

## We Exist: Culturally Constructed ABI (Acquired Brain Injury) Narratives from a Disability Studies Perspective

By: Hilary Pearson

### Introduction: Storytelling Methods and Indigenous Ways of Knowing and Being

Okanagan storyteller Jeannette C. Armstrong (1998, p. 181) tells us,

Through my language I understand I am being spoken to, I'm not the one speaking. The words are coming from many tongues and mouths of Okanagan people and the land around them. I am a listener to the language's stories, and when my words form I am merely retelling the same stories in different patterns.<sup>1</sup>

I am fascinated by the ways in which we tell, retell, and listen to the stories that we encounter in everyday life. More importantly, I am intrigued by the ways in which we interpret these stories, and how their narratives appear to mediate and construct meaning. Indigenous scholar (and master storyteller) Thomas King (2003) tells us: "The truth about stories is that that's all we are" (p. 2).

My research dives deeper into the truth about *my* story, as a disabled woman navigating life in downtown Toronto. I wonder: How do we *make sense* of our place in this world? What does it mean to take up space, and how do we construct meaning out of the ways in which disability appears and disappears in everyday life? (Titchkosky et al., 2022)<sup>2</sup>

My PhD supervisor, Dr. Devon Healey, along with mentor, Dr. Rod Michalko, have told many stories of their lived experiences as Blind individuals living in downtown Toronto. During our first *Blind Studies* lecture, Rod Michalko tells us: Blind "was what I was [...] not who I was" (Michalko, 2002, p. 117; Healey, 2021, p. 119).<sup>3</sup>

These words now influence and inspire my own research... my writing, my artistry, my stories. Here is where I engage with *a politics of wonder* (Titchkosky, 2011).<sup>4</sup> Here is where I engage with Jeannette Armstrong's (1998) perspectives and storytelling methods. Here is where I begin to consider my language's stories, and how I appear to tell and "[retell] the same stories in different patterns" (p. 181). I wonder: Whose land, whose tongues and whose mouths are

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<sup>1</sup> Armstrong, J. C. (1998). Land speaking. In S. J. Ortiz (Ed.), *Speaking for the generations: Native writers on writing* (pp. 174-194). University of Arizona Press.

<sup>2</sup> See Titchkosky et al. (2022) *DisAppearing: Encounters in Disability Studies*, for additional detailed discourse that engages with disability's disappearances from an interpretive disability studies perspective.

<sup>3</sup> In personal communication with Dr. Rod Michalko and Dr. Devon Healey (September 22, 2022) *Blind Studies* lecture at the Ontario Institute for Studies in Education of the University of Toronto. See Rod Michalko's (2002, p. 117) *The Difference that Disability Makes* for further discourse of Blind studies and interpretive disability studies perspectives, along with Healey's (2021, p. 119) *Dramatizing Blindness: Disability Studies as Critical Creative Narrative*.

<sup>4</sup> Titchkosky, T. (2011). Towards a politics of wonder in disability studies. In T. Titchkosky (Ed.), *The question of access: Disability, space, meaning* (pp. 129-150). University of Toronto Press.

speaking? What stories will they tell? And how will I listen, interpret, and make meaning out of the many stories being spoken to me, about me, and through my own expression?

My doctoral research explores Native storytelling methods, oral history pedagogies, and Indigenous ways of knowing and being as an approach for investigating storied encounters of disability in everyday life. In this way, we may begin to understand (i) how we relate to one another, and (ii) how we relate to the world around us in new, radical, meaningful ways (Michalko, 2022).<sup>5</sup>

## Significance

My guiding premise today asks us to consider the role that disability art plays in breaking down culturally constructed narratives that often seek to depict (i) who we are, and (ii) how we (as disabled people) operate and appear in contemporary Western society. This work asks us to consider the impact of Rod Michalko's (2002) words—to wonder about: “the difference that disability makes.”<sup>6</sup>

## Who I thought I was

My initial understanding of my personal identity was intrinsically interconnected with disability. I internalized this notion of what it meant to *live with the effects of brain damage*. I am understood as a brain injury *survivor*.

How does the word *survivor* define *what* and *who* I am? Is my identity synonymous with surviving, struggling to get by?

Is surviving *truly* all that my life will be? Is this what my artwork says to the world? Is this what my artwork has to offer? As if to leave my ghost to drift through the world as a partial and incomplete person?

Is this the message I want to portray with my artwork, my writing, my research? Is this what I want to say? My work makes me wonder: How does the *able world* make sense of us? Further, “how do we relate and how are we separated?” (Healey, 2021, p. 60)<sup>7</sup>

My vision of disability used to be anchored in the core belief that disability was meant to be something ignored, marginalized, poverty stricken, and (as David Mitchell [2002, p. 15] suggests) *problematic*.<sup>8</sup>

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<sup>5</sup> Michalko, R. (2022). Foreword. In T. Titchkosky, E. Cagulada, & M. DeWelles (Eds.), *DisAppearing: Encounters in disability studies* (pp. xxv-xxx). Canadian Scholars' Press.

<sup>6</sup> Michalko, R. (2002). *The difference that disability makes*. Temple University Press.

<sup>7</sup> See Devon Healey's (2021) *Dramatizing Blindness: Disability Studies as Critical Creative Narrative* for further reading about Healey's guiding question: “how do we relate and how are we separated” (2021, p. 60) as a way to investigate the relations existing in between blindness and sight.

<sup>8</sup> Mitchell, D. T. (2002). Narrative prosthesis and the materiality of metaphor. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 15-31). The Modern Language Association of America.

I saw my *old self* as a creature that died. And the broken, leftover pieces are all I have left to work with. By taking these fragments and piecing them together only to be made into public art, we (as disabled people) are put on display for the world to see (Garland-Thomson, 2002).<sup>9</sup> Society watches us and judges us no matter where we might move in the world.

And I wonder, is *this* what I want the world to see?

But whose eyes do we paint our art for? Whose ears do we speak for—sing for? Who are we trying to reach? Are we truly painting our pain onto paper and canvas for the stranger’s eyes to see, feel, hear, touch? Do we speak and sing and draw and sketch and scribble and splatter colour on a page to say:

*Look at me.*

*Look at my disability.*

*Look at the diagnosis that designates my identity as a brain injury survivor.*

Ask me this question. Ask me: *Who is my art made for?*

My art is meant for me. My art is an explosive expression of how I process and expel the pieces of my life that I cannot yet make sense of. Brain injury sometimes takes away my ability to find the words and the language and the emotion that might explain to myself what I feel and how I navigate my life with disability.

Let me tell you, my life makes a little more sense when I paint its pieces on a page. My life finds structure when I scratch my poetry in my notebook or on the back of my hand. I do not want to lose myself or forget this part of my life. My life is not about waiting for things to get better. It has been 6 years, 8 months, and 21 days since my first concussion. Life is different. Things are different here in this new world of mine...<sup>10</sup>

I nod along with Rod Michalko (1999)<sup>11</sup> as he describes his own introduction to blindness: “ordinary life was no longer ordinary; everything was wrapped in a cloak of anxiety.... fear, and confusion” (p. 2).

Let me tell you how I truly believed that I was the first person that *this* had ever happened to. I lay in the dark with a pillow over my head and I ask no one in particular:

*Why is this happening to me?*

*Why am I alone?*

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<sup>9</sup> Garland-Thomson, R. (2002). The politics of staring: Visual rhetorics of disability in popular photography. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 56-75). The Modern Language Association of America.

<sup>10</sup> Michalko, R. (2017). *Things are different here: and other stories*. Insomniac Press.

<sup>11</sup> Michalko, R. (1999). *The two-in-one: Walking with Smokie, walking with blindness*. Temple University Press.

*What am I supposed to do?*

I cannot be the only one who feels this way. Statistics tell us: Ontario is home to 500,000 brain injury survivors.<sup>12</sup> But, where are they? Where did you go?

Let me tell you, it was a piece of art that found me. A piece of art painted on a concrete wall, hiding in the side streets of downtown Toronto. A concrete piece of disability art that called my name and said to me:

*I am here. And I feel just like you.*

Let me tell you how I followed that artwork, and I found more members of that same disabled family, full of artists that understand exactly how I feel.

Paint, pencil, pastel, chalk, charcoal, clay, crayon, marker, music, words, stories, songs, sounds that all mean something to somebody.

And maybe this art resonates with you. Maybe this art shows you something different... a life that you have never had to think about living. Maybe this art reminds you of someone you used to know. Someone from high school, or someone you have seen on TV or in the news.

My art is not special because of a disability.

My art is a reckoning.

My art is not up for debate or theoretical analysis. That is not what this is about. That is not who it is for.

My art is *disability art* because my art calls out to the ones out there who think that they are the first and only one to live with the effects of brain damage. The ones who feel alone. The ones who are lost and need us to call them back home. Not to join a club. Not to label them with a name that they do not know or want.

My art is like propaganda. My art says: *we exist*.<sup>13</sup>

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<sup>12</sup> Ontario Brain Injury Association (OBIA). (2021). Social isolation focus groups – final report. *Brain injury speaks stakeholder engagement network of Ontario*. Retrieved September 16, 2022, from [https://obia.ca/wp-content/uploads/2021/10/Social-Isolation-Focus-Groups\\_Final-Report.pdf](https://obia.ca/wp-content/uploads/2021/10/Social-Isolation-Focus-Groups_Final-Report.pdf)

<sup>13</sup> A version of this paper was first presented at the Brain Injury Toronto's annual expressive art show: *Art on the Brain* on May 17<sup>th</sup>, 2023, at the Assembly Hall Art Gallery located in Etobicoke, Ontario, Canada.

### **Acknowledgements**

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Illustration Title: “**Chronic**”<sup>15</sup>  
Illustrator: Hilary Pearson

**Featured image description:** A pencil sketch created by the author of a woman sitting on the floor against a wall. Her knees are bent, her head down, and her long hair is covering her face. Her left hand is covering her left ear, and her right arm is cradling her head. She is wearing jogging pants that say ‘Adidas’ on the left leg. The pencil sketch is drawn on lined paper, which is cut out surrounding the image on the top, and gently ripped on the bottom and then placed over another white piece of paper.

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<sup>15</sup> Pearson, H. (Illustrator). (June, 2022). Chronic. [Illustration]. Brain Injury Toronto’s *Expressive Art Show 2022*, Spadina Museum of Contemporary Art, Toronto, Canada.

**Notes**

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- 4 Titchkosky, T. (2011). Towards a politics of wonder in disability studies. In T. Titchkosky (Ed.), *The question of access: Disability, space, meaning* (pp. 129-150). University of Toronto Press.
- 5 Michalko, R. (2022). Foreword. In T. Titchkosky, E. Cagulada, & M. DeWelles (Eds.), *DisAppearing: Encounters in disability studies* (pp. xxv-xxx). Canadian Scholars' Press.
- 6 Michalko, R. (2002). *The difference that disability makes*. Temple University Press.
- 7 See Devon Healey's (2021) *Dramatizing Blindness: Disability Studies as Critical Creative Narrative* for further reading about Healey's guiding question: "how do we relate and how are we separated" (2021, p. 60) as a way to investigate the relations existing in between blindness and sight.
- 8 Mitchell, D. T. (2002). Narrative prosthesis and the materiality of metaphor. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 15-31). The Modern Language Association of America.
- 9 Garland-Thomson, R. (2002). The politics of staring: Visual rhetorics of disability in popular photography. In S. L. Snyder, B. J. Brueggemann, & R. Garland-Thomson (Eds.), *Disability studies: Enabling the humanities* (pp. 56-75). The Modern Language Association of America.
- 10 Michalko, R. (2017). *Things are different here: and other stories*. Insomniac Press.
- 11 Michalko, R. (1999). *The two-in-one: Walking with Smokie, walking with blindness*. Temple University Press.

- 12 Ontario Brain Injury Association (OBIA). (2021). Social isolation focus groups – final report. *Brain injury speaks stakeholder engagement network of Ontario*. Retrieved September 16, 2022, from [https://obia.ca/wp-content/uploads/2021/10/Social-Isolation-Focus-Groups\\_Final-Report.pdf](https://obia.ca/wp-content/uploads/2021/10/Social-Isolation-Focus-Groups_Final-Report.pdf)
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### **Author Biography**

Hilary Pearson is a doctoral student at the University of Toronto. Making use of interpretive disability studies and Indigenous perspectives, her academic work explores the ways in which Western culture understands what it means to be human.

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