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Project Re•Vision: disability at the edges of representation

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The representational history of disabled people can largely be characterized as one of being put on display or hidden away. Self-representations have been a powerful part of the disability rights and culture movement, but recently scholars have analysed the ways in which these run the risk of creating a ‘single story’ that centres the experiences of white, western, physically disabled men. Here we introduce and theorize with Project Re•Vision, our arts-based research project that resists this singularity by creating and centring, without normalizing, representations that have previously been relegated to the margins. We draw from body becoming and new materialist theory to explore the dynamic ways in which positionality illuminates bodies of difference and open into a discussion about what is at stake when these stories are let loose into the world.

Keywords: arts-informed methodology; representation; digital storytelling; body; story; disability and difference

Points of interest

- In this article we talk about a research project, Project Re•Vision, which is exploring representations and meanings of disability and difference through digital stories.
- In our research project, we asked disabled people and healthcare providers to each make a digital story. We invite you to watch the digital stories as you read the article. Go to <http://projectrevision.ca/videos/>. Following the prompts, type in the password ‘projectrevision’.
- Digital stories are videos, two to three minutes long, that pair audio-recordings of personal narratives with visuals (photographs, short videos, artwork, etc.).
- We end with the suggestion of being open to the possibilities – the creative, communal, and artistic possibilities – of how the digital stories made within our project disrupt problematic representations of disability.

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Introduction

Stories are wondrous things. And they are dangerous. (King 2003, 9)

The problem with the ‘single story’ is not that it is untrue, but that it flattens the human experience. (Adichie 2009)

The history of disabled people in the Western world is in part the history of being on display, of being visually conspicuous while politically and socially erased. (Garland-Thomson 2002, 56)

The stories presented in our paper can be viewed online.¹

People living with disabilities and differences have been, and continue to be, displayed in freak shows, medical journals, charity campaigns, and as evil or pitiable tropes in novels and films (Snyder and Mitchell 2006). Bodies of difference have also been hidden in institutions, hospitals, group homes, and generally removed from the public eye (Reaume 2012; Schweik 2010). In his essay ‘Stolen Bodies, Reclaimed Bodies’, disabled essayist Eli Clare (2001, 363) writes that ‘Just as the [disabled] body can be stolen, it can also be reclaimed’. Representations of disability produced by disabled people have been central to the disability movement and the development of disability studies. Self-representations have countered tropes of the pitiful victim or the ‘super cripp’ and challenged assumptions of disabled people as passive and non-productive. While we recognize self-representation to be a powerful part of the disability rights and justice movement, feminist, critical race, and transnational disability scholars have provoked us to consider ways in which disability representations may run the risk of creating a ‘single story’ – typically accounts of disability told from the perspective of white, westernized, middle-class, physically disabled men (Erevelles and Minear 2010; Meekosha 2010). To resist such standardizing, we have produced a project that seeks to create and centre, without normalizing, representations that have previously been relegated to the representational edges.²

Project Re•Vision, a Canadian Institutes for Health Research-funded initiative, uses arts-based research methods of digital storytelling and drama to dismantle stereotypical understandings of disability and difference that create barriers to healthcare. To date, we have generated an archive of over 100 digital stories from women and people of all genders living with disabilities/differences and healthcare providers. Because what counts as a disability or difference varies across time and place, Re•Vision uses a broad definition that encompasses mobility and sensory disabilities, chronic illness, madness/mental health issues, and facial and physical differences. Following Mia Mingus’ (2010) call to centralize bodies that have previously been marginalized by the mainstream disability movement, such as racialized, poor, queer, trans, and sick bodies, in this paper we introduce stories created through Re•Vision that animate the edges of disability representation. We locate our work in the field of disability arts, tracing its connections to the disability rights and justice movements, and then situate our project in relation to theories of representation and of bodies/embodiments. Moving away from normative ideas of what disability is, we present stories created in our workshops that ‘edge out’ new meanings of disability and difference – stories that proliferate disabled voices, stories that transgress disabled/non-disabled binaries, stories that disrupt any singular theoretical account of disability, and stories that complicate and expand ideas of disability community. By offering a selection of stories that highlight common themes found

in our archive and giving readers direct access to them alongside brief curatorial statements, our intention is to create space for open-ended readings without delimiting meanings. We end by exploring some dynamic ways that positionality illuminates bodily differences and the stories that are ushered in when we open up to the edges of representation.

Re•Visioning disability and difference

Project Re•Vision is a mobile multimedia lab dedicated to exploring ways in which communities can harness the power of arts-informed research to advance social inclusion and justice. In broad strokes, we look at the value and efficacy of the arts to positively influence practitioners and decision-makers in healthcare and education. To that end we have run 15 digital storytelling workshops where participants learn the fundamentals of representation, storytelling, and filmmaking. Three of the workshops allowed all researchers involved in the project to make their own digital stories, and a further two enabled some of us to receive facilitator training. In these workshops, run almost exclusively by women who identify as living with disabilities and differences, participants created digital stories, which are videos, two to three minutes long, that pair audio-recordings of personal narratives with visuals (photographs, videos, artwork, etc.). We have adapted our workshop format for research and disability justice purposes from the format originally developed by the Centre for Digital Storytelling in Berkeley, California (Lambert 2013). What makes the Re•Vision process unique is our focus on: digital stories as research creation/knowledge mobilization methods; and art as activism – our exploration of the kind of art that can be generated in crip community and its power to open possibilities (Rice, Renooy, and Chandler *forthcoming*). Through our workshops, we explore experiences of how disability or difference is perceived in healthcare by creating spaces where people can unpack and ‘talk back to’ received representations and make new meanings. We also respond to disability studies’ call for representations of physical and mental difference that have previously been relegated to the margins (Erevelles 2011; Frohmader and Meekosha 2012; McRuer 2010) by inviting diversely-embodied people into our workshops to make digital stories that move these types of representations into the centre.

Project Re•Vision follows a generative disability arts movement that aims to give expression to disability experience and re-imagine bodily difference (Roman 2009). Since the 1980s, the disability arts and culture movement has been an integral part of the Disability Rights Movement across North America and in the United Kingdom (Abbas et al. 2004). The Disability Rights Movement, which emerged in the 1970s alongside other rights-based social movements, was initially concerned with, and quite successful at, securing legal and civil rights for disabled people by engaging in policy reform and creating accessibility legislation (Oliver 1996; Shakespeare 2006). However, the Disability Rights Movement was also critiqued for ignoring the corporeal, and thus valorizing a particular kind, a ‘normal’ kind, of disabled body – the white, straight, middle-class, wheelchair-using, mentally and emotionally normative man with citizenship (Corker and Shakespeare 2002; Mingus 2010). In response to such critique, the disability arts and culture movement posited that if justice was to be achieved for all disabled people, we must focus on how disability is represented and thus who we imagine disabled people to be and what we could imagine ‘full inclusion’ to become. In this way, the emergence of the

disability arts and culture movement marked a shift in the fight for disability justice from rights-based initiatives to a focus on more aesthetic and representational concerns (Gorman 2007/2011).

Disability arts and culture is now an integral part of both the disability rights and justice movements. Festivals such as Tangled Art + Disability, founded in Toronto in 2000, KickstART, founded in Vancouver in 2001, and Stage Left, founded in Calgary in 2003, have brought disability arts to the Canadian public, having supported and showcased the work of disability artists in Canada. Disability arts disrupt the notion that disability is a problem in need of solution through representations of the vitality and dynamism of disability life. We think that the power of disability arts is twofold: at the same time as disability artists produce new representations of disability and difference, the disability arts movement is an indication that disabled people have agency, are creative, and come together in community, which provides a powerful counter-narrative to the assumption that disabled lives are lives not worth living.

The continuous process of Re•Visioning

Re•Visioning is important because we live in a world filled with (mis)representations of disability. Disabled artists, activists, and scholars must contend with these when creating alternative representations of disability since they saturate our representational field. We thus borrow our name Re•Vision from the title of the essay ‘When We Dead Awaken: Writing as Re-Vision’ by feminist poet Adrienne Rich (1972, 18), who describes revision thus:

Re-vision – the act of looking back, of seeing with fresh eyes, of entering an old text from a new critical direction – for women [and people with disabilities] more than a chapter in cultural history: it is an act of survival. Until we can understand the assumptions in which we are drenched we cannot know ourselves. (Rich 1972, 18)

While one can take Rich’s version of revision to mean uncovering an authentic truth hidden behind false assumptions, a version that equates vision with veracity, here we emphasize another meaning: rather than fixing or correcting past falsehoods to reveal an unchanging universal truth, we interpret revision as a continuous process – of re-visiting, re-thinking, and re-creating – to interrogate the promises and limits of all representations. So when we revision disability, we do not create ‘new’ representations that are completely distinct from, or in opposition to, the ‘old’ ones. Nor do we attempt to elide old meanings altogether. Instead, we make our meanings in conversation with existing representations, through talking back, expanding on them, infusing them with lived experience, and reclaiming ourselves from them. We do this because existing meanings set the representational scene for how we understand, respond to, and embody difference. While we take self-representation to be a powerful part of the disability rights and arts/culture movements, Re•Vision also recognizes that such representations may run the risk of creating a single story, which provides a one-dimensional counter-story to dispute the dominant narrative of disability as undesired and lacking vitality. We are guided here by the insights of Nigerian novelist Chimamanda Adichie (2009, TED Talk), who warns of the danger of a single story: ‘The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story.’ Our goal is to move past the single story that collapses

the diversity of experience and replace it with a multiplicity of stories that proliferate disabled people's voices and experiences. In this way, Re•Vision seeks to contribute to the continuous process of revisioning by representing experiences historically relegated to the edges of the visual field, both in mainstream culture and disability movements.

We invite you to view digital stories³ made through our project that illustrate how disabled people live in the midst of many stories of disability, their lives rarely conforming to the single story that disability is only a problem in need of medical solution. The narratives show how Re•Vision storytellers resist and respond to dominant ways of thinking about disability, complicating and challenging viewers' understanding of disability as a lived experience. In *Shift*, for example, Eliza Chandler⁴ responds to mainstream stories about disability as a medical problem to be fixed or overcome with an alternative story of disability as a social and cultural identity, inviting audiences to consider what possibilities might open up when we welcome disability in. Shifting from a space of shame to pride, her story beautifully wavers between both registers to capture the contradictions of embodiment. In *Me and You*, Kirsty Liddiard reflects upon the fears, uncertainties, pleasures, vulnerabilities, and sensualities which encompass her lived experiences of disability and impairment. The film's interweaving themes of in/out, pride/shame, and joy/fear tell an intricately political yet embodied story of a precarious ongoing journey to self-acceptance and pride. In *Knitting*, Elisabeth Harrison relates her encounter with medical treatment for depression, picking up some of the threads that are dropped from dominant conceptualizations of experiences of difficult emotions. Recovering and working with these threads, Harrison invites audiences to question the dominant paradigms that shape the trajectories and treatments of 'mental illness'. Finally, Manuela Ferrari shares her journey of growing up dyslexic within the public school system in Italy. As she arrives at the current moment, Ferrari takes 'the little black dots of ink on the white pages' that used to give her so much trouble and transforms them, giving them new meanings.

Opening possibilities for becoming

As these stories demonstrate, the medical model seldom appears as unproblematic in digital stories created by disabled people who have participated in our workshops. Because one of Re•Vision's objectives is to help healthcare providers understand disability differently, workshop facilitators – ourselves people living with disability/difference with experiences in disability arts, disability community, and critical disability and health studies – educate providers about the social, experiential, and embodied meanings of disability during the workshop process. Introduced to these rich perspectives, providers usually also move beyond the medical model, in part guided by the experiential and creative insight of workshop facilitators. Often, in addition to speaking back to the medical model, Re•Vision stories contain responses and challenges to the social model of disability, which is, to some extent, dominant in the field of disability studies and often still forms the basis of disability policy and law. The brilliance of the social model has multiple roots: its simplicity in its call for change; its radicalism in shifting the meaning of disability from the bodies of individuals to a product of the social world; its emergence from disabled people's own movements; and its enabling of disabled people – for the first time in history – to claim a proud cultural identity, rather than one based on shame. This was disabled

people's radical rejection of, and resistance to, their medicalized and pathologized existence. Thus, we cannot underestimate the revolutionary underpinnings and effects of the model.

However, the 'strong social model' also has had problematic consequences. Wide-ranging critiques from feminist and post-structural theorists have challenged the model on various grounds: its rigidity and anti-experiential nature (Thomas and Corker 2002); its masculinist principles (Crow 1996); its neglect of the psycho-emotional consequences of disablement (Thomas 1999); its exclusion of those whose impairments do not fall into the category of 'physical disabilities' (Beresford 2000; Nabbali 2009); and its disembodied and somatophobic conceptualization of disablement (Shakespeare and Watson 2001; Williams 1999). Many people who live with bodily differences do not consider themselves disabled and the naming of disability itself varies depending on the context (D/deaf people are not disabled where everyone signs). From a constructionist perspective, then, the meaning of disability is slippery, multiple, and temporary – in other words, it cannot be fixed. Because the meanings of bodily variation themselves vary depending upon context, it is difficult, if not impossible, to set clear boundaries between what counts as disabled and non-disabled (Shildrick 2007).

From an embodiment perspective, the social model further fails to recognize people's intimate experiences of pain and pleasure, limitation and capacity, and the meanings that disability may hold for them (Lutz and Bowers 2005; Valeras 2010). Embodiment theory offers a useful entry point into understanding disability experience but it requires the corrective of critical theory to avoid assuming all human beings inhabit their bodies in a similar way – as bounded entities and containers for selves (Battersby 1998). The containment model is inadequate because it centres the self-enclosed, masculinist, western mode of embodiment while marginalizing embodiments perceived as unpredictable and unbounded (such as pregnancy, disability, or modes of embodiment of people from many non-westernized cultures) (Rice 2014). Over the past 20 years, feminist authors within disability studies have challenged these assumptions and omissions, and have at the same time located gender, race, and other categories within analyses of disability (Erevelles and Minear 2010). Much of this scholarship has taken the form of self-reflexive writing by authors about their own intersectional identities and lived experiences of impairment (Thomas 1999). Consequently, feminist disability studies has contributed to understanding how 'the body, bodily variety and normalization' may be integral to oppression and how 'reimagining the body and embodiment' may be critical for equity and inclusion (Hall 2011, 6 and 7).

From the late 1990s onward, social constructionism has been challenged by two theories about bodies/embodiment (Rice 2014). These are 'body becoming theory' (Battersby 1998), an offshoot of feminist philosophy of the body (Coleman 2009; Weiss 1999); and the new materialism, which has arisen, in part, from feminist studies of science (Birke 2000; Hird 2004). Unlike social constructionism, which analyses how bodies are conceptualized, these theories attend to lived experience and to the biology of bodies. Theorists do not see bodies as bounded, stable entities but as fluid forms that come to be through relations with natural and cultural forces that surround them. Body-becoming philosopher Elizabeth Grosz (1994) uses the Möbius strip to convey how body, mind, and culture can be thought of as continuous. According to Grosz (1994), the body, like the Möbius strip, has no clear distinction between inside and outside – instead, these fold into each other. Through this

‘infoling’ everything that happens to people – accidents, insults, or pleasures – becomes an ingredient in the history and development of their bodies (Grosz 1999, 2008). This approach does not discount the biological or the psychological but is non-determinist in theorizing opened-ended ‘rhizomatous’ trajectories for what bodies can become. Building on her work, new materialist biologist Anne Fausto-Sterling (2000) uses Russian nesting dolls as a way of visualizing the various layers that make up human beings – from the cellular to the social – to convey the inseparability of biology from culture. Like body-becoming philosophy, the new materialism conceptualizes the physical body as a source of knowledge in itself and understands matter to have agency independent of people’s perceptions or manipulations of it (Barad 2003). This means that all matter – from rocks and birds to blood and fingernails – has agency through the energy it possesses at an atomic level and through the ways it affects, and is affected by, the matter that surrounds it. Theorists see the becoming of bodies as a relatively open process, which cannot be predicted or determined in advance, and seek to explain how nature and culture affect and transform each other to jointly construct our world.

Body becoming and new materialist theories converge in theorizing bodies as emergent systems that materialize as a result of their own agency and other forces acting upon them (Rice 2014). Since cultural contexts, physical and social environments, and personal habits shape each person’s physical being, no one can predict with certainty what any body will become. Thus, within these frames, bodies do not come to be before their interactions but emerge through interacting. What makes these theories unique is their stress on the body’s open-ended becoming, which speaks back to older, deterministic models of the body, both biological and social. They suggest that like other categories of difference, disability emerges through the interplay of broader social contexts with peoples’ psyches and the biological agency of their bodies. Such theoretical shifts are important to revisioning disability because they recognize, as exemplified in the films of Chandler, Liddiard, Harrison, and Ferrari, the roles of physicality, process, unpredictability, and context in understanding the human body and embodiment. By positing that multiple interacting forces, including representation, play a part in influencing what bodies can be, these theories, like the stories featured here that illuminate them, suggest that revisioning disability may be critical to opening up possibilities for what disabled bodies can become.

The next four digital stories reflect upon the social and biological processes that produce our bodies, and open new representational (and therefore ontological) possibilities for disabled people’s embodiments. In *Reading Blind*, Sheyfali Saujani provokes us to imagine accessibility as a collective desire rather than an individual accommodation. Through this provocation, Saujani opens up to us about how, for her, accessibility and disability identity are fully intertwined. Janna Brown shows in *Untitled* how her story of madness shrinks when handled in the space of the emergency room. Although Brown’s story is rendered illegible within medical discourse, her centring of her rich embodied account of psychic rupture also disrupts medicalized understandings of madness. Turning to *Leaving Eustachian*, gender queer artist Jes Sachse reveals the possibilities that arise from hearing impairment, which enables them to navigate the world differently by tuning on and off the world around them and thinking in interesting ways about the relationship between their body and the surrounding environment. Finally, Jan Derbyshire shows us a surprising thrift store find in *Value Village*, explaining how the objects she found at the

thrift store led her to contemplate the dominance of pharmacological interventions, and the ways we might use sequins and a sense of rhythm to resist them.

Body becoming and embodiment theories, considered alongside the evocative narratives of Derbyshire, Sachse, Brown, and Saujani, offer rich correctives to medical and social models. Through these theoretical and experiential lenses, the becoming of bodily selves can be seen as open ended and unpredictable, as shaped by people's psyches and biologies intersecting with their social, relational, and material worlds. By showing how multiple interacting forces, including our ideas about disability, play a part in influencing what bodies can be, these theories and the digital narratives that animate them suggest that revisioning disability may be critical to open up possibilities for what disabled bodies could become.

Re•Visioning the problematics of disability representation

Re•Vision participants provide counter-narratives, which disrupt assumptions and normative ideas about what disability is, whether from the dominant culture or disability rights movements. In what follows, we identify and animate each of four problematics – of categories/worlds, of bodies, of community, and of intelligibility – that we see as emerging from normative representations of disability in mainstream and disability movements. We start with the first way we do this through Re•Vision: by inviting vulnerability and intercorporality as a way of blurring boundaries between disabled and non-disabled categories and worlds.

The problematic of categories and worlds

The digital storytelling process requires that all storytellers make themselves vulnerable. Yet vulnerability is defined so negatively in our society: a conventional definition describes it as a susceptibility to being wounded or hurt and an openness to criticism or attack. Vulnerability is also associated with the feminine, the disabled, the weak, and all groups seen as prone or predisposed to being harmed due to their embodiment (illness, disability, pregnancy) or social disadvantage (poverty, ableism, racism), especially in the western world that privileges self-contained, autonomous, independent, and strong selfhood. While vulnerability can increase people's susceptibility to suffering and inequality (since groups marked as vulnerable are socially rendered violable), it is also the ground for human exchange, empowerment, and growth. It is necessary for human being and human understanding. It is fundamental to relationship and to social life. Legal scholar Martha Fineman (2008, 8) re-claims the term vulnerability from its negative associations for its potential as a 'universal, inevitable, enduring aspect of the human condition' shared by every human being. She argues that both the negative and positive possibilities of vulnerability are important since they capture the inherent interdependence that underpins human existence. This challenges the myth of the autonomous self that is the basis of western legal systems/social policies and enjoins us to re-think these by taking the vulnerable self, our shared common human experience, as our starting point building a more equitable society.

Anthropologist Ruth Behar coined the term the 'vulnerable observer' as a way of talking about the value of vulnerability to research (and we would extend her claim to include professional practice). Here researchers and practitioners make themselves vulnerable in the sense of sharing something about themselves that sheds

additional light on the subject in discussion – in the same way that they focus on ‘other/ed’ people’s lives to shed light on a topic. According to Behar:

vulnerability doesn’t mean that anything personal goes. The exposure of the self who is also a spectator has to take us somewhere we couldn’t otherwise get to. It has to be essential to the argument, not a decorative flourish, not exposure for its own sake. (1997, 14)

Being a vulnerable researcher or practitioner means being present and honest with ourselves throughout our work, namely with our contradictory, unresolved, or difficult thoughts and emotions. At the same time, it requires a willingness to be present with others’ emotions and embodied experiences, to approach respectfully, tread carefully, and resist attempting to master differences (which by their very definition are not fully knowable). Because our culture justifies cultural abjection and social exclusion through perceptions of vulnerability, it is difficult for people to be vulnerable. Some groups are forcibly positioned as vulnerable. And people learn that they may be violated if they show vulnerability. But when people decide to make themselves vulnerable, this can interrupt prevailing norms, and provoke personal and collective transformation. This is especially true when individuals in privileged positions unmask their vulnerabilities in an effort to deepen understanding and expose the operations of power in social situations and relations.

In our workshops we were not necessarily anticipating, but were excited to discover, how providers’ stories so eloquently spoke back to similar taken-for-granted beliefs about providing professional care. In contrast to the typical ways we culturally ‘know’ healthcare providers as ‘disembodied expert’, they told embodied stories; stories of how their own body histories informed their practice; stories of shared vulnerability, animating Fineman’s declamation of the term; and stories of intercorporeality – that is, the intricate way in which bodies come together in interactions (Weiss 1999), such as providing care, in which the corporeal boundaries between the person providing care and the one being cared for become blurred, the two bodies becoming almost indistinguishable. Healthcare providers’ articulation of vulnerability was very much in the context of, and tempered by the medical cultural imperative to be, or at least appear to be, ‘all knowing’. In this way, their vulnerability, although deeply felt, was often described as being stifled by cultural expectations of what and who a healthcare provider should be from both sides of the metaphorical hospital bed.

The next set of videos explores themes of vulnerability, the complexities of embodied affinities across differences, and how providing care can lead to intercorporeal experiences. We begin with Hilde Zitzelsberger’s story, *My Impossible Invulnerability*. She contemplates the way we all occupy many roles in our lives, roles that could be considered contradictory. Her piece opens up space to consider how the positions of ‘expert’ and ‘cared for’, as well as the distinction between these, may be fluid rather than fixed, thus gesturing toward the kind of interdependence that Fineman describes. Carla Rice’s story, *The Elephant in the Room*, explores the layering of professional and personal vulnerability that accompanies the experience of having a body history that is not written, or readable, on her skin. Within her exploration of these vulnerabilities, Rice offers a meditation on how beauty standards haunt us all and shows how these hauntings connect us, by provoking intercorporeal experiences. Nadine Cross explores the complexities of living with depression, her self-understanding of which she ultimately describes to be a

‘gift’. With honesty and humour, Cross explores the boundaries between living with and not living at all, giving us the gift of her vulnerability, with which we might all connect. Finally, in *I Am a TAB (Temporarily Abled-Body)* Karen Sutherland foregrounds her love of movement, and the experience of physical pain that brought her into contact with the medical system. She explains how after her pain was diagnosed as an ordinary part of aging, she began to contemplate her feelings about the physical and mental changes that come with getting older. While in presenting these stories we recognize that there are differential consequences for those whose vulnerability is imposed rather than (ethically) impelled, researchers/providers’ articulation of vulnerability in the context of the cultural imperative to be, or at least appear to be, ‘all knowing’ challenges expectations of who and what a vulnerable self is or could be (Rice [forthcoming](#)).

The problematic of bodies

Another way we disrupt normative ideas about disability is through gathering stories in response to Mingus’ (2010) call to centralize bodies that have previously been marginalized by the mainstream disability rights movement, such as racialized, poor, queer, trans, invisibly disabled, and sick bodies – a call both echoed and responded to by many disability studies scholars writing today, including Erevelles (2011), Goodley (2011), Meekosha (2011), McRuer (2010), and Schalk (2013). Taking from Mingus, we recognize that disability is imbricated on sexuality, overlaps with gender, and is clarified by race. All disabled people do not have the same, or even similar, experiences of disability and/or difference. Given this, people with disabilities and differences are not all ‘talking back’ to the same dominant representation. Through inviting diversely-embodied storytellers to talk back to these and other representations, our project seeks to uncover some of the ways in which positionality illuminates disability. We recognize that centralizing stories of disability and difference that have historically been marginalized is an ongoing, never-finished process. We also recognize that there are many other disability justice groups that have been centralizing these kinds of stories for a long time. Re•Vision is committed to fostering the continuation of centering marginalized stories.

The final set of videos engenders this commitment. mel g. campbell’s *Puzzle Piece* articulates how people are kept out of public space because of ableism, but also how other forms of systemic oppression such as racism and poverty contribute to the exclusion of disabled people, revealing that creating accessible space involves more than simply making environments barrier free. In her untitled story, Kristen Mommertz recounts the difficult circumstances and profound emotional and intellectual connection that brought her together with her best friend, Benjamin. Mommertz explains how her relationship with Benjamin enabled her to share her own story. Using fragmented images and memories, she describes the experience of losing Benjamin to suicide, and contemplates a future without – and with – him as she continues to share her stories with the world. Finally, Aboriginal artist Vanessa Dion Fletcher’s (Potawatomi/Lenape) *Words* uses homophones to juxtapose her first-person experiences of a learning disability with the objectifying language of diagnostic tests. She asks us to consider how the language of lack and deficiency limits children labelled with a learning disability but how the magic of words also might open up possibilities for their being and becoming. These stories present relational and intersectional accounts of embodied disability experience, highlighting

the experiences of racialized, Aboriginal, poor, queer, and invisibly disabled bodies previously relegated to the representational edges within disability movements.

The problematic of community

We try to make our workshops open to everyone, following the assertion that, as we believe, ‘everyone can make a digital story’. We welcome disability in and desire the disruption that disability and embodied difference can make. We work hard to create spaces where crip community can be enacted and where crip(ped) friendship can be formed. We make sure our workshops are barrier free and follow our own practiced accessibility guidelines: before the workshop begins, we ask participants what would make the workshop accessible and comfortable for them; we ask them again in the workshop; we think about what would make the workshops accessible to us; and we work with an ever-expanding understanding of accessibility. To begin each workshop, we frame Re•Vision as a feminist project and discuss how everyone can contribute to making an anti-oppressive, safer space. Still, for all of our intentions, we acknowledge that, sometimes, we fail. For example, we have not always anticipated how workshop room conditions, such as flickering fluorescent lights in one space, can cause migraines; how hiring sign language interpreters only during workshop hours is insufficient to ensure the full inclusion of Deaf storytellers; and how hierarchies of disability can be reproduced even in spaces where disability is welcomed in. We encounter uncomfortable moments – ableist, racist, sexist, hostile, dangerous moments. We also have encountered more transformative moments than we could have ever hoped for.

Enactments of community, we have learned, cannot be wholly planned for; they may not even be fully describable. Communal enactments are based on relationality; they are experienced, they are generated between those of us in the ‘room’, so to speak. We have observed that since there are few crip-run spaces for people with disabilities to do emotion and identity work, the workshops provide space for participants to articulate their own conceptions of embodied disability experience and begin to form the intimate relationships that have come out of Re•Vision workshops. Yet community cannot be mandated under universal design best practices because difference cannot be fully anticipated, planned for, known, or mastered, as we have learned. Put differently: as much as we hope for and desire community to be enacted in our workshops, sometimes it happens and other times it does not. So, then, how do we sit with the problematic of community, knowing something that we so desperately want to have happen in and for our workshops, cannot be planned, for all of our efforts and intentions? We are left with an enigmatic rub between the labour we undertake (our extensive planning, careful consideration of group dynamics and of creating a safe space, critical reflections on what worked and what did not in the last workshop, etc.) and the affect generated in the workshop space itself – the spark (or lack thereof); that unexplainable, ineffable, feeling of community.

The problematic of intelligibility

None of us inhabits a social context that has fully adopted principles of universal design, so we must often identify ourselves as disabled in order to access accommodations. In many cases, we are required to define our disabilities in accordance with medical model ideology, irrespective of our understanding of our bodies as

process, or of disability as a complex social and cultural experience. If we do not identify ourselves as disabled in the ‘right’ way, we are often prohibited from accessing the resources we need (assuming these are available at all). When we engage with disability in ways that embrace complexity by bringing the margins to the centre, we open up space for representations that change our perceptions of disability, our perceptions of ourselves and our communities, and that even change our very bodies. By doing this we enter a space of great possibility but also of danger: when we challenge or resist the dominant discourse of disability, we risk becoming unintelligible to the – often oppressive – systems with which we must interact. In some circumstances, if we resist fixing our identities in accordance with dominant ideologies of disability, the consequences can be severe. Re•Vision, through its engagement with providers as well as disabled women and people of all genders, seeks to foster change in the understanding of disability and difference within the healthcare system. Hopefully, in promoting a better understanding of these blurry, complicated, dangerous, and productive problematics, projects like this one will ultimately enable the development of a social, cultural, and political context that is truly welcoming and supportive of all of us, with all of our differences and vulnerabilities.

Conclusion

In insidious everyday ways and in pervasive, representational ways, our culture is taught that disabled people live unliveable lives. We learn that we, as people who live in and with different embodiments, must normalize ourselves, apologize for our differences, or live uninhabitable embodiments. It is in resistance to normalizing and surveilling forces of contemporary life that we have explored the possibility of representations of disability and embodied difference from the margins. The digital stories created through Re•Vision experiment with a variety of mediums, including photography, film, poetry, digital art, painting, drawing, and sound in order to refigure the corporal in our social imagination and thus re-signify the meaning of disability and other forms of embodied difference. Rather than focusing on persuading people to act/think differently, representations created in Re•Vision workshops contribute to the becoming of disabled bodies by embodying and materializing disability differently so as to challenge reductive scripts about body, ability, and normality. The stories created by participants teach us that when we allow ourselves to touch and be touched by an ever-expanding circle of difference, we might find ways of living with/in the aleatory aspects of communal life as well as the ambiguity and uncertainty of human embodiment.

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Notes

1. Go to <http://projectrevision.ca/videos/>. Following the prompts, type in the password 'projectrevision'. Please note: these videos are intended for readers only and are not for public screening.
2. In this paper, we use the pronoun 'we' primarily to refer to ourselves as authors and as Re•Vision facilitators and participants. We also use 'we' to refer to imagined and intended readers who may be familiar with the issues raised.
3. Please consider filling out the following online survey ([www.http://projectrevision.ca/videos/](http://projectrevision.ca/videos/)) so that we can evaluate the effect of these videos on viewers and keep the dialogue about disability representation going.
4. As part of Re•Vision's protocol, storytellers own their stories, decide whether they wish to use their name/identifying information in their work, and retain control over the type of audience to which their story is shown. Additionally, all storytellers whose works we feature here have reviewed this article and given us permission to use their names and stories prior to its publication.

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