sisters, Lindsey Anderson and Tanya Coffield. Great thanks to all for promoting acceptance of difference and pride!

The following provides a brief overview of the circumstances/outcomes of Richard's experience. Before midnight on Thursday, December 31, 1987 as a pedestrian, a car without headlights ran through Richard, then fled the scene. Richard experienced a severe TBI with coma lasting nearly one year. Additional brain damage occurred as his breathing failed for a time before rescue personnel revived him. Richard is hemiplegic, only able to control his right side of his body. Richard is unable to process like most, with no awareness of time, speaks haltingly in perseveration loops, and has few intact memories.



Figure 1. Captured in 1984, this image shows Richard Kidd kneeling in front of fellow members of his tank platoon while he served in the United States Army in South Korea.

Note impact of Richard's accident on me and presentation music: An avid Miles Davis fan, I obtained new albums as they issued. *Siesta* appeared in November 1987. Richard's accident occurred 6 weeks later. I could not cope with Richard's tragic circumstances then, so I abused drugs many times per week, and listened at full volume to the hauntingly beautiful music from Miles Davis and Marcus Miller. Now, 25 years in recovery from substances, I am empowered as I listen to *Siesta*. Often, I am tearful as my mind/body recalls those dark times, but I am renewed, and celebrate Richard's life. As never before has this full presentation occurred, please forgive any confusion between competing volumes of the music and my voice.



Figure 2. This image from 2008 shows Richard Kidd seated in his wheelchair at his nursing facility in Sylvania, Ohio. Douglas Kidd is standing just behind Richard with arms wrapping around and hands resting on his chest.

The following two poems explore the impact of Richard's experience on me.

Richard is Lost

1987 ended with crime injury agony - catalyzed odysseys of pain

Heart-breaking anguished moments - continue 'til this day

Severe traumatic brain injury - oxygen-deprived brain damage

Coma medically-induced coma - bored holes in his skull - relieved pressure

Multiple compound cracks/fractures - cranium rocked - how ever did Richard survive?

Extraordinary efforts to save him? - Yes, please do - with all speed skill haste

Savagely stolen childhood/lifelong friend - suddenly and forever grave

Happy New Year 1988

The following surged to paper nearly fully formed in less than two minutes. It was December 2008, I just returned from holiday shopping when an image of Richard alone in his wheelchair in his room came to mind. Never before had anything remotely like the urgent need to express sorrow/hurt/anger/frustration/loss/guilt occurred. The experience left me sad, shaking, terrified!

Richard, Christmas, and Me

Gifts for Richard?
People, me included,
Scurry about achieving little
Except buying things
We could easily live without.
As if we are trying to
Put salve on a wound that is not there.
His concerns - more immediate.
View seldom changes only
Interrupted by sessions of pain caused by others
Who make a living on his inability
To do for himself what
Most of us take for granted.
To dress himself - impossible.
And, why should he attempt to cover what
His survival wrought?
He did not choose life like this, but was
Thrust upon him by people who could not
Bear the thought of life without him
What hell to bear witness to the
Collapse of another's life!
Oh! The lives he could have lived!
Desolates the mind, breaks open the heart!
Torment to watch
Little relief to his life!

People, me included, distracted by trivia
Days flit past usually beginning with
“What will I do today?”
Personal trial yields this question:
Best gift of the day?
Make easier the paths for Richard!

A critical difference in the realities we confront stems from Richard’s inability to self-advocate. Consequently, he is unable to resist others, therefore vulnerable, his life subject to chance. Especially early during my recovery, I shared similar circumstances and experiences to Richard. My close connection with Richard leads to total acceptance, identification, and love. While Richard’s journey is a series of disabling events, my experience is largely one of impairment. In stark contrast to the abuse and neglect of Richard’s experience; my journey is one of recovering and enhancing physical, cognitive, psychological, and emotional abilities to meet demands/challenges from society.



Figure 3. This photo from June 2005 shows Douglas Kidd with ventilation tubes surrounding his neck and projecting into his mouth as he lay in coma in an intensive care unit (ICU) in Waterville, Ohio. - Photo Courtesy of Mary D. Kidd.

Now, pieces of my experience...

Oblivion

Hurling mass

Crushes metal Shatters glass

Hips fracture Heart drains

Brain damage

Pain ascends Hope fades

Whelmed by wreckage

Sleep Not asleep Time sweeps past

Another terrifying stream of consciousness surfaced nearly fully formed in less than 5 minutes

Coma Amnesia Survival

Desperate cry Rends night

Crimson pain Sears sight

Cavern dark Absent light

Stony silence Burns bright

Blood pressure Falling slight

Compartments stretched Swellings affright

Brain compression New height

Infection clutches Grips tight

Amnesia enters Confusion fright

Blankets memory Shatters might

Severs confidence Enter blight

Emerging identity Fragile fight

Machines rescue Working right

Hope reverberates *Survival* tonight

Corners turned Hearts delight

Life certain Cognition alight

Death & Rebirth

Like devastation precipitated by molten magma sliding
Through the oceans depths - compelling massive shifts to tectonic plates
Releasing tremendous energies that coalesce, rise, surface, form waves, speed away
Bring into being destructive tsunami
The tremendous concussive forces of the collision
Caused bloody brain damage/trauma/coma/amnesia - beleaguered cells
Time passed...cells eventually settle, reassemble, reorient, restructure, realign
Flicker back to life, disjointed identity reforms, cognition resumes, nascent self-returns

A few years ago, my friend Dr. Steven Singer helped me develop memoir. Parts of the next section I owe to him. Earlier this year, I presented in Malta to the Euro-Mediterranean Conference on Disability Studies and Disability Activism organised by the Department of Disability Studies, Faculty for Social Wellbeing, of the University of Malta. My presentation was so well received I was encouraged to submit to *Encounters between Disability Studies and Critical Trauma Studies* published by the Romanian journal *Word and Text: A Journal of Literary Studies and Linguistics*. This publication is now issued. The following developed through work with editors Dr. Arleen Ionescu of Shanghai Jiao Tong University and Dr. Anne-Marie Callus of the University of Malta. Great thanks to both for their many efforts!

Now, I ask simple questions and provide conceptual frameworks illustrating how massive forces of an automobile collision erased conventional understandings of my essence-identity and reduced me to a collection of cells struggling for survival in an indifferent, even hostile universe. First question, *'what is reality?'* Answer: reality may be seen as matter/energy existing within the space-time continuum. *Second question: 'what is a human being?'* Answer: a human being can be regarded as a discrete mass of biological tissue – a matrix/factory where electrochemical exchanges, interchanges occur. Reality shapes/defines human beings as biological tissue, awash in nutrient molecules, interacts with external matter, energy, gravity. Most human beings from birth acquire abilities to process reality. Imagine however, processing reality; but at a slower rate; so much slower, society leaves you behind. For weeks, my body existed, but I was separate, outside of time.

2005's longest day swept past, no awareness of self or time, detached – apart. Vague impressions of the outside world: sounds, voices, some comforting/familiar, brought the world closer, then receded. Who am I? What am I? When did this happen? Why was I held captive? In an agitated state, compelled to flee – ripped tubes from throat/body – left bed, only to hit the cold, antiseptic floor, hard. Subdued by staff – tears streaming – fought with every fibre of my being for release; until finally collapsing under the weight of strong hands, exhaustion, sedation; ensnared – entombed in my mind – enmeshed by a strait jacket, unable to escape, pinned to my bed. Few visible scars exist – others indelibly submerged. As memories surface, tears well in my eyes, splash down my face.

As the delicate electro-chemical structures of my brain experienced massive damage and disorientation, I existed for months without a sense of time. In the days following my attempt to leave, I complied with treatment. Later, as machines healed me, noises and terrible odours

emanating from the devices summoned me to surface. For months, adult cognition failed. The operational fulcrum developed for decision-making became damaged, diminished – reverted. Slowly, steadily I re-engaged my surroundings, but with the cognitive/emotional abilities of a young child. I am informed, my childlike curiosity developed an insatiable hunger for audio/visual stimulation. I would spend hours in bed absorbing the sounds and images of children’s programming on a small television held so close that it touched my nose. Days passed..., friends read me children’s books. Others report, I would giggle and bounce my legs up and down in eager anticipation as pages turned. This stimulation helped me greatly as I first re-engaged the world.

Acquisition of spatial relationships, cognitive/psychological/emotional abilities gained in first days and years of life are small, incremental; individuals on neurotypical life trajectories experience a progression of days where knowledge gained from previous lessons is retained, enhanced, sharpened, and cemented. This usual development over time creates the neural pathways that become tools, or lenses with which we learn to recognize, process, and navigate our surroundings. We are equipped at the cellular level to identify and interpret the world we encounter. The brain, encased inside dense bone, receives input from eyes, and sensory organs to process and understand external environments. Most take for granted the time required to navigate disparate elements of reality successfully – to process – make sense of the mélange of ordinary and extraordinary environments in which we find ourselves immersed. I took for granted the neurotypical development I enjoyed prior to my accident; then the disconnection from time and self I experienced, mark the beginning of my new life. As coma/amnesia subsided, somehow, I filtered back through damaged brain tissues, enough neurons realigned, reactivated and I surfaced fully in late-July 2005. Without a clear understanding of what had occurred,

disoriented,whelmed by emotion, overjoyed with simply being alive, I reunited with family/friends, then resumed life with my identity profoundly altered.

Brutally cold winter's night, at home lying in bed, exhausted; caught a reflection in the mirror, but did not recognize the stranger. Who is he? Looks familiar, but... Suddenly, the sinking realization: face in the mirror was I. Time then dilated for many intense minutes, body convulsed, mind collapsed, tears fell. Like falling from a great height, I shattered on the cold, hard ground of pitiless reality. The episode left me breathless.

My mental/physical decomposition that night was hardly surprising. Only eight months passed since 4:34 pm, Tuesday, May 17, 2005, when I initiated a call, then failed to yield to a 3,000 kilogram SUV travelling 80 kph and it smashed into me.



Figures 4 & 5. The image on the left shows a large and blue Sport Utility Vehicle (SUV) with relatively minor damage to the front driver's side of the vehicle.

The image on the right shows Douglas Kidd's two-door white car with its mid-section damaged by the SUV. The driver's side rear wheel is twisted and is nearly parallel with the ground.



Figure 6. This photo is an interior view of Douglas Kidd's car showing extensive damage following the collision with the SUV. The driver's side door is crushed and covers the operator's seat. The image shows broken glass scattered throughout the cabin with Douglas Kidd's cellphone clearly visible in the lower left of the image. Photo Courtesy of Thomas J. Behrle]

Catastrophic injuries: severe traumatic brain injury with haemorrhaging led to coma/amnesia of 75 days; massive internal bleeding from lacerations to rectum, liver, spleen, abdomen; compartment syndrome injury to right leg; multiple hip fractures; cardiac arrests; respiratory failure; MRSA. I was discharged, September 15, 2005. Instead of daily workouts in hospital, I underwent 3 sessions per week of outpatient physical, occupational, and speech therapy. By October 2005, I resumed my work as an industrial designer. In January 2006, eight months after the accident, returned to university. All pressures combined to produce the episode. Like using a treadmill that suddenly spins too fast, I fell. Exhausted, brain ceased to process, overwhelmed by fear, shutdown, shuddered. Time sped by so fast – too fast – I could not breathe. I felt like I plummeted towards a bottomless pit looking to swallow me whole; hoped if enough fell, the pool of tears would break my fall; then gently I would float to the surface safe,

whole, alive. Twelve and a half years removed as of this writing, searing remembrances of my first temporal dissonance remain. As memories surface, tears well in my eyes, splash down my face.

Now, a few more pieces of me...

Chasing Paths

Wandering through wintery wastes trying to find purchase

Attempting the cold stone slippery steps cut by nondisabled minds

Slipping here falling there perseverating on the flecks of fool's gold?

No wounds cut so deep as those ministered by the capacitated on the incapacitated

And, why do cognitively disenfranchised undeservedly inherit such animus?

No reason/rhyme - 'cept lack of power to meet whelming tides of speed/contempt/disregard

Nondisabled leader's threat: "If you repeat this, I will deny it...they do nothing all day"

Cognitively nondisabled's prerogative (whim) sets tone/pace - exclude

Observant eyes listening ears feeling bodies caring hearts

Othered minds - see hear feel - offer a way through

The following is a brief description of the genesis for my next poem entitled, *Ableism's Anvil - The Treadmill*. Over the decades, a great admirer of Charles Dickens' many achievements, each holiday season I read from *A Christmas Carol*. Ebenezer Scrooge suggests disadvantaged people apply to workhouses for assistance when he was asked to make a donation for the poor. Scrooge asks the men soliciting provisions for the poor if the prisons, workhouses, or treadmills remain in operation. The men stated sadly these state institutions were in operation. Scrooge stated taxes he paid supported the workhouses and directed the men to seek assistance for deprived people elsewhere. Upon reflection, the treadmill seems an apt analogy for ideas regarding arbitrary and questionable standards of production, as well as the implications for disabled people in society.

Ableism's Anvil - The Treadmill

Caught (splayed out) by ideals of arbitrary standards of production

Hypothetically conjectured quotas to maintain and so remain

Felonies against human dignity - and thus divinity is lost

By oppressors need for efficiency - no thought given to cost

Effects of insatiable greed - cruelty and pain - simmer as in a tempest tossed

Best practice for humanity sacrificed on the alter of throughput

Those considered defective - discredited - disabled - helpless - relegated without thought

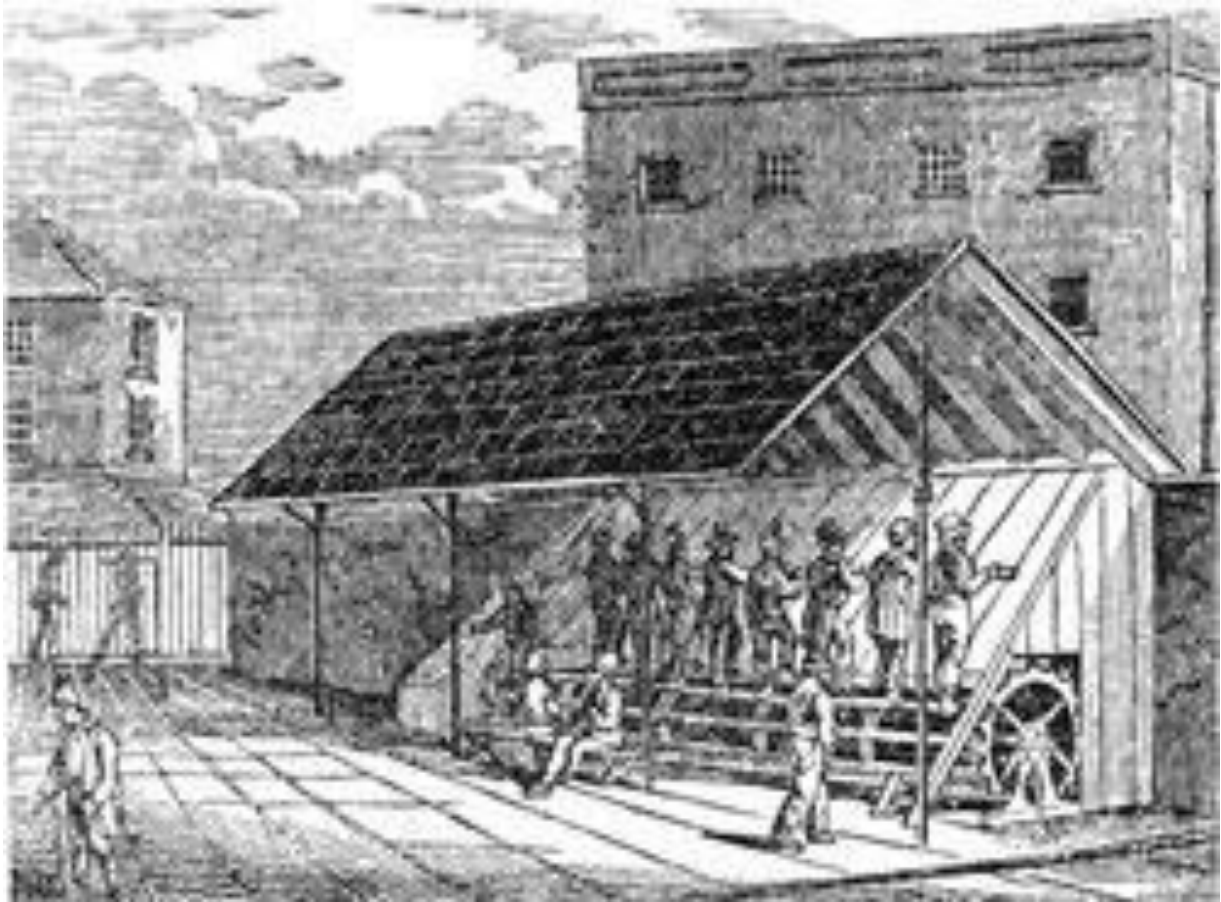


Figure 7. The Treadmill [Public Domain image]

This image shows an illustration of a large cylinder about 4 feet in diameter and 40 feet long with wooden planks attached which were used as steps to revolve the device. There are eight human beings evenly spaced along its length.

Invented in 1818, the nasty device consisted of a metal cylinder with steps built on it so far apart that one had to step way up to catch the next one before the cylinder revolved around under one's feet, rather like a wheel in a hamster cage. Convicts were required to walk on the treadmill six hours at a time. <https://www.geriwalton.com/the-treadmill-for-punishmen/>

Next, this poem attempts description of the aftermath of trauma, disorientation and disconnection; yet slowly turns to recovery, reclamation of self and identity, and re-assimilation with others.

Lost

Centered in The maze I turn
Only to find No way through
Or out bereft of Cognition I spin
Faster - until Smothered by the high

Walls of Achievement that lean
In - cowed by the Temples of know
Forced to (re)build My collapsed mind
Making difficult the Ability to grow

Up & out - Caught - splayed - locked
In by enveloping Coma consuming
All - terrified by People - profound
Uncertainty with the Scope - pacing

Of society - life - Searching for ground
To stabilize - within - Chaotic sowing
And managing of Confusion - weakened
In the midst of the Higher level processing

Required to maintain even a tenuous
Grip - grasp - fragile hold - on reality
Which (re)forms Identity & encourages
Nascent self To (re)Join humanity

This poem moves from complete dissolution of self to describe aspirations for reclamation.

The Well

How far down did you go?
Fathomed depths Few have been.

How long were you gone?
Soo much time Never the same.

What did you come to know?
Coma dark fear Hurt isolation strain.

How long were you gone?
So many days Left behind my name.

Why attempt to return home?
Ask salmon Why they spawn.

Whence comes the spirit to grow?
Hawking argues Law of gravity alone.

What marks Sears to the bone?
Upward journey Unconquered pain.

Where discover/fix joy?
Places tender Meek being.

Why compelled Produce tome?
To find/order Mind/self Sane.

What gives You hope?
Community sharing Kindness humane.

Why move out From well's shadow?
To reclaim all Before last lights wane.

Last poem,

The Crucible of Trauma: Melding the Fragments Whole

From death coma/amnesia straight jacketed by walls of damaged brain tissue to life/rebirth
Hearing thinking touching feeling verbalizing remembering trying organizing standing walking
Driven to relive (replay) events so they turn out differently compel fear & frustration
Grieving quietly (passing) turn to identification/acceptance/belonging
Renewed, refreshed, driven to express, find community, roads to
Oświęcim Paris Berlin Vienna Palantino Sliema Montréal

In closing: human beings emerge from and exist within reality. Personal experience illustrates how sensitive the mind/body are as processing tools of reality. Envision the gelatine-like brain defined, ordered, separated by dense bone into compartments of knowing. Consider this working system suddenly, violently shaken so hard, brain damage ensues and total negation of self occurs. For a while, loss dominates. Time passes... Slowly brain tissues heal, reconstitute, reassemble, restructure at the cellular level. Cognition flickers, self steals back, reclaiming the void. Now, examine one restored human being processing reality in space/time, but with a tendency to slip/disorient; yet throughout recovery possesses a great desire to realize identity, uncover meaning, discover belonging, find community, and celebrate.

As I daily embrace outcomes of our catastrophic accidents, I hold memories of the Richard I once knew close in my mind. The aftermath of accident, trauma, coma/amnesia, and resultant impairments, along with bonds of identity forged through common experience created the closest connection, deepest admiration, appreciation for Richard and the wondrous experience of simply being alive. I treasure Richard's life and look forward to our futures with hope. Peace and thank you very much for your time.

Glossary of Terms

Advocacy: the act or process of supporting a cause or proposal

Auto-ethnographical: a method or form of social research that serves the purpose of exploring personal experiences of the researcher

Decompensate: functional deterioration of a previously working structure or system

Detrimental: obviously harmful

Dissonance: lack of agreement

Neurodivergent: sometimes abbreviated as ND, means having a brain that functions in ways that diverge significantly from the dominant societal standards of “normal.”

Neurotypical: often abbreviated as NT, means having a style of neurocognitive functioning that falls within the dominant societal standards of “normal.”

Severe Traumatic Brain Injury (TBI): commonly described as a loss of consciousness or coma lasting more than 24 hours, post-traumatic amnesia of more than 24 hours, or abnormal brain imaging results. Source: <http://www.northeastern.edu/nutraumaticbraininjury/what-is-tbi/severity-of-tbi/>

Temporal: of or relating to time as opposed to eternity

Vocation: the work in which a person is employed

Bio:

Douglas, in his 17th year of recovery from severe traumatic brain injury has poetry, essays, and articles published; presented to international audiences from Honolulu to San Francisco to Chicago to Bergen, Norway to Amsterdam, Netherlands to Sliema, Malta to Montréal, Québec, to Debrecen, Hungary; leads a brain injury support group; his safe-driving advocacy non-profit is affiliated with the National Safety Council in Itasca, Illinois; he improves the community as member of Disability Rights Ohio; and performs social work for the largest mental healthcare provider in Northwest Ohio.