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## Canadian Journal of Disability Studies

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### Paved Trails and Shampoo Shopping Sentiers pavés et achat de shampoing

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#### **Abstract:**

Poetry is a gentle but relentless coach, a lover, personal benchmark, and record for growth. She shifts beliefs, practices, and emotions, tracking pitfalls, steps back, steps around, stillness, like a smooth laketop or slow-streaming river. In this Research-Creation piece, I develop my version of 'Crip Poetics' through autoethnographic methods including video poems and hybrid prose-poetry writing. Drawing on Critical Disability Studies, Indigenous Studies, and Mobility Studies, I bring questions of white supremacy and settler colonialism into conversation with accessibility in Canada. I interview Indigenous people with varying relationships to disability and disabled people of multiple settler cultures, using qualitative methods including Hangout as Method (Warren Cariou) and Wheeling Interviews (Laurence Parent). Engaging with interview transcripts as text, to continue conversation and exchange with interviewees, this study offers reflections on interviewing as a method. Reflecting on the limits of participant-action research and representation, I interrogate the role of researchers in marginalized knowledge production, engaging with the limits and possibilities of 'unsettling research'. I aim to redirect eugenic trends in disability discourse and history towards prioritizing the telling of our own stories. It's my hope that these conversations and the intersections of these struggles are brought to the fore—this selection being one avenue among many to further this work. Dance with me between words and beyond political affiliation.

#### Résumé

La poésie est une guide, douce mais implacable, une amoureuse, une référence personnelle et un journal de croissance. Elle change les croyances, les pratiques et les émotions. Elle traque les pièges, recule, fait quelques pas et reste immobile, comme un lac lisse ou une rivière au courant lent. Dans cette pièce de recherche-création, je développe ma version de la « poétique crip » à travers des méthodes autoethnographiques comprenant des poèmes sous forme de vidéos et une écriture hybride prose-poésie. En faisant appel aux études critiques du handicap, aux études autochtones et aux études sur la mobilité, j'introduis les questions de suprématie blanche et de colonialisme de peuplement à la conversation sur l'accessibilité au Canada. En utilisant des méthodes qualitatives, notamment passer du temps ensemble comme méthode (Warren Cariou) et les wheeling interviews ou entrevues roulées (Laurence Parent), j'interviewe des personnes autochtones ayant des relations variées tant avec le handicap qu'avec les personnes handicapées de différentes cultures colonisatrices. Entamant un dialogue avec les transcriptions d'entrevues sous forme de texte, pour poursuivre la conversation et échanger avec les personnes interrogées, cette étude propose des réflexions sur l'entrevue en tant que méthode. En réfléchissant aux limites de la recherche-action participative et de la représentation, j'interroge le rôle des chercheur·es dans la production de connaissances marginalisées, en réfléchissant aux limites et aux possibilités de la « recherche décolonisante ». Je vise à réorienter les tendances eugéniques

dans le discours et l'histoire du handicap vers la priorisation de la narration de nos propres histoires. J'espère que ces conversations et les intersections de ces luttes seront mises en évidence - cette sélection étant une avenue parmi tant d'autres pour faire avancer ce travail. Dansez avec moi entre les mots et au-delà de l'appartenance politique.

## **Keywords:**

Crip Poetics; autoethnography; Disability Studies; film; Indigenous Studies; Mobility Studies; participant-action research; unsettling research; poetry; poetics

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Bodies of Knowledge (link: <a href="https://youtu.be/lpd0Y">https://youtu.be/lpd0Y</a> tYOU)

I would never be able to find the public garden we ended up in again. It was probably a magical garden that we assembled in our shy, intragroup fabric, our shared imaginations. Hands brushing scratchy leaves, right ears listening to the road, left ears listening to back yards. At the end of the walk, in the public garden, they prompted us to write on small squares of paper. I tilted my chair back, placed my feet on a splintery wooden bench, and wrote.<sup>1</sup>

<sup>&</sup>lt;sup>1</sup> This took place during a soundwalk curated by Elizabeth Ellis and Helena Krobath in Vancouver on September 23, 2018.

I have heard
skytrain and rebel cry: not
angry, but catalytic
bees purposefully landing on ragged small edged
leaves, while a human power washes or power vacs a machine or home
I have heard smells entering my nose as I
breathe deep and twigs are bent under me – the cli-click of my joystick
engaging as I consider moving, staying still;
mechanical and natural blending.
rolling over?

Caressing
masking?

A way in.

Scraping beeping sound renders me visible witnessed, without my express consent

"disabled people are very visible by our presence and by our absence." sound renders me visible a selection of observations and questions Is there a way to be present. without being witnessed?

 $<sup>^2</sup>$  Former Mayor of Vancouver, and former MLA for Vancouver False Creek, Sam Sullivan, Personal correspondence, May 25, 2017

Steps and crunching of browned and yellowed leaves; the attention of buzzing, furry, hurried bees, not drawn to bent twigs or beeping or occasional humming of seat angle adjustment

(1)
To be
present without
being witnessed? (2)
to be present without
being an object of attention
(3) to invite witnessing by those
I choose (4) unspectacularly belonging
(5) To be present, welcomed and move alongside with
negative, positive, ambiguous, uncertain space accounted for and

Not contradictory, these things are complementary; could they become counted on?

filled with warmth. To want to be included, to desire unspectacular belonging;

To be present without being witnessed, unspectacular belonging; these are the blessings of bees and moss. We called it being in nature unmediated.<sup>3</sup>

The cli-click of my joystick engages. Attention of intelligent, thirsty bees remains on task– and petal– at hand. Mechanical and natural blend, finesse a way in.

 $<sup>^3</sup>$  Writer and associate professor of English at the University of Manitoba, Warren Cariou, Personal correspondence, June 21, 2018

Moving in chair feels different than moving through air. To dance in wheelchair a larger radius, mass moving through space, less assemblage of body parts, more entirety.

To dance in a field with strangers is like shopping for shampoo; more decisive if standing, more connected to products, air through the grass.

Move with more certainty, out and up and out.

What difference does it make?

The weight of other people's' gaze? A craving of monotony uniform mobility, equal footing?

Medium, mode determines the shape that my current body can take.

Medium
determines the mode
my mind's in

energetic messages, blocked

by the metal and cushion of my chair.

We called it being in nature unmediated<sup>4</sup>

If you have trail riders more available, they would help people to access these beautiful parts of our country $^5$ 

<sup>&</sup>lt;sup>4</sup> Warren Cariou, Personal correspondence, June 21, 2018

<sup>&</sup>lt;sup>5</sup> Sam Sullivan, Personal correspondence, May 25, 2017

7 the cli-click of my joystick engaging as I consider moving, staying still; mechanical and natural blending rolling over? Caressing masking? A way in So there I was, wheeling along what felt like the edge of a dream, my research question in the sidecar.6 <sup>6</sup> This 7-part poem is called *I Have Heard*.

Selfishly searching for crip ancestors

For connection to this land that I'm temporarily and hungrily and unbeknownst to la RAMQ<sup>7</sup> calling home

The settler project of I belong

I belong here too

Searching for connection to ancestors connected by curb cuts and chirping lights and paved trails - not gravel trails - paved trails. Gravel trails are bullshit

and I swear a lot; can't take the Alberta outta the girl.

Gravel trails are bullshit, unless I'm on foot and then they're nicer, like moss if it's small gravel. Moss is best.

If I have my wheels, then paved is best.

Searching for ancestors in specks of asphalt and ribbing of new curb cuts and sitting-shoulder height light buttons,

and trails, paved for the wheeling iteration of myself, so that I can feel connection

—beyond enjoyment,

to this place.

Jessica Johns is a Cree on the coast, and she said she's training herself how to be ok in the water here

"Go into the water up to your thighs. Put your hands through them. The love, not the water. Get to the heat of it, the carved out space in your body"8

I have no problem with the water, I can feel its love for me.

At home in it.

my feet then my legs then my undergarmented self then my undergarmented self and a love, ebbing and swelling into each other;

the ocean wanted us

welcomed us, held us together.

It's the land I'm looking for connection to - with?

The pained and abject body project of *I belong I belong here, too.* 

How do I move forward without knowing connection to the past?

Fuck, it's been over three years, have I come any closer to touching that connection to the past? I told you, I swear a lot.

Looking for lineage beyond the activists that have moved on to better things:

<sup>&</sup>lt;sup>7</sup> The RAMQ is Quebec's public health agency

<sup>&</sup>lt;sup>8</sup> Excerpt from *WILL THE WATER HEAR ME IF I CALL THEM IN CREE* by Jessica Johns.

"What's happened over the decades is, you know, we used to have strong advocacy groups, full of angry disabled people who couldn't get on with their life because society was not dealing with their issues well enough, and when society did finally loosen up and deal with the issues all the disabled leaders left and went off and lived their lives and did what they wanted to do... disability organizations, advocacy and service, very few are run by disabled people... in a way it's a great tragedy, and in a way it's a great success, people with disabilities don't have to be advocates, it's all being done, or much of it has been done."

This feels different than the case in Quebec and my queer crip communities

This feels like non-crips being more hirable than crips in the job of administering our lives.

It's my dad's 50th anniversary of coming to Canada this year. The South African woman in our rental building has

never gone back, why would they - everyone's moved on and where she grew up in Johannesburg, where her boyfriend now husband would step over the cute little stone wall, has now been replaced by ugly barbed wire fence. No, why go back, coming to Canada was the best thing they've ever done.

Does her description of Johannesburg turning ugly and falling apart mean she regrets the fall of apartheid?

How to clarify I'm not in on the secret,

on her team?

Her accent perks my ears up every shared elevator ride.

And then she asks if I want help opening the door and I mumble something about the door opener never really having worked

she opens the door and she stops to chat with another neighbour and we wave and I head off towards the Skytrain.

I swear a lot, like my dad, and I fucking love the Skytrain and I still don't know who made it so accessible. J probably knows. He was on the Translink accessibility committee. I considered joining but it was at the same time as my writing group and guess which one I chose? Sam said it wasn't him who made the city accessible when he was the mayor:

"When I was mayor people would come to the office and say, ah! This makes sense why Vancouver is so accessible, because it has a disabled mayor, and I would say, mm, actually it's the opposite, Vancouver has a disabled mayor because it's so accessible... but once I was mayor, I mean, it was not even uh, something anybody would do is bring an inaccessible project to me, you know, I didn't even have to say anything they just took a look at me and say, mm, I think we're going to go back and redraw this thing you know (laughs)."<sup>10</sup>

<sup>&</sup>lt;sup>9</sup> Sam Sullivan, Personal correspondence, May 25, 2017

<sup>&</sup>lt;sup>10</sup> Ihid

Searching for ancestors in the words of an earlier generation of People With Disabilities, on waves actuated by water taxi towards my interview with Sam Sullivan,

the 1.5 generation project of *I belong I belong here too* 

Selfishly searching for crip ancestors It began feeling a bit like searching for connection in other people's ancestors. So I'm turning inwards and gonna look at my own.<sup>11</sup>

 $<sup>^{11}\,\</sup>mbox{This}$  poem is called  $\mbox{\it Crip Ancestors}$ 

But seriously, how do crips get the language to describe things that we've never heard or seen described - until they are happening under our skin? The hard days, the pain that's not stabbing or burning or whatever else is on that pain scale no doctor's ever asked me about? Eaton Hamilton describes a 'pleasure scale' in what is a close description of many things I've experienced or have thought about.<sup>12</sup>

How do crips find our kin? How do we speak amongst each other on each other's rooftops or around crowded kitchen tables?

um, people that I've interacted with that kind of have the disability justice language under their belts just from even just from experience, not even reading anything yeah... well, it's one of those cool fields where it's like, it comes from like, embodied experience first...

and then some people write it down...

totally, yeah

at least that's my perception of it

(dog barking)

yeah, it's always, you have your own language first, and your own lived experience, and then after that, like, yeah, like you said, some people write it down, and it's kind of, it's kind of cool when people write it down, because, like, you can compare and contrast and be like, oh yeah I understand this one, or no, like, this one doesn't make sense to me, I haven't lived this one... they're all interesting, they're all different ways of getting through the world, um, yeah (dogs barking and yipping) (laughs)

pupper (laughs)<sup>13</sup>

<sup>&</sup>lt;sup>12</sup> Eaton Hamilton, *The Pleasure Scale: On a scale of 1–10, with ten being highest, where would you rate your pleasure?* 

<sup>&</sup>lt;sup>13</sup> This poem is called *and then some people write it down*. It consists of found lines from my conversation with writer, content creator and community leader Q, transcribed from our hangout/ interview in Trout Lake park, Vancouver on May 30, 2017. I removed our names from the lines we spoke as an experiment pointing to the shared knowledge that exists and is assembled by our exchange.

Louw, Paved Trails and Shampoo Shoppin  CJDS 10.2 (August 202)	Shopping gust 2021	
My friend said no one teaches u to be disabled		
I figured out my way of learning how to be myself is through writing it		

Poetry is my primary partner

Poetry helps me express my emotions, frustrations, desires

Poetry is a safe space for me to channel or tunnel the excessive observations I have of others, myself, interactions, tiny elements of our environment; the things that are none of my business.

Poetry is who I tell the shameful or hard parts of my day to, first;

the exciting, silly, naughty, unacceptable parts of my days and mind to.

Poetry listens, holds my experiences so I don't have to

Poetry is a space where I can, increasingly, catch my own shit.

Poetry is a way of dialoguing with myself, when there are multiple ways of seeing a thing, which is always.

Poetry is my primary partner, and is calling my attention to past mistakes, spaces to grow, ways to apologize?

Poetry is a way to engage with contentious stories, highly politicized lives and scorned communities, a way to celebrate the unexalted.

Poetry, she calms me, makes me feel closer to whole, welcomes - demands honesty.

Poetry is a gentle but relentless coach, lover, personal benchmark and record for growth, shifting beliefs, practices, emotions, pitfalls, steps back, steps around, stillness. She is always available by phone.

She invites others' poetry to be in dialogue, in love with me.

She is where disagreements and difference of experience and perception come to explore, touch, play.

She believes in every imagined future I secretly agit; a perfect accomplice.

She holds me, encouraging me to be brazen in my vision, faithfully consistent reminding me not to be a know-it-all.

Poetry has been my research partner, through every stage from scribbled note in the margin to central creation, exploring the previously unworded.

She is an antidote to the "poverty of language" that Virginia Woolf lamented over a century ago in her call for increased attention to illness as an experience of so many, and a literary focus of so few.<sup>14</sup>

We are dancing together towards a scattering of the "hierarchy of... passions."<sup>15</sup> For all the love and faith she has given and continues to give me, I pray, try to articulate the truth that now is her time.<sup>16</sup>

<sup>&</sup>lt;sup>14</sup> Virginia Woolf, in On Being III: with Notes from Sick Rooms by Julia Stephen

<sup>&</sup>lt;sup>15</sup> Ibid

<sup>&</sup>lt;sup>16</sup> This poem is called *Poetry is my Primary Partner* 

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#### Bio:

Aimee Louw is a writer, journalist and facilitator living in Tiohtiá:ke (Montreal). Her work incorporates disability justice politics with imagining flourishing futures. She has written and produced for CBC Radio, Canadaland, and the Growing Room festival, and was the 2020 Walrus Fellow on Disability and Inclusion. Her debut poetry book, *Less Sweet than Chocolate or Concrete*, was nominated for Best New Poets, and she is the proud co-host of #CripTalkCorner, an online video series by and for crips. This year she launched the Unruly Writers Club, which is a drop-in writing group for disabled and queer writers and friends, in collaboration with Metonymy Press. And whenever she can, she works with arts and media organizations, festivals, and schools to build sustainable accessibility practices. She invites connections on <a href="https://www.aimeelouw.org">www.aimeelouw.org</a> and on social media @aimeeiswriting.