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**Writing Institutionalization and Disability in the Canadian Culture Industry:
(Re)producing (Absent) Story**

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Abstract

From the lens of a non-survivor ally who is also a journalist, activist, sister, and educator, I offer a reflexive account of reconciling with failed media activism. By applying Horkheimer and Adorno's (1972) concept of the culture industry to my own experience of pitching a story about the impending closure of Saskatchewan's Valley View Centre to a Canadian publication, this article investigates the theoretical underpinnings of a Canadian culture industry confronted with the politics of institutionalization, survivorship, and intellectual disability. The culture industry operates on the inclusionist premise that the public needs to understand cultural locations of disability that bestow an artificial sense of bodily agency on the spectator, thus placing media producers in "expert" roles by culture industry standards. This article combines memory and critical theory in a writing-story that addresses the unresolvable task of un/covering disability's presence and absence in a journalistic practice that cannot penetrate the walls of an institution.

Keywords

Disability, journalism, culture industry, survivor narratives, institutionalization

Writing Institutionalization and Disability in the Canadian Culture Industry: (Re)producing (Absent) Story

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The Beginning: Trying to Story Disability

There is a damp, grassy spot in the centre of Canada that the Plains Cree once named after its warm breezes. Here, southward on the prairie, a short drive from Moose Jaw, Saskatchewan, stands a three-story yellow brick building called Valley View Centre. Valley View is an institution that opened in 1955. At the time of this writing, it reportedly housed 123 people.

In 2012, the Saskatchewan government announced that Valley View would close by 2016. I'm told that to date about 70 residents—intellectually disabled people—have left Valley View. Some have died, some are transitioning to community-based housing, and a few are in long-term care facilities. Advocacy organizations are struggling to find and build homes. The Canadian Press (2014) reports that a government-led transition committee and a family group representing those who live in the institution recommended 2018 as a more realistic guess at when the facility will close—and the government listened, extending the closure deadline to 2018. The sources I speak to, both on-and off-record, predict the date of closure will shift forward even further. CUPE 600-3 represents the 500 staff that once worked at Valley View. The union has fought back fiercely, staging petitions and letter-writing campaigns to keep the institution open (Canadian Union of Public Employees, 2012).

I learned about Valley View in the summer of 2014 when I pitched an investigative, feature-length essay to an independent Canadian magazine about my brother Kevin's rocky experience finding a job in Saskatchewan as a man labeled intellectually disabled. The story was

really about my experience writing on this topic as a journalist who is also an ally, and as an ally who is also a sister, and as a sister who is also a currently non-disabled outsider. The story was about what it means to feel powerless against Kevin's social marking as "nonproductive" by consequence of his disability label.

In my pitch, I recalled my brother smiling and urging me to observe the toy section in Walmart where he had diligently organized toys during an unpaid high school work experience program. My observation of Kevin's marginalized, though apparently joyful, engagement with low-waged labour had me reassessing my own journalistic priorities. I wrote: "Nobody asked Kevin if he wanted to be written about as an object under provincial policy that forces people with intellectual disabilities toward the margins"—referring specifically to rules set by the 1995 *Saskatchewan Education Act* that disqualify special education diploma holders from accessing post-secondary schooling. I suggested that these policies, which make special education diplomas badges of unemployability, were an expression of working-class disavowal.

The story was about the political structures that make it impossible for special education graduates like Kevin to fit into the income-generating, neoliberal citizenship model that disability rights groups have fought for in Canada for decades, paired with my general sense of uselessness in witnessing the failure of the state, activism, and myself in creating possibilities for citizenship for Kevin (Prince, 2012). More discreetly, the pitch was also about my growing sense of disappointment in how stories about intellectual disability are framed in a journalistic context, where such stories are often told through specific, stereotypical and generally uncritical tropes, and where people like Kevin are rarely invited to tell their own stories outside of these tropes (Clogston, 1991; Devotta, Wilton, & Yiannakoulis, 2013; Haller, 2010; Jones, 2014; Sgroi,

2016). I was feeling caught between my roles of journalist and advocate, and I tried to write my way through this tension.

The pitch was accepted. The magazine's pro-union edge meant, of course, that although it seemed to me that my brother was generally unsupported by labour activism in the province, I had to figure out if perhaps, all these years, my family just hadn't sought support in the right places. Perhaps I was simply wrong. Perhaps I could uncover new advocacy strategies through journalism and frame intellectual disability differently.

I started sniffing around. A few weeks of phone interviews led me to CUPE 300-6. In 2014, the union claimed to informally support the 15 non-union-member employees with intellectual disabilities then working in the laundry facilities at Valley View where most of them were also residents. CUPE 300-6 advocated to keep these workers' wages hovering at or slightly above the minimum wage mark at \$14 or \$15 per hour, and, years later, the union also attended meetings to support laundry workers as these jobs were cut. At the time, Valley View also had a sheltered workshop whose workers were neither paid nor represented by the union (personal communication, July 22, 2013).

I went back to my editor with more questions to consider as we mapped out the story. I was beginning to suspect that, perhaps, the union's concern for the closure of this institution was an articulation of governmental normalizing agendas built on the bodies of disabled people. That is, those insidious, normalizing agendas wherein intellectual disability is a social identity made to disappear from normative citizenship via modernist tools such as institutionalization, only to be reintegrated later (Stiker, 1999). Such rehabilitation, following Henri-Jaques Stiker (1999), is a "team" effort that moves disabled people out of internment toward an assimilative performance of normality, wherein disabled people and their apparent supporters ensure that all adapt to

society as it is. In Michel Foucault's writing on both biopower (1978) and "the abnormals" (2000), he suggests that such regulation takes place at the level of the body: where knowledge is accumulated and enacted, and where the body becomes an object to be transformed and corrected—a connection Claudia Malacrida (2015) makes extensively clear in her writing about the professionalization of normalizing knowledge within institutional walls, specifically Alberta's Michener Centre. It was becoming plain to me that the Valley View "team" whose work involved disappearing (or "looking after") disability included molding those intellectually disabled people who were considered adaptable enough to fit the empirical norms reinforced by the resident care staff, registered psychiatric nurses, clerical workers, and other staff backed by CUPE 300-6 whose jobs were at stake. I wouldn't have minded being wrong about that.

Inconvenient as they were, questions were gathering like storm clouds that might crack open lines of inquiry and drive the first draft: What was the union's business condoning (sometimes) unpaid labour? With hundreds of jobs on the line, could it be that the union was maintaining systemic discrimination in an effort to protect its own members before thinking of those disabled people whose lives that were also at stake? Could the union be counted as part of the normalizing "team"? Would the union be supporting survivors after Valley View closed?

I never had a chance to ask these questions aloud to anyone. But at that stage, I had found no hard evidence to suggest that CUPE was willing to support, let alone include, survivors in its agenda. I wondered: what is a union's role in protecting the disabled people who make its members' jobs a reality, albeit a threatened reality? I also wondered: do unions—inadvertently or not—protect administrators that promote ableism? Or, are there unions who *are* working with survivors, self-advocates, and non-survivor allies with agendas that resist normalization?

My story was becoming crowded with questions. When your story takes a turn, you need to tell your editor. But when I posed these questions, the editor immediately cancelled my story. She said a simple Google search would surely demonstrate countless instances of unions advocating for disabled people. She was right, of course: the Canadian Labour Congress has an annual award recognizing a union member for their disability rights activism; CUPE claims to support a social model approach to disability in the workplace, and calls itself a “leader among unions on disability rights” (2016); and, as another example, Genna Buck’s 2015 *Maisonneuve* cover story mentioned CUPE’s advocacy for community care staff across New Brunswick. Though neither of us seemed to know who (if anyone) was advocating specifically for the intellectually disabled workers and residents at Valley View if not CUPE 300-6.

The editor explained that my hunch about unions protecting deeply embedded ableist systems was indistinguishable from Conservative rhetoric and flew in the face of the magazine’s social justice mandate. The final sting came with her suggestion that readers would not understand what a “sheltered workshop” was—typically a training center that, for some, would be a dead-end situation where people are legally paid below minimum wage (Gill, 2005). She claimed that such situations did not exist in Canada outside of my overactive imagination. As I mentally filed these critiques, Kevin was beginning his first days of assembly line work stuffing envelopes and shaving wood for less than minimum wage at a sheltered workshop in Regina.

The Middle: Navigating the Canadian Culture Industry

I’ve heard it said that a journalist is only as good as their last story. So when my story was killed, I was bruised for a long while. I did not immediately interpret my failure as what Sharon Snyder, David Mitchell, and Linda Ware (2014) call a reasonable response to the “finite

goals of inclusionism” (p. 298). Instead, in the year that followed I dreaded opening the palimpsest sitting on my desktop. My questions slid to a quiet halt. If a lefty social justice magazine I’d been connected to for years didn’t believe me or trust me to think through such a story, who would?

As a journalist, an activist, a sister, and an educator, I occupy a few positions that sometimes help me glimpse into my own vulnerabilities and think through what constitutes knowledge. Being situated to engage in disability studies is one such privileged position. Perched here, I shift away from my positivist research training in journalism to a post-structuralist qualitative approach of reflective writing that understands disability as “a culturally fabricated narrative of the body” (Garland-Thomson, 2013, p. 336). Inspired by Laurel Richardson and Elizabeth Adams St. Pierre (2005), I take writing as a “seductive and tangled *method* of discovery” and a way of thinking through the knot of epistemology and ontology that leads me to reflect on a singular writing experience. Simply put, writing allows us to “investigate how we construct the world” and to “find something out” (Richardson, 2000, p. 924). Writing is a process that makes way for “*evocative representations*”—interpretive frameworks that re-create lived experiences and “[reveal] the rhetoric and the underlying labour of production” (p. 931) of such experiences so that we may relate to our material differently.

Specifically, my method here is a short writing-story. Writing-stories are narratives that reflect on writing contexts and processes in order to demystify those processes “rather than hiding the struggle” (Richardson, 1995, p. 191; 2000, p. 931). Such writing centralizes the ethics of representation and surfaces other facets of the author’s life, including familial ties and institutional barriers, while reflecting on contextual and often emotionally ridden acts of writing and working through memories (Fine & Weis, 1996; Richardson, 1995; Richardson & Adams St.

Pierre, 2005). My thoughts here have been apprehensively gathering for five years through re-reading scraps of notes, emails, phone calls, on-and off-record interviews and their respective transcripts, and through quiet discussions with researchers, families, and students concerned about Valley View. As with journalistic work, much of this unwieldy data is hushed, informal, and confidential, and therefore hovers backstage in the peripheral shadows of the writing itself. Such under-the-radar critique and deconstruction are, following Adams St. Pierre (2014) and Foucault (1978), practices of freedom insofar as they allow us to embrace the contingent, interpretive nature of validity and structure—thus allowing me to scribe an account of my own struggles to write amid multiple and intersectional discourses and communities (Richardson & Adams St. Pierre, 2005).

Through this reflective process, I began realizing that one part of coming to terms with a killed story is working through memories of the writing experience in an exploratory way. As Snyder, Mitchell, and Ware (2014) point out, “Not only is the personal political, the personal is the grounding for theory” (p. 927). Though mine is an experience of one article being rejected by one publication, the cultural negation of disability by journalism is indisputable and unquestionably linked to personal experience (Hockenberry, 1995; Jones, 2012, 2014; Rodan, Ellis, & Lebeck, 2014; Sgroi, 2016). This realization led me to think about power. From a Foucauldian (1978) perspective, power can be thought of as a set of relations performed by individuals who become the “place” where power is both enacted and resisted. To put a name to this particular power relation, I looked to the culture industry and set myself within it as a way of re-understanding my situation. The culture industry is Max Horkheimer and Theodore Adorno’s concept—a foundational element of cultural theory that emerged from the Frankfurt School, published first in 1948 (and translated to English in the 1972 book *Dialectic of Enlightenment*).

Marxist in their thinking, Horkheimer and Adorno (1972) argued that the system of cultural production as dominated by film, radio, newspaper, and magazines—which, today, constitute a much longer list of online venues—is controlled by commercial imperatives and serves to create subservience to systems of consumer capitalism. Where the culture industry is resisted, I argue, is in individual failures to re-produce an ableist cultural imaginary.

Horkheimer and Adorno (1972) assert that “each branch of culture is unanimous within itself and all are unanimous together” (p. 94). When I read intellectual disability through this rather radical perspective of unanimousness, I’m reminded that my orientation toward the culture industry is always-already multi-directional: as journalist I am both constitutive of and constituting its schemas through an ongoing generation and production of stories; as activist I aim to interrupt the patterns of the culture industry and the meta-narratives of normality with which it is infatuated by inserting disability (some way, somehow, and sometimes unsuccessfully); and as educator I support students in the development and dissemination of their own stories into and around these schemas. I am constantly moving between keeping stories intact for the culture industry, yet fracturing them to resist absorption into said industry. This is the work of a journalist-advocate.

Thankfully, resistive disability writing offers tools to critically analyze these processes: Tanya Titchkosky’s (2008) phenomenological readings of news media prompt readers to orient themselves toward it critically and carefully; Mitchell and Snyder’s (2001) *narrative prosthesis* is applied widely to many texts; Michael Bérubé’s (2016) declaration that disability is ubiquitous turns the latter reading around a bit and helps us to “crip” text; plus, a helpful influx of public “writing” or “talking” back by Canadians such as Catherine Frazee (2014), Jeff Preston (2016), Kim Collins (2013), Ashif Jaffer (2009), Helen Henderson (2015), and others set fine examples

of the hybrid journalism-advocacy action of writing for disability activism by both resisting and adapting to culture industry standards in order to surface disability narratives.

Underlying the experience of studying this writing is an awareness that the boundaries between journalism and ally-ship are contingent on the culture industry—because what’s radical is always part of the culture industry’s schema, and the choice to be part of that schema is only a choice between it and silence.

Horkheimer and Adorno (1972) insist that it is difficult to resist the culture industry because it makes up both our work and leisure time. Anyone who does not conform is destined to be left behind and marked as an “outsider” for being disconnected from the mainstream. Or they are labeled “villainous,” “eccentric,” “poor,” “lazy,” “suspect,” “sick and certainly not beautiful”—to directly borrow words offered by Mitchell and Snyder (2001) and Horkheimer and Adorno (1972). Such outsider characters created by the culture industry are meant to evoke feelings that disability studies familiarizes: pity, inspiration, “disability drift,” and shock (Dolmage, 2014; Haller, 2010; Mitchell & Snyder, 2001). Everyone living beneath the culture industry’s ideology enjoys a type of freedom within its prescribed social boundaries, which are linked to normalization and inclusionism, as well as a sense of helplessness in that they cannot escape this ideological system and its characters and must publicly identify with them (Horkheimer & Adorno, 1972). For example, as a journalist and an activist I am led to think: this person (perhaps a survivor) whom I feel for is one (finally, maybe for the first time) to bring to the forefront of a story because that would shake up what makes a conventional story, thus making a story pitch-able.

What’s more, if the purpose of the culture industry is to confront consumers with “a false identity of the universal and the particular” (p. 125), then disability—as both familiar and

unfamiliar, present and absent—is an important piece of universality *and* particularity that holds news value. If there is a character who can evoke a fresh, new emotion in the audience and whose eccentricity in contrast to normalized society is conspicuous or unexpected, then yes, we have a good, pitch-able, publishable story idea—a product that generates a reaction, not through actual coherence and perception, but through routinized signals that it emits to an audience. This move is one that I regrettably demonstrated all too well by leveraging my brother’s experience as a metaphor for ableism at the centre of my own experience in my original story pitch.

Yet, it is important to reflect on why my decision to draw on Kevin’s experience would (or should) be regrettable. On the premise that writing is an interdependent activity wherein writers and their contexts are always informing texts, Richardson (2000) asks, “How do we put ourselves in our own texts, and with what consequences? How do we nurture our own individuality and at the same time lay claim to ‘knowing’ something?” (p. 925). These are difficult questions to confront when lines between exploitative and constructive representation are not always clear because the universal and the particular are at work: the culture industry demands broad stories with specific characters—not one or the other. I put myself in my work through my positioning as sister, which means intellectual disability will always be a relational intersection of my identity, and Kevin is always on my mind even when he is not named on the page. As Anne McGuire (2016) writes, disability is with me because I am part of a culture in which intellectual disability appears, including through cultural production via journalism and academia where my claims of “knowing” unfold. Whether I have done Kevin or my larger narrative a disservice by centering on his experience here is up for debate—perhaps I shouldn’t

have mentioned him at all; the question remains as to why leveraging Kevin’s experience is a better or worse decision than remaining silent.¹

Further, questions of how (not) to write about such topics is already documented in discussions of the metaphorical utility of disability in media narratives. Most notably, Beth Haller (2010), John Clogston (1991), Rosemarie Garland-Thomson (2001), Paul Longmore (1987), and Jay Dolmage (2014) attend to long lists of disability tropes. Some of these tropes align with what Horkheimer and Adorno (1972) call “frozen genres”—a formula that “represent[s] the average of late liberal taste threateningly imposed as a norm” (p. 107). A frozen genre thins out complex stories and preserves the culture industry’s interchangeable outcomes, such as the common narrative of *overcoming* (Linton, 1993). However, as Dolmage (2014) so aptly writes, “‘normal’ is the myth that sublets all other disability myths within its broader real estate” (p. 60). And it is not just the assimilative pushing of disabled bodies toward normality that constitutes dangerous writing, but also the binary nature of disability-related reporting that uses disability to keep notions of abnormality intact—such as through a story of a brother who does not fit into a Canadian landscape where citizenship and employability intersect.

Dolmage (2014) suggests that the negative effect of such tropes could be met with a demand of overcoming that “we place on the *narrative*” in order to get over normative fears of disability and move beyond the message that disabled people ought to “get to work” overcoming disability (p. 121). And it is not only the involvement of “we” the readers that matters. Indeed, the “expert” journalist knows the formulas that tell stories of disability and, as with any good story with a twist, “we” the audience are pleased when stories strike the sweet tone of

¹ Though there is not room for expansive discussion on the topic here, we arguably need to make space for questions that ask how claims of knowledge connect with disabled and non-disabled subjectivities, and who can write about such topics.

comfortable predictability (Horkheimer & Adorno, 1972). Therefore, I know that there are certain “acceptable” intellectual disability narratives that cater to mainstream audiences—affect-evoking tales where the disabled person is depicted as living a life both fascinating and horrific, but fitting the narrative of overcoming in the end. Tales of survivorship, you could say. We have collectively watched survivorship narrative arcs haunt higher-profile self-advocates whose stories humanize major lawsuits, namely: Alberta’s Leilani Muir, whose lawsuit against the provincial government for wrongful sterilization earned national headlines, as well as Patricia Seth and Marie Slark of the Huronia Speakers Bureau whose names forefront much media coverage related to the settlement agreement reached in a class action lawsuit against the Government of Ontario.² There is, perhaps, a sense in disability studies that stories of survivorship should be honoured, whereas in journalism the job is not honouring but reporting—and indeed the work of reporting calls for a human story. Therein lays a substantial conflict for the journalist-advocate who desires to both honour and report. When storytellers cannot do both, and instead fall into the seductiveness of “normal” as a way to frame such stories, they risk doing the work of re-constructing modernist imaginings and cultural memories of both institutionalization and intellectual disability as worthy of erasure in the name of “normal” (Snyder & Mitchell, 2001). Thinking through institutionalization (past, present, and future) only in escapist terms diminishes complex stories of survivorship whose authority can be found in survivors’ rich reservoir of personal knowledge.

However, such unorthodox conceptions of survivor knowledge are not (yet) the culture industry’s story. Even if they were, in 2014 my story about expanding notions of survivorship to include the divide between my sense of citizenship and the cultural disavowal of my brother’s

² I am referring here to *Muir v Alberta* (1996) ABQB 7287; and *Dolmage v HMQ* (2013) ONSC 6686.

meant treading on the terrain of “normal” and perhaps scoring some culture industry points. Yet, I could not even name normalcy as the goal of workers’ rights activism surrounding Valley View, which seemed entirely uninterested in disability. Such a suggestion, without a strong narrative trope to lean a pitch on, made the story moot.

Let’s face it: a writer’s expertise is demonstrated when they can recognize the norms of the culture industry and perform both inside and outside of it. Yet, this performance puts journalists and the objects of their stories in a repetitive cycle by allowing them the “expertise” to recognize the falsehoods that they must embody. As Horkheimer and Adorno (1972) write, “in the culture industry the subject matter itself, down to its smallest elements, springs from the same apparatus and the jargon into which it is absorbed” (p. 102). Titchkosky (2008) puts it otherwise: discourses that focus on *solving* or explaining the *problem* of disability also serve to *make* disability a problem—by pointing to people as *possessing* the problem; by relying on other “experts” to point to whom being supposedly disabled means *being* disabled.³ It is only recently with the emergence of collective initiatives such as the Huronia Speakers Bureau that survivors are usurping journalistic “expertise” and making themselves publicly available to tell their own stories, thus reshaping our cultural imaginary of what survivorship can mean. We are witnessing an interruption of the culture industry’s norms wherein self-advocates tell stories and journalists are asked to listen or step out of the way. Such resistance calls into question the need for journalistic intervention via a writer’s expertise.

³ Consider, for instance, Shaw Media Inc.’s 2013 Annual Report to The Canadian Radio-television Telecommunications Commission (CRTC), which boasts its stab at “cultural diversity” with a one-day 30-minute program called *Profiles of Courage* that “profiles up to eight Albertans who have a disability or illness and how they are helping others with inspiring stories.” Even if we have never watched *Profiles of Courage* perhaps we can imagine how such a show feels; repetitious (supercrip) disability media narratives are easily recognizable because they subscribe to the perfunctory sameness and illusory originality demanded by the culture industry (Global Edmonton, 2013).

Writing Disability and Institutionalization in an Ableist Context

In a sense, being embedded in writing is my cultural location of disability. I am buried somewhere within the cultural conventions and challenges of an ableist modernity that both accepts and rejects my work. It was somewhere within this ballpark that I pitched a decidedly uninspiring story about institutionalization that simply didn't land.

Writers often work in response to instructions they've picked up about how to write—turns of phrase, syntax, tone—all the mechanics of writing that make it the effective, normative technology that it is. Writing subscribes to ableist desires to separate the normal from the abnormal and carries the dualistic representation of disability into our contemporary discourses, including media-driven discourses of the culture industry which identifies, catalogues, and classifies humans and their social roles as part of its schema (Olson, 2009; Richardson & Adams St. Pierre, 2005). There is a well-established discussion in both cultural studies and disability studies that understands stereotypical representations of disability as symbolic signifiers that are responsible for encoding character traits that impact identity (Dolmage, 2014; Garland-Thomson, 2001; Haller, 2010; Zhang & Haller, 2013).

If only vaguely, media-makers are not oblivious to these conversations, and are aware that much misrepresentation stems from inaccuracy. For example, *The Globe and Mail* loosely calls up *narrative prosthesis* (Snyder & Mitchell, 2001) when its style guide warns journalists against misrepresenting people through metaphor:

The expressions 'turned a deaf ear' or 'she was deaf to his entreaties' are marginally acceptable in copy, where it is clear we mean a refusal to listen. But we should be more circumspect in headlines, where...in the absence of context, [these phrases] could be taken to equate deafness with stubbornness or

intransigence (*The Globe and Mail*, 2014).

Narrative prosthesis refers to both the prevalence of disability representation and the meanings ascribed to it, of which the definition above offers at least two clear metaphorical meanings to be treated somewhat delicately (Mitchell & Snyder, 2001, p. xii). Yet, even though disabled people's marginalization occurs amid a perpetual circulation of disability images—such as deafness in this context—the guide cautions against writing about deafness in ways that might compromise our cultural imaginary of what it means to be disabled. Therefore, the way we write disability influences our negotiations with disability representations emerging in the culture industry: deafness is not to be equated with stubbornness or intransigence unless such equations are metaphorical because aligning disabled people with these qualities does not channel them into “acceptable” representations. Notably, the same guide also cautions against using “retarded” to mean “slow” in even a general sense, and directs writers to the term “mentally handicapped” (because “developmentally disabled” is also too vague, despite being part of a historically charged charity- and rights-based Canadian disability vernacular). Such labels work to other groups or individuals and often act as replacement names for a group. These labels are created by people outside of the group in question and without accurate knowledge of this group, which is a phenomenon *The Globe and Mail Style Guide* (2015) seems to acknowledge.⁴

As Titchkosky (2012) has noted, the appearance of disability always attends to the relations between the self and the other, which poses particular questions of relationality in journalism-advocacy. One such question came from a reviewer of this piece who asked me what

⁴ Though immediately afterward, the national newspaper's guidelines perplexingly strike out any attempt at accurately representing people's life experience by suggesting journalists employ the long-ago debunked myth of mental age to quantify intelligence (Dajani, 2001): “the words retarded and retardation are truly informative only if the degree is included. For this reason, ...when speaking of an individual we may be able to replace it with such expressions as ‘functions at a Grade 4 level’ or ‘at the level of a 10-year-old’” (*The Globe and Mail*, 2014).

responsibilities journalists have to neuro-diverse populations when telling their stories in a way that avoids the pitfalls found in the culture industry. This is an important cross-disciplinary question that teeters between journalism and disability studies as it also asks in whose interests (if anyone's) journalists are supposed to operate. That the culture industry is aware of, and responding to, outside concerns about disability representation suggests that such concerns are always-already intermingling with the culture industry's "making" and circulation of disability that relies on the separation of the self and the other. So, if we are to begin thinking theoretically and ethically about journalists' responsibility to others, we must first consult with journalists and begin asking if (and where) journalists are in a position to write in resistance to the culture industry, or if they are faced with a choice between activating violent tropes or abandoning disability-based stories altogether.

If I ask myself about my own responsibility to others, I weigh the pros and cons of commodifying the body through writing (pros being things such as publications, cons being the potential wrongfulness of it all). I continue to mull through the culture industry as one useful, though incomplete, analytical tool. The concept of the culture industry allows us to think of journalism as a rather complicated web in which particular stories are woven, rather than referring ambiguously to "the media" as getting something right or wrong, or doing something good or bad. The point of departure for much writing is a perceived "goodness" in its aim of making sure disability, including tales of survivorship, is centered (or at least included) in conversations. Yet, such centering doesn't necessarily get to the core problems of inclusionism in a neoliberal context. Rather, such narratives can/may surface as single-issue stories void of any intersectional analysis. Meanwhile, we are left chipping away at a task of critiquing how bodies are made and made to do as they do in ways deeply intertwined with the culture

industry's inclusionist agenda: *keeping up has much to do with fitting in.*

Consider one journalist's perspective on practicing journalism when, in 1993, the story of Tracey Latimer's murder broke. Former CBC journalist Ing Wong-Ward said of her experiences covering the story:

the disability organizations, in terms of the spokespeople they were putting up, they were not...articulating a point of view that people could understand. ...I do think there was a failure on the part of disability organizations to really grab hold of the issue and say, 'this is what's at stake' (as cited in Jones, 2014, p. 1216).

This isn't always the case, but when advocacy organizations, survivors, allies, and educators won't go on record even with a single-issue mandate, it means they won't conform to the ethical standards of journalism; it is another way of choosing silence. Silence, of course, is fatal to storytelling. On the other hand, Maria Truchan-Tataryn (2003) points us toward the *risk* of going on record. Her work has involved "storying" (through media coverage) Tracy Latimer's murder. She argues that there is a eugenic stream in news-making that urges audiences to identify with caregivers or those *surrounding* disability, thus releasing the readers (the all-important "we" above) from ethical responsibilities toward others. Her work detects patterns of disavowal in Canadian literature that she links to news media, not to advocacy groups. If silence is not always an effective tool of resistance, and if storytelling is akin to disavowal, journalist-advocates surely have to think carefully about the ethics behind the stories that they choose to tell and the ethics of leaving some stories behind.

What's more, part of the journalist's labour is to write, and to write is an imperfect, interdependent exercise in representation amid a flurry of prospectively fatal misrepresentations (Haller, 2010; Jones, 2012, 2014). Indeed, another important task is to find sources who will

share their stories—a difficult (but not impossible) thing to do when the most fitting sources live and work behind heavily surveilled institutional walls.

Stories of institutionalization and survivorship reach beyond the rudimentary instructions that journalists are given about covering disability, yet they appear edgier and more progressive than our senses might otherwise detect if other patterns were welcome (Horkheimer & Adorno, 1972, p. 102). These schemas exist both inside and outside of journalism, and even into our leisure consumption. They are repeated in films like *The Sessions* (2012) and *Me Before You* (2016), where disability is accompanied by whiteness and the blatant disregard for the disability community's socio-historical roots and contemporary activism; in radio programs that include disabled people, their speaking conforms closely enough to verbal norms; and in *The New York Times* where Dan Barry's "The boys in the bunkhouse" (2014) went viral and taught us our atrocities only in the safety of retrospect, much like Pierre Burton's 1960 writing on Huronia that was resurrected by *The Toronto Star* online in 2013 under the headline "Huronia: Pierre Burton warned us 50 years ago." Thus, as a journalist and activist, I am caught up in the question of what (unpublished) activism looks like when I cannot sink my teeth into the questions that I must in order to gain access to storytelling and, from there, figure out my own story.

Disability, as it is produced, distributed and circulated by the culture industry, is only one of many junctions in our cultural stories. Disability discourses, such as those represented through journalism, do not exist outside of themselves. Communication itself is an intermingling of technologies and affect represented through language and word choice, none of which operates independently of another: a journalist does not write a story about disability without their own interpretations and bodily experiences of disability influencing them, or without the aid of their

style guide, editor, sources, social media commentators, and other gatekeepers.⁵ Nor do I, as a journalist, write without the overlapping experiences of ally-ship, sistering, learning, and teaching. As Richardson (2000) explains, “The individual is both site and subject of [such] discursive struggles for identity and for remaking memory” (p. 929). What’s more, language constructs subjectivities in ways that are historically and locally specific (Richardson & Adams St. Pierre, 2005). All of these processes—from word choice to subject-making—are intertwined in culture industry standards.

Nevertheless, as a journalist, I refer to a consensus of what is acceptable to the cultural imaginary, which is oriented—captivated even—by the stories it reels out. This point was made in 1988 when Patrick Boyer (1988) found out about Canadian disability coverage by interviewing several journalists:

News is created as a result of the symbiotic relationship[s] that decide that a story will be covered, the writer who is sent to dig up the necessary information, and the sources, which provide the necessary information. If an editor sends a reporter out to write a “hero” story and the sources, regardless of the actual situation, provide a “hero” approach to the story, then the writer is stuck. This journalist is in no position...to write anything but a “hero” story (p. 39).

Such stories become signposts for our cultural memory and shape how we understand phenomena such as intellectual disability, survivorship, institutionalization, and ally-ship.

Although each of these issues is being taken up in many new ways—especially online where some discourses are not yet absorbed and elevated to the norm, like crip videos, for instance

⁵ Perhaps in more tangible terms, as sociologist Kurt Lewin (1999) was one of the first to point out, news flows through channels that serve as “gates” through which information may or may not pass; this led to the concept of gatekeeping as we know it today, where stories are not only controlled by editors and style guides, but also by popular opinion that is shaped by a persuasive culture industry.

(Cachia, 2013)—editorial vetting is still connected to audience expectations and therefore still weighs heavily on how writers can reasonably represent themselves, others, and issues larger than themselves (Jones, 2014). And the disavowal of wide, critical, disability-based stories by means of exclusion from the culture industry is still ongoing.

The End: (Re)producing and (Re)distributing Disability through (Absent) Story

The culture industry's tolerance for disability disavowal is high because it relies on notions of normative citizenship and rationality to appease even its most radical audiences. As Horkheimer and Adorno (1972) write, "The explicit and implicit, exoteric and esoteric catalogue of what is forbidden and what is tolerated is so extensive that it not only defines the area left free but wholly controls it" (p. 101). The forms that these stories take on continually (and sometimes subtly) re-iterate our low expectations of how disability should appear in public conversation, including in both legislation and activism, and in our limited conceptions of what resistance looks like.

When my editor killed my story, I was grateful when a journalist friend told me that my experience isn't uncommon. She directed me to a 2004 *Monthly Review* article by Sunny Taylor who rolled from Philadelphia to Washington, D.C. with over 200 other wheelchair users for the organization ADAPT (American Disabled for Attendant Personal-care Today). No press showed up. Taylor writes about how disabled people are routinely excluded from leftist politics and its media—including unions (specifically, as Bob Kafka (2003) points out, from the often-ignored relationship between labour unions and the struggles toward deinstitutionalization). This point is where, I think, my story was heading. In my reading of Taylor's (2004) work, I detected hints

that this muffling of disabled people is part of a larger system of communication that nods toward the culture industry. Taylor identified:

The disabled are viewed with sympathy as victims of ‘bad luck’ who will simply have to accept disadvantage as their lot in life. ...Unlike sexism and racism, which are perceived to be significant social problems, disability falls under the social radar and disablism is not recognized as a damaging or even particularly serious form of prejudice (para. 7).

Currently, this overlooking of dis/ableism is especially troubling for people *in-relation-to* intellectual disability in Canada—be they survivors, activists, or non-survivor allies.

Intellectually disabled people remain a group commonly considered unable to communicate in normative form; a group too often excluded from research and stories about themselves (Ignagni & Church, 2009).

The culture industry’s reaction to such dis/ableism is revealed in the stories it tells, such as those pertaining to intellectual disability and work. In such stories we witness a disability-as-pathology trope (Dolmage, 2014): disabled folks are “fixed” in achieving inclusion in a capitalist framework and their employers take an ownership role in this rehabilitative dynamic, such as in CBC *The National*’s 2014 feature “The economic benefits of hiring disabled employees,” which chronicles the experiences of workers at Tim Hortons franchises in Toronto. These types of human interest stories depict disabled employees as demonstrating the neoliberal freedom and charm of gaining access to a late capitalist system in an era inaccurately described as de-institutional—the very vantage point from which Horkheimer and Adorno (1972) cast out their critique. Through repetition and predictability, the culture industry continues to crowd our conceptions of what disability looks like in journalistic terms and to create its own credibility by

making the radical recognizable (1987/2002). The existing order demands that the subjects of the stories are always commodifiable objects, leaving the tension between journalism and advocacy largely unresolved.

So where, then, have I positioned disability in this article, which by its very nature is undoubtedly another tier of culture industry production? The storytelling that I engage in because it is my job often leaves me trying to write against a tide of propelling stories toward goals of normalization and inclusionism. Even if I attend to the taken-for-granted social orders in which this writing takes place, I cannot confidently claim to be resisting the culture industry. There are moments in this writing where disability is present and thus disavowed. There are other moments where disability is absent, yet its absence denotes its presence elsewhere such as in an undermined corner of our cultural consciousness. I'll likely never get it right, because there is no one "right" way to write disability. Yet here, in a writing-story, I have attempted to take writing "as a method of inquiry that honours and encourages the trying, recognizing it as embryonic to the full-fledged attention to the significance of language" and, I'll add, cultural production (Richardson, 2000, pp. 923-924).

I don't think that my writing-story is complete. I may never gain access to the people at Valley View. And I may never resolve the ethical quandaries that come up when I choose to write Kevin into my work, or back away from his/our stories in silence. For me, these experiences at least have pedagogical possibilities both for my own writing process and for students engaged in writing for disability activism. The notion of writing for disability activism is one increasingly invested in the "curricular cripistemologies"—"the turning over of failed capacities into productive incapacities"—or, more simply, in teaching and learning moments that interrupt normative culture (Snyder, Mitchell, & Ware, 2014, p. 269). Surely exclusion from the

culture industry's radical veins is one avenue to recalling a tilted pitching and writing process embedded in a modernist media landscape. Yet, the idea still floats, and stories from Valley View will emerge with or without me. And, though I went on to write up disability in other ways for other publications, I still wonder about the story in question.

I wonder about new challenges for meeting public needs through uncovering hidden stories and querying how it may be possible to write disability without using people as commodities, but also without solely relying on text-based research that fails to include people (Snyder & Mitchell, 2006). Perhaps, in an era of what we can critically conceptualize as survivorship, we need to begin not only telling stories relationally but also re-casting and deconstructing presences and absences. Through this lens, storytelling means thoroughly examining the nature of certain stories' absorption into, absence from, and resistance against the Canadian culture industry's schema. Storytelling also means skirting into the wild, unpublished rough edges of exclusion where you may not be believed. It means asking inconvenient questions not only of the writing but also of the reading: When I read about Valley View Centre, which stories are left behind, and why?

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