

Making Mad Home and Other Love Stories: Mad Performative Autoethnography, Collaborative  
Research-Creation, and Mad-Accessible Trauma-Informed Practice

by

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## Abstract

This is a love story about Mad research-creation, and about what we can learn when we draw together Mad theory with Mad performance and Mad-accessible, anti-oppressive, trauma-informed practice. This research-creation project gives weight to social and political conceptualizations of, as well as deeply embodied and sensorial engagements with, both ‘mental illness’ and trauma. Informed by my work as a Mad artist, performer and inclusive creative movement practitioner who works in the field of adapted physical activity, this project also centers artistic creation, performance, and practice-based suggestions for inclusive and adapted movement programming. In the first chapter of this dissertation, I introduce Mad studies and Mad theory, offer some exemplars of Mad performances that inform this project, and discuss how mental illness and trauma is currently being taken up in the field of Adapted Physical Activity. In chapter two, I explicate research-creation as this project’s overarching methodology, and articulate this research-creation dissertation as a series of nesting dolls: three smaller inter-related research-creation projects that nest together and speak to one another. One of these nesting dolls, discussed in chapter three, mobilizes performative autoethnography and performative writing to theorize Mad autoethnography as episodic and cyclical. To do this, I reference three episodes that (de)compose this cycle of autoethnography, including a performance entitled “Mad Dance,” a publication of Mad performative writing entitled “Loose Leaf,” and a participatory performance entitled “The Mad Dance of Grad School: A Choose Your Own Adventure.” Another nesting doll, detailed in chapter four, highlights choices and learnings from the collaborative research-creation project *Mad Home*: a sensorio-political participatory performance and website. These choices and learnings include: becoming affected by friends and ancestors across time and space; decorating our walls with the stories we want to tell; finding

home through dialogue; honouring our needs and desires in collaboration; inviting into discomfort and distress; curating for anti-pathologization, access, and support; curating for memory and breaking-as-resilience; curating Mad sensory worlds; and sharing *Mad Home* beyond these walls. A third nesting doll, discussed in chapters five and six, introduces trauma-informed practice to the field of Adapted Physical Activity. Chapter five unpacks a multiplicity of ways to conceptualize trauma and mental distress, including: psychiatric conceptualizations; social and political conceptualizations; embodied conceptualizations; as well as intersectional, intergenerational and historical conceptualizations. Chapter six outlines eight action domains featuring practice-based suggestions for enacting Mad-accessible, anti-oppressive, trauma-informed practice. These include: challenging pathologization, normalization, and sanism; acknowledging that structural inequality exists and does damage; recognizing privilege; dealing with embodied discomfort; doing our homework; valuing marginalized histories, struggles, perspectives and choices; shifting language; and shifting environments. These suggestions are offered to support adapted and inclusive movement practitioners in making our practices more accessible, affirming, and invitational for all, but most especially for those impacted by trauma and distress. In my conclusion, which is really about beginning again, I outline what I have learned about what maddened art and living can do, and the ways that this project continues to craft new nesting dolls, episodes, homes, practices, and love stories of survival and flourishing.

## Preface

Ethics approval for the collaborative research portion of this dissertation was obtained from the University of Alberta's Research Ethics Board. This study (study ID number: Pro00063550) was approved on February 27, 2017, under the project name "Collaborative Research Creation on Madness and Performance".

As discussed in chapter 3, a portion of my autoethnographic work has been published in the *Canadian Journal of Disability Studies* during the course of writing my doctoral dissertation. I am the sole author of this work. See Appendix A for a copy of this publication. The citation for this publication is:

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## **List of Abbreviations**

APA –	Adapted Physical Activity
CAAWS –	The Canadian Association for the Advancement of Women and Sport and Physical Activity
CBC –	Canadian Broadcast Corporation
c/s/x/m –	consumer/survivor/ex-patient/Mad
CRIPSiE –	Collaborative Radically Integrated Performers Society in Edmonton
DSM –	Diagnostic and Statistical Manual of Mental Disorders
DSM-V –	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
EMDR –	Eye Movement Desensitization and Reprocessing
ID -	identification documents
IOC -	International Olympic Committee
LGBTQ2I –	lesbian, gay, bisexual, trans, queer, two-spirit, intersex
LGBTQQIP2SAA –	lesbian, gay, bisexual, trans, queer, questioning, intersex, pansexual, two-spirit, asexual, and allies
MI –	mental illness
OCD -	obsessive compulsive disorder
PE -	physical education
PMR –	progressive muscle relaxation
PTSD –	posttraumatic stress disorder
TSY –	Trauma-Sensitive Yoga
WTP –	Workman Theatre Project

## **Chapter 1 - Introduction: Mad Theory, Performance, and Mad-Accessible Movement**

### **Practice**

This work is a series of Mad episodes in a cycle. This cycle is one of making Mad homes, in our bodies and our worlds. It is one of holding our trauma and darkness and sharp edges gently, preciously, because it is the sand and layers upon layers of nacre that make the pearl. It is one of calling us in, to new relations with madness, trauma, anti-pathologization, multiplicity, artful living, participatory connection, and invitational engagement. It is one of shaping spaces, of making space. My dear friend Nathan, a collaborator on one of these episodes and one of the guardians of this cycle, asked me this: “Did you know that those physics people have found evidence of life in the vacuum of black holes in outer space? Of course you did.” This work is made of this same stardust. It is the flickering life in the vacuum of a star’s death, the ‘you belong here, even when you don’t feel you belong elsewhere,’ making spaces for survival and flourishing (which includes spaces for dying, or wanting to die, knowing death and life are not so far apart). This cycle is also, above all, a love story. A love story to myself, and to my communities, and to all of the thinkers and makers and doers that have come before, are here now, and will join in the future. Perhaps you will find a home or two here as well. Welcome.

In this cycle, I write of both beautiful and hard things. I must tell you about what I am writing about, so you can consent to reading it. I do this as intentional access practice, in line with a number of critical disability scholars calling for content or trigger warnings as a trauma-related access need, and a matter of consent (Carter, 2015; Clare, 2017; Kafer, 2016). I will be discussing mental illness, mental distress, and trauma in a variety of forms. I will talk about psychiatry, psychiatric violence, pathologization, sanism<sup>1</sup> and suicide. You or someone you know likely has experience with at least one of these things. I want to honour that you have

developed coping strategies that work for you– I trust deeply that you know best how you take care of yourself. If you need to stop reading at any time, please feel free to do so, and if you need to debrief this information with anyone, please do so, as I have surely done so in writing this.

This research-creation cycle takes place at the nexus of madness, performance, and access. I come to this research with investments. I experience madness, I am psychiatricized, and I access mental health services. My experiences of madness are interwoven with experiences of homophobia, heteronormativity, classism, and sanism. I have been asked numerous times if I was manic by family, friends, and psychiatrists: when I was a ‘bad wife,’ when I am ‘bossy,’ when I ‘take on too much,’ when I wear red lipstick, and when I begin a queer relationship. I grew up poor enough that fresh fruit and vegetables were a treat, too poor to afford dance classes, and yet I now have access to post-secondary education. I have been denied accommodation within my professional occupational therapy program, and had to advocate for myself when I was forced to withdraw from the program. I have been protected from full institutionalization, in part because I am racialized as White, and in part because I have come to engage with mental distress from a social and political perspective. I am constantly learning what it means to embody madness. In the midst of all of this, I am just learning about what it means to politicize madness.

I am a scholar, an artist, and an integrated dance practitioner. In my masters’ research, I collaboratively co-created a research-based dance about how social justice is practiced and performed within my integrated dance community. Partially because of my own Mad subjectivities, I erased madness (my own and likely others) from this project. I told myself I didn’t want to take up too much space. In this doctoral project, I take the time and space to explore madness and performance: both by interrogating my own experience, and by collectively engaging and creating with others who experience madness.

Loveless (2015) urges us do research in order to “tell stories-that-matter,” and that to do so, we must “ask, when examining our research practices: which stories animate us, and why?” (p. 54). I came into this doctoral project driven by three interrelated and inseparable questions that animated me, occurring at the nexus of madness and performance. How might Mad politics and Mad activism be engaged and enacted through dance? How does one perform Mad dance and Mad aesthetics? How do I develop more Mad-accessible dance/movement practices and environments? I delve into each of these questions through the methodology of research-creation. Drawing together and blurring the boundaries of research and artistic practice, research-creation enables me to engage simultaneously with the political, aesthetic and practice-based investments that drive this project.

In doing this work, the stories that animate me have been shifted and layered. As I will discuss in my collaborative creation chapter, I have moved away from examining dance specifically, to think and do performance more broadly. This shift echoes through my work on Mad autoethnography and trauma-informed practice: all of these chapters are animated by a wider range of performance and movement practices than dance alone can encompass. I also began by engaging with stories of madness, and over time my work has become layered with stories of trauma as well. My autoethnographic and collaborative creation work drew my attention to trauma in a number of ways, including that: trauma is individualized and pathologized via psychiatric systems and knowledges; some of my research-creation collaborators identified more with surviving trauma than with ‘mental illness’; and that trauma and madness are intimately interconnected, and can be thought together socially and politically. Further, weaving trauma and madness together has been generative, particularly in terms of how madness and embodiment relate. Thus, in my last two chapters, trauma comes to take center

stage. In my two chapters on trauma-informed movement and physical activity, I have also come to imagine Mad access to include considerations of trauma, and access to movement practices and environments that are not only anti-oppressive, but also radically trauma-informed.

This dissertation consists of chapters on research-creation methodologies, Mad autoethnographic episodes, collaborative *Mad Home* creation, and radical anti-oppressive trauma-informed practices that facilitate access to movement and physical activity. To set the stage for these chapters, this introduction engages with scholarly, artistic, and activist literature around Mad studies, madness and performance, and adapted physical activity (APA). I will begin by outlining the academic and activist field of Mad Studies. Second, I will discuss how madness has been taken up in performance, ending with some considerations around Mad performance and aesthetics. Third, I will briefly discuss approaches to ‘mental illness’ within the field of Adapted Physical Activity (APA), as well as the potential offered by drawing together madness, trauma, and APA: the potential to inform the development of more Mad-accessible and radically trauma-informed physical activity and movement practices and environments.

### **Mad Studies**

Mad Studies is an umbrella term used to describe a nascent field of inquiry lead by activists, academics and critical practitioners who have experience being diagnosed and/or treated within the psychiatric system (Diamond, 2013; Gorman, 2013; Menzies, LeFrançois, & Reaume, 2013). As Menzies, LeFrançois and Reaume (2013) argue, it is:

a project of inquiry, knowledge production, and political action devoted to the critique and transcendence of psy-centred ways of thinking, behaving, relating and being.... [It] is an interdisciplinary and multi-vocal praxis... tak[ing] as its principal source, inspiration, and raison d’etre the subjectivities, embodiments, words, experiences, and aspirations of

those among us whose lives have collided with the powers of institutional psychiatry. (p. 13-14)

In other words, like this research-creation project, Mad Studies brings together political action with interdisciplinary knowledge production in a way that centers the experiences of those who have been psychiatrized. In other words, “to take up ‘madness’ is an expressly political act” (Menziés, LeFrançois, & Reaume, 2013, p. 9-10).

Mad Studies demands a critique of “psy-centred ways of thinking” (Menziés, LeFrançois & Reaume; 2013; see also Diamond, 2013). Gorman (2013) argues “Mad Studies takes social, relational, identity-based, and anti-oppressive approaches to questions of mental/psychological/behavioural difference, and is articulated, in part, against an analytic of mental illness” (p. 269). Thus, authors critique medical, psychological, and psychoanalytic engagements with ‘mental illness’, and explicate socio-political, socio-historical, and activist engagements with the production and treatment of those deemed ‘mentally ill’. In this regard, many Mad Studies scholars and activists have borrowed significantly from Foucault’s (1969, 1979, 2003, 2006) critiques of psychiatry (Adam, 2014; Crossley, 2006; Finkler, 2013, 2014; Martin, 2009; Morrow, 2013; Parker, 2014; Poole & Ward, 2013; Rembis, 2014).

### **Mad Studies and Foucault**

Menziés, LeFrançois and Reaume (2013) articulate a number of ways that Mad Studies continues to draw on Foucault. They argue, for example, that there is a “need to engage with structural contexts and relations of power within which Mad subjectivities, embodiments, experiences and engagements play out” (p. 15-16). Relations of power, within the psychiatric system and beyond, are central to the constitution of a Mad subject. Foucault (1982) argues that “something called Power, with or without a capital letter, which is assumed to exist universally in

a concentrated or diffuse form, does not exist. Power exists only when it is put into action” (p. 788). What is crucial here, for Foucault, is that power is not something that can be possessed. It exists only when one acts in relation to another’s actions. “What defines a relationship of power” for Foucault, “is that it is a mode of action which does not act directly and immediately on others. Instead, it acts upon their actions” (p. 789). For example, I am in a relation of power with my psychiatrist, in that I have a range of possible actions in which my psychiatrist intervenes. In this relationship of power, I can act in a number of ways in relation to the actions of my psychiatrist. When I am prescribed medication, I can fill my prescription, throw it away, sell the drugs, etc. However, my possible actions are delimited and influenced by how my psychiatrist will act if I do not take my medication as prescribed, such as refusing to see me or having me involuntarily committed. Likewise, my psychiatrist has a range of possible actions, defined and delimited by numerous forces including their professional education, the healthcare service organizations that employ them, and their relationships with drug manufacturers. Foucault argues that:

in itself the exercise of power is not violence... it incites, it induces, it seduces, it makes easier or more difficult; in the extreme it constrains or forbids absolutely; it is nevertheless always a way of acting upon an acting subject or acting subjects by virtue of their acting or being capable of action. A set of actions upon other actions. (p. 789)

Understanding power as relational within Mad Studies opens up space for both critique of, and resistance to, the range of ways that psychiatric systems influence and constrain the actions and lives of people who are deemed ‘mentally ill.’

“Psychiatric power is that supplement of power by which the real is imposed on madness in the name of a truth possessed once and for all by this power in the name of medical science, of

psychiatry” (Foucault, 2003, p. 133). In other words, our current ‘truth’ about madness is produced through dominant psychiatric knowledge (Foucault, 1969; 2003). Psychiatrists are implicated in the production and reproduction of psychiatric knowledge, and vested with expertise through this knowledge (Foucault, 2003). Therefore, the ‘truth’ about (a Mad) me can be proclaimed and taken seriously to a far greater degree than what I might say about myself. The psychiatrist can diagnose me with a psychiatric condition, and I cannot do the same for them (nor for myself). The psychiatrist can write me a prescription that I cannot write myself. The psychiatrist can deem me non-compliant and can threaten me with involuntary confinement if I do not take these medications. The ways in which the psychiatrist can exercise power by acting upon my actions is greater than the ways I can act in return. The ways in which the psychiatrist constructs and employs psychiatric knowledge, and exercises power from this position of expertise created through psychiatric knowledge, shapes how I can act and how others act in relation to me. Psychiatric knowledge and psychiatric power shape truths about me, and thus further structures my “possible field of action” (Foucault, 1982, p. 790).

Reciprocally, Foucault (1982) draws on struggles against psychiatric systems directly when suggesting that “in order to understand what power relations are about, perhaps we should investigate the forms of resistance and attempts made to dissociate these relations” (p. 780). Engaging with Mad scholarship and activism, thus, offers us a way to better critique, and therefore act in relation to, psychiatric power relationships. In response to psychiatric power and the deployment of psychiatric knowledge and ‘truth’ that constitutes, in order to constrain, Mad subjects, Menzies, LeFrançois and Reaume (2013) argue that “practitioners of Mad Studies are concerned with deploying counter-knowledge and subjugated knowledge as a strategy for contesting regimes of truth” (p. 14). Subjugated knowledges, for Foucault (1976), include

knowledges that have been hidden or disguised by progressive, linear, unified historical accounts. They also, importantly for Mad Studies, include:

a whole set of knowledges that have been disqualified as inadequate to their task or insufficiently elaborated: naive knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity... unqualified, even directly disqualified knowledges (such as that of the psychiatric patient...) ... it is far from being a general common sense knowledge, but is on the contrary a particular, local, regional, knowledge, a differential knowledge incapable of unanimity. (p. 82)

The knowledges of psychiatrized people have been subjugated, in part because they have been constructed as unreasonable and incapable of insight (Foucault, 1969; 1976). One project of Mad Studies, and this research, is to excavate and honour the diverse subjugated knowledges of people who have been psychiatrized, and to challenge psychiatric and sanist assumptions and practices that undermine their knowledges. Engaging playfully, critically and artistically with our own subjectivities can be an important mode of resistance to dominant knowledges and power relations. “Maybe the target nowadays is not to discover what we are but to refuse what we are. We have to imagine and to build up what we could be... We have to promote new forms of subjectivity” (Foucault, 1982, p. 785). In the following sections I will briefly outline the overarching development, aims, and interventions of contemporary Mad-informed movements, each of which build up and promote diverse forms of maddened subjectivities. I will then discuss the specificities of various overlapping and divergent movements that are led by people who have been psychiatrized and can be articulated under the umbrella term “Mad”.

### **Mad Movements**

The academic field of Mad Studies is “inseparable from the far-reaching aspirations of

the Mad movement” (Menzies, LeFrançois, & Reaume, 2013, p. 13). Diamond (2013) suggests that:

this movement is made up of smaller political communities in different locations around the globe that come together on the basis of political orientation, priorities, experiences, identity, culture, and history... Each of these communities consist of people representing different backgrounds and experiences, but who share a common concern about how people who are defined as Mad within dominant culture are being treated, particularly under the current psy regime known as the ‘mental health system.’ (p. 64)

Contemporary western Mad movements began to take shape in the 1960s and 70s alongside various medical and societal developments, including: the rise of biopsychiatry (the pathologization of mental illness as a disorder of the brain, body chemicals, and other biologically-based understandings); the initial development of pharmaceutical interventions such as neuroleptics (the first generation of ‘anti-psychotics’); the psychiatric practices of involuntary confinement and treatment as well as electroshock therapy and chemical straightjackets; the ever-expanding diagnostic categories of the American Psychiatric Association’s *Diagnostic and Statistical Manual* (DSM); and the mass de/re-institutionalization of Mad people by moving them from asylums to hospitals and eventually to the community (where many were subsequently re-incarcerated in jails and other social institutions due to the criminalization of poverty and homelessness) (Crossley, 2006; Menzies, LeFrançois, & Reaume, 2013; Rembis, 2014). The movements that developed in reaction to these trends were also deeply influenced by psychiatric consumers/survivors/ex-patients, radical psychiatrists, Foucault’s *Madness and Civilization*, feminist critiques of the gender-biased nature of psychiatric diagnosis and treatment, gay liberation movements challenging the psychiatrization of homosexuality, and the

(re)emergence of self-help practices (Menzies, LeFrançois, & Reaume, 2013; Starkman, 2013).

The activists and academics involved in Mad Studies and Mad movements engage with madness on a number of fronts: by naming the violences that they have experienced in the name of psychiatric intervention; by launching critiques against psychiatry; by challenging the dominance of pharmaceutical companies and their collusion with psychiatric systems; by questioning and undermining the individualistic pathologization of mental distress and non-normative ways of knowing and acting in the world that have been labelled ‘mental illness’; by reclaiming their position of alterity as a generative and potentially desirable way of being; by (re)imagining what support can and should be for people in mental distress; by celebrating the unique culture, art, action and history that has grown from these above engagements with mental distress and psychiatric systems; and by connecting with and supporting other social movements that politically address issues of sexuality and gender identity, disability, racialization, colonialism, poverty, class, and age, among others (Beresford, 2013; Burstow, 2013; Menzies, LeFrançois, & Reaume, 2013; Reaume, 2002; Shimrat, 2013; Starkman, 2013). As I will detail in the following chapters, this research-creation work nurtures, and is nurtured by, many of these engagements.

The Mad movement in Canada was sparked in 1970-71 by Vancouver’s Mental Patients Association, a peer-led support and activist organization (Beckman & Davies, 2013; Menzies, LeFrançois, & Reaume, 2013). Reaume (2002) described the publication *In a Nutshell* as further documenting and disseminating the activist perspectives of Mad people in Vancouver since 1971 (see also Menzies, LeFrançois & Reaume, 2013). Toronto’s Mad movement followed, with the publication of the psychiatric survivor journal *Phoenix Rising* (from 1980-1990) and the development of Toronto Mad Pride (originally called “Psychiatric Survivor Pride Day”) in 1993

(Toronto Mad Pride, 2018). Moncton's *Our Voice/Notre Voix* began in 1987, and also offered an alternative, radicalized perspective on people's experiences with the psychiatric system. Today, arguably the largest centers of Mad activism in Canada exist in Toronto and Vancouver.

### **Mad Articulations**

There are numerous ways in which scholars and activists involved in the above movements articulate themselves, their experiences, and their movements, each of which signals a particular orientation to the social and political nature of mental distress and psychiatric service provision (Burstow, 2013; Menzies, LeFrançois & Reaume, 2013). Reaume (2002) points out that the nomenclature used within Mad movements over the past 40 years is evidence of an ongoing struggle over how to best represent a widely diverse set of experiences and politics. There is a multiplicity of ways that scholars articulate the breadth of these movements. For example, Crossley (2006) outlines five distinct social movements that have comprised the collective resistance of people affected by the mental health system in Britain, including: a mental hygiene movement; a civil rights movement; an antipsychiatry movement; a patients/users/survivors/Mad movement; and a movement representing "the interests of families of 'the mentally ill'" (which tends to support quicker diagnosis and treatment, and is often in conflict with most of the above movements) (p. 5). Likewise, Diamond (2013) outlines three main (sometimes overlapping) constituencies in the Toronto community of activists, including: "the psychiatric survivor constituency, the Mad constituency, and the antipsychiatry constituency" (p. 65). Reaume (2002) details a complex lineage of nomenclature that has been employed by both medical professionals and activists, and explicates the implications of this nomenclature for different movements' politics and actions. Further, Burstow (2013) offers a detailed reflection on the political implication of the choice of words employed by specific

movements, and explicitly differentiates between psychiatric terms (used by both medical professionals and the general public), refusal terms (largely used by antipsychiatry movements) and reclaimed terms (often used by Mad movements). There are both significant tensions and allegiances amongst the various camps of people associated with critiquing psy-knowledges and psychiatric systems, as well as reimagining mental distress. These terms matter; most of them have been deliberated and consciously chosen by members of particular movements in order to “reshape both popular language and attitudes to a point where we see someone with a psychiatric history as being a person rather than a label” (Reaume, 2002, p. 425). Burstow (2013) argues, “simply by how we speak...we are either tacitly upholding or undermining psychiatric rule” (p. 82). However, Menzies, LeFrançois, and Reaume (2013) argue that:

without downplaying the very real differences in identities, political values, and forms of expression that mark (and sometimes set apart) the many strands of antipsychiatry, critical psychiatry, mental patients’ liberation, psychiatric survivor activism, and Mad pride, local and global mobilizations for psychiatric citizenship and social justice in mental health have evolved into a dynamic social movement that is unquestionably here to stay. (p. 8)

In the following section, I will outline some of the major terms employed by the numerous overlapping strands of this social movement, in an effort to contextualize these strands of the movement further and to delineate my own position in this project.

**Ex-inmates/ex-patients.** The term ‘inmate’ is rooted in an understanding of asylums during the late 19th and early 20th century as no different from prisons - a place to confine the undesirables of society (Crossley, 2006; Reaume, 2002). With the rise of medical authority over psychiatric conditions in the early 20th century, the term ‘inmate’ for people confined to asylums

was eventually replaced by medical practitioners with the term 'patient' as the nature and intent (and the desired public perception) of asylums shifted to more closely approximate hospitals (Reaume, 2002). The term 'ex-patients' was used initially as a way to self-identify as having a history of being a mental patient in order to destigmatize this experience. Often 'patient' is articulated in quotation marks to demonstrate that it is a contentious term laden with medical connotations (Burstow, 2013). However, some activists felt this term was not militant enough and maintained too strong ties with the psychiatric systems in which they encountered violence. Activists chose to use the term 'ex-inmate' in order to highlight the ways in which 'mental health' institutions continue to operate like (and collude with) prison systems, specifically in their ongoing acts of involuntary confinement and 'treatment' (Burstow, 2013; Reaume, 2002).

**Antipsychiatry movement.** Proponents of the antipsychiatry movement explicitly reject the medical/psychiatric notion of mental illness, refuse diagnostic labelling, and focus largely on dismantling the psychiatric system (Burstow, 2014; Crossley, 2006; Reaume, 2002). Diamond (2013) articulates that:

the antipsychiatry constituency is based on a rich history of resistance efforts led by ex-patients, ex-inmates, psychiatric survivors, academics, and professionals... The primary goal... is to abolish institutional psychiatry, or at least undermine the power and authority it is granted in large part by the state... it is open to all people who are interested in undermining psychiatric dominance and included both those who have been psychiatricized and those who have not. (p. 66-67)

The term 'psychiatrized' points to the process by which people are constituted as psychiatric subjects through the medical system (Reaume, 2002). Diamond (2013) argues that this alliance, between those who have been psychiatricized and those who have not, is regarded as a potential

site for opening up critical analysis about the ways in which psychiatric dominance affects all people. Antipsychiatry critiques have not only been launched by those who have been psychiatrized, but also by psychiatrists (Menziés, LeFrançois, & Reaume, 2013), nurses (Adam, 2014), academics (Beresford & Menziés, 2014), and mental health workers (McKeown, Cresswell, & Spandler, 2014). For antipsychiatry activists, the critics from within the systems of psychiatric knowledge (re)production are valuable allies in the goal of psychiatric abolition. Antipsychiatry activists such as Burstow (2014), Kirby (2014), and Rembis (2014) also argue that there are critical links between psychiatric abolition and prison abolition, and Burstow (2014) puts forth an attrition model of psychiatric abolition — focused on slowly wearing down the psychiatric system with the ultimate end goal of totally dismantling it — that draws directly from the work of prison abolitionists.

Diamond (2013) outlines some activists' critique of antipsychiatry movements, including: striving for 'unrealistic' goals of eliminating psychiatry; negating positive experiences people have had with psychiatric support services; and placing the blame on psychiatric systems for the oppression experienced by psychiatrized people, which can ignore other ways that people are discriminated against. Further, scholars such as Minkowitz (2014) and Withers (2014) critique antipsychiatry activists for their rejection of disability-related labels, and thus their distancing from disabled people and disability rights movements. At the same time, radical anti-psychiatric activists do acknowledge that the immediate destruction of the psychiatric system would leave many people without any form of support — including social assistance, employment, housing and education supports that require one to have a psychiatric diagnosis in order to access them (see Burstow, 2014; Diamond, 2013). These activists engage in nuanced reimagining of social structures that would enable these forms of support to be available without the necessity of

psychiatric intervention.

**Mental health consumer.** The term ‘consumers’ began being used by mental health professionals in light of the activist backlash against the term ‘patient’. Its ties to “North American capitalist systems of a consumer society and the prospect of choice” were attractive to professionals promoting their services (Reaume, 2002, p. 418). The focus on choice and autonomy in accessing mental health services aligns with early activist demands (Reaume, 2002). Further, Diamond (2013) argues that some view the consumer movement as an opportunity to be involved directly in, and be paid for, the work of instituting policy change within government and psychiatric systems. However, some psychiatric survivors and politicized people within the Mad movements are suspicious of how this term has begun to be co-opted by psychiatric systems, service providers, and governments, who claim to be attending to the demands of psychiatric survivors and providing choice while maintaining the status quo of psychiatric intervention and violence (Burstow, 2013; Diamond, 2013). “By using the word ‘consumer’, we are upholding the regime’s pretense that there is real choice in the system” (Burstow, 2013, p. 87). Further, Menzies, LeFrançois and Reaume (2013) argue that Mad Studies must “take account of the many mutual affinities between neoliberalism and biogenetic psychiatry” (p. 13). The ways that ‘consumer’ movements are complicit in neoliberal systems and the individualization of mental distress has resulted in many activists and scholars rejecting the term in favour of other articulations of their experiences (Burstow, 2013).

That said, some people desire to identify as consumers, especially those who do not align themselves with a more politicized agenda, as well as people who desire to access and reform medical-model-based psychiatric services from within (Diamond, 2013; Reaume, 2002). Alternatively, some people who resonate with medical understandings of mental illness draw

from person-first language advocated by some disability scholars, preferring to be identified as ‘a person with a mental illness’ or ‘a person with a psychiatric disability’: The latter of which highlights the importance some scholars and activists place on developing allegiances with other people who experience disability, and pointing to the social nature of inclusion and exclusion (Kirby, 2014; Minkowitz, 2014; Poole & Ward, 2013; Reaume, 2002). Reaume (2002) also suggests that people who identify as ‘consumers’ are more “inclined to regard their mental health condition as a disability due to organic causes and thus turn to mental health professionals for treatment” (p. 421). This is in comparison to people who identify as ‘survivors’ who would more likely regard themselves as having a mental disability only as a result of the iatrogenic (illness induced by medical intervention) side-effects of electro-shock, lobotomy, and overmedication (Withers, 2014).

**Survivor.** The term ‘survivor’ was employed initially by antipsychiatry activists in reaction to the term ‘consumer’: as a way of (re)centralizing the experiences of violence many activists had in their encounters with the psychiatric system (Reaume, 2002). Using this term represented antipsychiatry activists’ rejection of medicalized notions and treatments of mental illness, in favour of community-based, survivor-run alternatives. More recently, according to Diamond (2013), the term ‘survivor’ has come to be used less by antipsychiatry activists and more broadly by those with experience of the psychiatric system:

Psychiatric survivor initiatives tend to prioritize connecting people who have experienced the psychiatric system and improving the conditions of their lives, alleviating pain and suffering, and finding ways to meet their needs. Peer support and consciousness-raising initiatives are seen as foundations of the community...there is also a major focus on curtailing forced psychiatric interventions, ending stigma and discrimination, and

creating accessible survivor-positive employment opportunities, affordable housing options, and other non-psychiatric alternatives. (p. 65)

Furthermore, ‘survivor’ is now being taken up not only as a way of signaling that someone has survived the psychiatric system, but alternatively, that they have survived mental illness (Diamond, 2013; Reaume, 2002). Reaume (2002) argues that some activists are cautious of using the term survivor, however, as it implies a degree of violence and threat that many people who have encountered the psychiatric system have not experienced. In an attempt to find a middle ground between antipsychiatry positions and access to treatment under medical models of mental illness, some people have begun to use the term ‘consumer/survivor’ or c/s/x/m (i.e., consumer/survivor/ex-patient/Mad) (Crossley, 2006; Reaume, 2002; Withers, 2014). However, Burstow (2013) argues that such hybrid definitions dilute the political stance behind the survivor identification, and have also been co-opted by governments and service organizations under the ruse that they are actively engaging with activist critiques.

**Trauma survivor.** Some people regard themselves as surviving psychiatric systems, some as surviving mental illness, and some as surviving trauma. Trauma and mental illness are not (necessarily) the same thing. However, Mad movements are concerned with the ways that mental distress is pathologized, and trauma-related mental distress is increasingly being pathologized through psychiatric diagnoses and psy-knowledges (Menzies, LeFrançois, & Reaume, 2013; Poole & Ward, 2013). For example, the new diagnostic category “trauma and stressor-related disorders” in the American Psychiatric Association’s (2013) Diagnostic and Statistical Manual DSM-V. Trauma and mental illness create a mutually reinforcing cycle: people who have experienced trauma are more likely to be diagnosed with mental illness (Brownley, Fallot, Wolfson Berley & Himelhoch, 2015; Vitriol et al., 2017) and people who are

diagnosed with mental illness are more likely to experience some forms of trauma (O'Hare, Shen & Sherrer, 2014, 2017). Shimrat (2013) argues that "I have yet to find a single person who did not enter the [psychiatric] system after some precipitating trauma" (p. 146), and this is specifically amplified when someone experiences other forms of oppression. As Gorman (2013) details, some racialized (and I would argue queer) people may disidentify with 'Mad identity' or 'mental illness' but may resonate with trauma, specifically when our understandings of trauma incorporate historical, intergenerational, and oppression-related trauma. However, the risk with 'trauma' is a slippage to considering it as a pathological individual response, devoid of the historical, social, and material conditions that (re)produce it, which opens us up to further therapeutic intervention, governance and violence (Gorman, 2013; Tam, 2013). As I will argue in two chapters on trauma-informed practice, I believe we can take an anti-oppressive Mad approach to trauma, in part by challenging the pathologization of trauma survivors, examining the historical, social and material conditions that differentially distribute exposure to trauma, and considering that Mad accessible practice includes radical anti-oppressive trauma-informed practice.

**Mad people.** Diamond (2013) suggests that the Mad constituency in Toronto evolved out of, and aligns with, the psychiatric survivor constituency. However, she argues, that "Mad is frequently used as an umbrella term to represent a diversity of identities... there is a common emphasis on the oppression faced by people who have been oppressed as crazy" (p. 66): this umbrella term has been used in relation to, for example, survivor, consumer, anti-psychiatry and neurodiversity<sup>2</sup> movements (Diamond, 2013; Menzies, LeFrançois, & Reaume, 2013; Richter, 2014). The inclusion of a diversity of identities under the term Mad is particularly appealing for this project, as it makes space for the people involved to conceptualize their subjectivities and

experiences in a variety of ways that include critiques of psychiatric systems, stigma, sanism, and other overlapping systems of oppression. In addition to the shared critique of psychiatric systems, Diamond (2013) makes a distinction between the survivor and Mad constituencies by noting “the shift from focusing on psychiatric oppression to the development of positive understandings of Mad identity and experience” (p. 66). Menzies, LeFrançois and Reaume (2013) argue that:

people in resistance against sanism and mind control have been invoking “madness” both as a means of self-identifying and as a point of entry into the fields of power where their encounters with organized psychiatry, and their very lives, play out. (p. 9-10)

In other words, madness can function as a means of asserting a liberal identity politics, and/or as a collective intervention into the broader relations of power that come to constitute the psychiatric subject. This project focuses significantly on the generative potentials of madness as a site of collective interventions and creations, and much less so on madness as an identity. At the same time, it is worth unpacking some of the pitfalls that are possible when employing madness to identitarian ends.

### **On Mad Identity**

It is not surprising that Mad activists have come to champion a Mad identity, given the long history of activist movements that have taken up identity politics in order to galvanize marginalized groups, to demand rights in relation to their struggles, and to promote positive perceptions of these groups in order to fight stigma (e.g., civil rights, gay rights, women’s rights and disability rights movements). While staunchly anti-psychiatry, even Burstow and LeFrançois (2014) argue that identity politics have significantly shaped psychiatric resistance movements, and “have an essential role to play” (p. 4). “We can draw on elements of identity politics,”

Diamond (2013) also suggests, “recognizing that an analysis of the everyday lived experiences of marginalized people leads to knowledge about systems of domination that shape all of our lives” (p. 74).

However, Burstow (2013) argues that one pitfall of taking up such politics is that Mad identitarian “discourse can easily slide into liberalism, displacing the structural”: that is, focusing on individual identity can shift focus away from the institutions and relations of power that construct people as Mad in the first place (p. 85). For example, Diamond (2013) suggests that an important aspect of the Mad constituency, in comparison to other constituencies, is that they place “a greater emphasis on exploring and celebrating individual experiences of madness” (p. 66). The celebration of individual experiences within Mad pride movements can center marginalized perspectives, but also runs the risk of depoliticizing the movement and making it vulnerable to co-optation by individualizing psychiatric systems and neoliberal discourses of personal overcoming. Further, centering identity politics that serve to simultaneously individualize and homogenize can create ever-smaller factions that become “exclusionary and internally hierarchical” (Tremain, 2001, p. 635). Burstow (2013) argues further that, Mad identity politics enables “the [psychiatric] regime in question [to] accommodate, provide space for celebration and consultation, offer minor concessions, and yet not appreciably change anything” (p. 85). In other words, by simply changing the tone and language of policies to be more ‘Mad friendly,’ and potentially seeking some consultation from psychiatrized people, psychiatric systems can appease identitarian demands without changing many of the structural systems that continue to subject, incarcerate, and inflict violence.

Along the same lines, Diamond (2013) argues that some antipsychiatry and survivor activists argue that identitarian perspectives, which are sometimes privileged within the Mad

movement, are often the “least disruptive to the hegemonic order, thereby further marginalizing critiques of psychiatry and other sanist institutions” (p. 70). Other activists articulate a resistance to Mad identity politics, stating that this approach runs the danger of essentializing madness and centering madness, thereby obscuring the multiplicity of processes by which psychiatrization functions in connection to gender, disability, racialization, class, and other axes of oppression (Burstow, 2013; Diamond, 2013, 2014; Gorman, 2013; Tam, 2013; Withers, 2014). In other words — as Diamond (2013) and Gorman (2013) both demonstrate in their research, outlined below — claiming a singular Mad identity has the potential to erase the complex and diverse ways that various subjects are more or less vulnerable to psychiatrization.

Based on a critical ethnography conducted with one Mad community in Toronto, Ontario, Diamond (2013) highlights how identitarian politics complicated community members’ shared desires to build stronger connections to other movements and “to develop more effective strategies for solidarity work” (p. 64; see also Beresford & Menzies, 2014; Burstow, 2014; Kirby, 2014). Diamond (2013) notes that:

many activists are concerned about the under-representation of certain groups of people at events organized for psychiatric survivors, Mad people, and antipsychiatry activists... Community members often pondered questions about why stronger coalitions do not exist among the various communities that are particularly vulnerable to psychiatrization... questions about identity and experience were front and centre in explorations of divisions among differently situated people. This is not surprising, given that identity politics have been a hotly contested area since this community came into being. (p. 68)

Within this community, identity politics served to faction activists and dilute their efforts.

Diamond (2013) also notes that in her experiences discussing psychiatric oppression with feminist and racialized women, many did not identify with the psychiatric survivor or Mad constituencies, centering their experiences of psychiatrization in a broader context of racism, sexism and patriarchy.

Gorman's (2013) work provides insight into Diamond's (2013) findings about a disidentification with the Mad movement on behalf of racialized and colonized women. Gorman (2013) argues that identitarian-based movements around madness have typically been constructed around a White Mad subject, wherein articulating a Mad identity is currently "a position of privilege" (p. 269). Specifically, in exploring which students identify themselves as Mad in university contexts, Gorman demonstrates that it is most frequently the White middle-class students who feel safe enough to articulate themselves as Mad and ask for accommodations based on this identification. She argues that constructions of an essential Mad identity neglect the ways in which racialized and colonized subjects are explicitly, implicitly, and unequally subjected to psychiatrization and psychiatric intervention (see also Burstow, 2014; Burstow & LeFrançois, 2014; Diamond, 2014). Gorman (2013) suggests that "challenges for Mad-identified activists includes: uncovering culture- and class-specific relations through which Mad identities emerge; and articulating solidarity with, and recognizing privilege in relation to, people who have complex, ongoing, and involved experiences of legislative, institutional, and carceral oppression" (p. 269). She highlights "the potential of anti-racist Mad subjectivities, and hazard[s] against the solidification of an 'essential' Mad identity" (p. 269). In other words, it is necessary to interrogate the ways in which Mad scholarship and activism neglect, reproduce, and collude with racist, colonial, ableist, misogynistic, homophobic and transphobic systems and practices (Daley, 2013; Gorman, 2013; Kirby, 2014; Tam, 2013; Withers, 2014). Importantly, also,

Gorman (2013) argues for the possibilities of mobilizing Mad activism around multiplied, socially constituted Mad *subjectivities* as opposed to a singular, essential Mad identity.

### **Post-Structuralist Mad Praxis**

Kuppers (2007) argues that “naming oneself part of a larger group, a social movement, or a subject position in modernity can help to focus energy, and to understand that solidarity can be found — precariously, in improvisation, and always on the verge of collapse” (p. 90). It is possible to align oneself with movements and subject positions in activist ways without necessarily ascribing to identity politics. Diamond’s (2013) “paradigm for anti-sanist community praxis,” offers a post-structuralist, non-identitarian, approach to madness that shaped my project. This author outlines a series of pragmatic guidelines for working with communities under the umbrella term of “Mad” (p. 73). Anti-sanist community praxis works to hold together the conflicts, tensions, and desires for solidarity that exist within and beyond Mad movements. The paradigm for anti-sanist community praxis, according to Diamond (2013):

rejects any universal claims made about Mad people or madness, recognizing that madness is constructed differently in various historical and cultural contexts, and that there is no real basis of inherent or natural characteristics that define an eternal Mad subject. (p. 74)

In other words, the ways that people understand and experience madness will be widely diverse, and by honouring the specificities and situated knowledges of these diverse orientations to madness we can work to undermine universalist claims. Further, by acknowledging that there is no eternal Mad subject, it is possible to make space for how identification is culturally produced and culturally productive.

Echoing Gorman (2013), I argue that identifying *with* Mad communities, politics and

aesthetics is a different theoretical and political act than identifying *as* a (essential, enteral, universal) Mad subject. Diamond (2013), similarly, suggests that:

many of those who identify with the term *Mad* hope to address some of the divisions stemming from psychiatric identity politics, to celebrate a *plurality of resistances* and subversive acts against sanism. The Mad constituency offers people places to connect in their resistance against sanism while decentering psychiatry and making space for divergent perspectives on the role of institutional psychiatry. (p. 69, emphasis in text)

Identifying *with* Mad communities, politics, and culture/aesthetics thus offers this project numerous important exciting opportunities, which I outline below.

First, identifying *with* Mad *communities* enables me to imagine and enact collective critiques across difference. It makes space, for example, for people (such as myself) to have conflicting and complicated interactions with psychiatric services (e.g., Antipsychiatry activists working alongside those who politicize psychiatric domination while still accessing services). Not only does it make space for differing perspectives on, and (dis)investments in, psychiatric systems, but actively holds space for everyone involved in the project to have diverse subjectivities and relationships to other overlapping systems of oppression. Diamond (2013) suggests that:

a starting point [for anti-sanist community praxis] is to emphasize a clear understanding that being psychiatrized, or being perceived as mental ill, has consequences in the world we inhabit that are often unjust and vary depending on one's economic and social marginality and privilege...putting some people at greater risk of violence and [further] marginality. (p. 73)

That is, psychiatric institutions and the sanist institutions and practices beyond formal psychiatry

“respond[] to people differently based on various dimensions of power” (p. 74). It is important to honour the complex ways in which people within my communities are unequally subject to psychiatric institutions. For example, women and gender-queer people are more likely to be psychiatrized (Daley, 2013; Kirby, 2014), and racialized and colonized people are more likely to be institutionalized (Gorman, 2013; Tam, 2013). Through this honoring, I can work collaboratively to build more expansive collective Mad knowledges that address multiple dimensions of marginalization, and thereby develop more far-reaching, nuanced, and relevant activist interventions with my community.

Second, identifying *with Mad politics* enables me to interrogate sanism as it functions both within and beyond psychiatric systems: within psychiatric hospitals and outpatient services, but also within education systems, immigration systems, carceral systems and in everyday relations with family and friends. Anti-sanist praxis “insists that resistance efforts are based in the recognition that all people are implicated in, and affected by, psychiatric dominance,” and requires us to be “highly critical of dominant constructions of *madness, normality, or sanity*, recognizing the flawed nature of simplistic dichotomous and oppositional constructions of difference” (Diamond, 2013, p. 74). To enact a Mad politic is, in part, to critique the socially constructed binaries of sane/mad and normal/abnormal — because it is precisely what is constructed as normal or sane that comes to constitute, and thereby justify punishment of, what is considered abnormal or insane. To do so, I draw from various above-mentioned Mad scholars, specifically those who are engaging critically with how the construction of normalcy and sanity is deeply intertwined with patriarchy, racialization and colonization (Diamond, 2014; Gorman, 2013; Mills, 2014; Tam, 2013). I also draw on disability studies critiques by Davis (2002; 2006), McRuer (2006), and Withers (2012), who interrogate the construction of ‘normalcy,’ ‘able-

bodiedness' and 'disability.' Identifying with Mad politics in this project challenged me to question how constructions of sanity/insanity and normal/abnormal are at work in my own movement and activist practices, and pushed me to enact anti-sanist praxis in both this research-creation process and my wider practice.

Third, identifying *with Mad culture/aesthetics* enables me the opportunity to create with the generative potential of Mad movements. Diamond (2013) argues that an important aspect of activists employing the term Mad is their emphasis on “developing Mad culture” (p. 66). Mad culture and Mad aesthetics are rarely defined by Mad scholars, so I borrow heavily from disability studies in my imaginings of what Mad culture and aesthetics can do. Disability scholars, artists and activists focus on the development of disability and crip culture, as a collective means of challenging the pathologization of their bodies-minds, and asserting the creative potential that emerges from commonalities in their experiences (Kuppers, 2003; Sandahl, 1999). Kuppers (2003) notes “disabled people use cultural interventions in order to subvert and query these meanings [of tragedy, loss and dependence associated with disability], and disability culture emerges as a counterculture” (p. 6). Just as disability culture has intervened in the narratives, meanings, and systems that constructed disabled peoples' lives, so too have Mad cultural interventions made shifts in the narratives, meanings, and systems surrounding madness (Diamond, 2013).

Further, disabled performers explore, develop and promote new aesthetics in their art practices and performances, contributing to both disability culture and mainstream culture (Fox & Lipkin, 2002; Smith, 2005). Fox and Lipkin (2002) argue that disability aesthetics cannot be separated from disability politics and communities, stating that disability aesthetics is “equal parts art and advocacy” (p. 82). Likewise, Sandahl (1999) argues that “exerting some control

over metaphorical representation in language, theory, politics, and artistic practice is a vital strategy for radical disability culture” (p. 13). Artistic practice, and the development of aesthetics, is an indispensable aspect of politicized disability culture, and Mad culture as well.

Aesthetics can be understood in two ways; relating to beauty (as in modern understandings of aesthetics), as well as relating to sensing, perceiving and feeling (Conrad & Beck, 2015). I am interested in madness in terms of both meanings of aesthetics: what is Mad beauty?; and what does sensing, perceiving and feeling madness do to our art/culture-making and to our subjectivities? In Canada, Decottignies (2016) credits Dr. Rachel Gorman for developing disability art techniques and aesthetics (in dance and theatre) that are “non-normalizing” (p. 45). Building from this notion, we might consider Mad aesthetics to be, in part, about non-pathologizing practices and representations.

### **Madness and Performance**

Scholarly writings about madness in performance have focused largely on madness in theatre (Bialo, 2013; Escolme, 2014; Harpin, 2014; Reuning, 2002; Wallin, 2013), and, to a lesser degree, dance (Ehrenreich, 2007; Green, 2000; McCarren, 1998). In relation to dance, McCarren (1998) argues that “images and conceptions of madness have arguably always been in the background of dance interpretation, and it is precisely this subtext that has lent dance the powerful social, cultural and political significance it has” (McCarren, 1998, p. 3). However, these writings are infrequently about performances by people who experience madness (for exceptions, see Johnston, 2010; Koppers, 2003, 2005; Tighe, 2014), and are often about presumed normative performers acting Mad (see Cox, 2014; Rudolph, 2014). We can consider writing on madness in performance as it relates to: medical performances of madness; representations of madness in performance; and performing madness against and beyond

medicalization/psychiatrization.

### **Medical Performances of Madness**

One way that madness and performance connect is within medical performances of madness, wherein madness is medicalized through performance, and performance reproduces and reifies medical understanding of madness. I will discuss two types of these performances: public performances that stage madness for general audiences, and private performances that occur within clinical contexts.

The most predominant figure in early public performances of madness is Jean Martin Charcot (1825-1893), a French neurologist who publicly displayed ‘hysterical’ women on stage and in photographs. Charcot explicitly cited physical symptoms such as vomiting, convulsions, fainting, and speech disturbances as the visible manifestations of neurological and psychological deficits (Kuppers, 2005; McCarren, 1998). These performances, and the work of Charcot and his student Freud, functioned to simultaneously: separate the mind from the body; make the workings of the mind visible on and through the body; and open up the mind as a site of medical intervention (Kuppers, 2005). Charcot used these performances as a part of his academic lectures with the “aim to fix a specific symptomatology, to make it visible and categorizable” (Kuppers, 2005, p. 148). It is this use of Mad performances — as a means of categorization and pathologization — that many Mad scholars and activists are working against.

Harpin and Foster (2014), Kuppers (2003; 2005), and McCarren (1998) all argue that vestiges of Charcot’s staging of the hysteric are still predominant in much of popular culture’s representations of madness. Kuppers (2005) argues that contemporary performances dealing with mental health issues hold the potential to reify the medical gaze and fix mental illness as an immutable, stable state of being (tragically unwell) — further stigmatizing Mad people and

further justifying medical interventions into their lives. Such stagings are not unlike other contemporary medical “freakshow” performances that continue to constitute many disabled people as medical subjects through, for example, documentary films and talk shows (see Clark & Myser, 1996; Snyder & Mitchell, 2006; Stulman Dennett, 1996).

The public displays of symptomology staged by Charcot not only impacted public perception of madness historically, but have come to influence the private performances of madness within psychiatric institutions today. Psychiatric systems have come to rely on ‘deviant’ performances, often based on reified symptomologies first produced by doctors like Charcot, to mark madness on the body. Wallin (2013) argues that “‘deviant’ performances of self in everyday life often mark madness in the first place, leading to stigmatization that creates alienation, discrimination, and the absence of support” (unpaginated). Not only are psychiatric professionals responsible for performative utterances that bring Mad subjects into being through diagnosis based on ‘deviant’ performances (Burstow, 2013), but Mad subjects must engage in particular kinds of medically-scripted performances in order to access psychiatric services while minimizing violences like institutionalization and electroshock ‘therapy’ (Budd, 2000; Koppers, 2005; Olsen, 2000).

Olsen’s (2000) tongue-and-cheek guide on how to perform madness appropriately for medical professionals highlights the extent to which these performances are privately staged both by and for psychiatry. The author touches on how to perform emotionally, intellectually, financially, psychopharmacologically, and in terms of demeanor, hygiene, eye contact, handshakes, and punctuality. This performance script functions as a way to ensure access to psychiatric service while avoiding direct psychiatric violence. These performance guidelines relate to interactions both within the psychiatrist’s office and within the hospital more broadly.

Speaking directly to Mad activism, Olsen suggests that Mad people “do let professionals know that you are socially engaged, when your condition permits, with other mad people. Not only does this confirm your malfunctioning, it cements it” (p. 63). Engaging politically is regarded as a symptom; it is illegible within an individualizing psychiatric framework. Olsen goes further in defining a satirical clinical performance script, suggesting that the reader:

never let a professional see you in a confident state. However, if you can't help yourself, make sure to overdo it so as to fit into one of the following categories: elation, mania or megalomania. These labels are handy when professionals are asked by benefits people what your problem is. (p. 63)

As Olsen (2000) suggests, this ‘private’ clinical performance is not only limited to the psychiatrist’s office, but is demanded in order to navigate other social institutions, social support networks, access to accommodations, and even intimate interpersonal relationships.

Kuppers (2005) echoes the need to navigate performances of madness in clinical contexts and beyond. The author writes on her experience with staging ‘invisible’ disabilities including mental health and pain issues, stating:

whether visibly impaired (as I am when I am using my wheelchair) or in a problematic relationship to visibility (with mental health or pain issues), disabled people are often asked to describe their experiences, and to open up their personal histories to both the medical gaze and public curiosity. (p. 147)

Her use of the phrase “in a problematic relationship to visibility” is particularly interesting in relation to performing madness. There are real privileges that come with the possibility of concealing disability to which people who are visibly disabled do not have access. At the same time, there are unique barriers involved in navigating the world with ‘invisible’ disability, such

as: the pressure to assimilate into assumptions about normative functioning; the difficulties of ‘coming out’; the burden of proof required to access supports, services and accommodations; and the complexities of performing disability legibly. Koppers (2003), in working together with performers “diagnosed with mental health difficulties” (p. 125), notes that the performers “all have experienced discrimination and, sometimes, violence. They are aware that exposing themselves, making their differences visible, can be a dangerous choice with harsh consequences” (p. 147). There are dangers to performing madness, especially within the historical and cultural contexts of psychiatric domination, but also considering the popular representations of madness in performance today.

### **Representations of Madness in Performance**

A great majority of writing on madness in performance is about representations of madness (Bialo, 2013; Escolme, 2014; Harpin, 2014; Koppers, 2010; McCarren, 1998; Oyebode, 2012). Medical models of madness, wherein deviance from ‘normal’ behaviours and experiences are categorized as disorder or illness, inform a large part of the representations of madness in popular culture and performance today (see Harpin & Foster, 2014; Reuning, 2002). This medicalization, combined with frequent performances of Mad subjects as spectacular, dangerous, murderous and obscene, often serves to stigmatize madness (Harpin, 2014; Harpin & Foster, 2014; Wallin, 2003).

The histories of public medical performances of madness (for example, the staging of hysteria) certainly influence the representations and interpretations of the Mad subject in contemporary performance. Though not the sole focus of this dissertation work, we can look to dance scholarship to unpack some of these representations and interpretations of the Mad subject in performance. Koppers (2010), for example, highlights that “the connection between [*Giselle*,

*Swan Lake*, and other] romantic ballets and psycho-pathological diagnoses are well-established in dance studies” (p. 202). Both Giambrone (2011)<sup>3</sup> and McCarren (1998) focus specifically on how hysteria is interwoven with dance performance. Giambrone (2011) traces the staging of hysteria — from the performances/presentations of ‘hysterical’ patients for medical and general audiences, to the presence of ‘the hysterical gesture’ in 21<sup>st</sup> century European dance-theatre. McCarren (1998) similarly argues that historically, dance, medicine, and madness have been intimately interconnected (see also Ehrenreich, 2007). McCarren (1998) charts how, in the 19<sup>th</sup> and 20<sup>th</sup> centuries, dance reflected predominant medical understandings of madness as well as providing commentary on these understandings. Focusing largely on the feminized catch-all category of hysteria in the 19<sup>th</sup> century, and the physical nature of its symptoms (which later became understood as an indication of underlying mental pathology), the author suggests that “hysterias have been understood to imitate dance, and dance has represented madness” (p. 24). Dance was not necessarily responding to specific medical theories, but instead to an overall culture of medicine. McCarren (1998) writes:

while not asking the same kinds of questions that medicine asked — which have to do with the cause, etiology, and treatment of disease — and not answering the questions it does pose in the same way, dance enacts ideas of how the mind controls the body, of how the body produces meaning without words, and of how those meanings can be decoded.  
(p. 14)

The moving body was understood as a window into the dancer’s mind, and madness — like in Charcot’s work — was understood as readable on the (dancing) body.

McCarren (1998) echoes Kupper’s (2005) argument that Charcot’s staging of hysteria served to fix a specific symptomatology of madness, such that it could be ‘known’ and diagnosed

on future bodies. Harpin and Foster (2014) concur, arguing that in popular culture and performance today “madness is not only visually [hyper-present and] exuberant in ways that Other its sufferers, it is readable and, by extension, knowable and diagnosable” (p. 4; see also Harpin, 2014). These authors argue that the presumed ability to know and diagnose madness as a result of (and within) popular cultural representations is troubling. Popular representations do very little to complicate the problematic narratives of madness as dangerous, terrifying, or tragic. Further, this kind of ‘knowing’ madness fails to question psychiatry (or in fact enacts a popular practice of psychiatry), and fails to bring depth and complexity to the lived experience of mental distress. For example, Reuning (2002) pathologizes a female character in the play *‘night Mother*, by ‘diagnosing’ her with depression. This author highlights the way that reading madness into this play shifts its meaning, rejecting scholars’ celebration of the liberatory nature of the suicide that ends the play — claiming, instead, that it is a depression-induced tragedy. Not only does this author take on the role of popular psychiatrist, but the author also serves to stigmatize madness in the process by reproducing the tragedy of depression. While scholars have read madness into performance texts, contemporary choreographers have appropriated and sensationalized Mad movement in their performance works. For example, choreographer Alain Platel appropriated movement vocabulary from early 19<sup>th</sup> century recordings of psychiatric asylum inmates (which were historically used, much as Charcot did, to diagnose psychiatric disorders based on physical symptoms) in order to explore ‘extreme’ emotions with his company of dancers (Cools, 2013). Madness is frequently stigmatized within performance, because it is a useful, sensational, narrative trope that does little to illuminate the personal, social, political and institutional complexities of people who experience what is deemed ‘mental illness’ (Harpin & Foster, 2014; Wallin, 2013).

Madness is often employed in performance as both “a private affliction and social metaphor” (Harpin & Foster, 2014, p. 6; see also Harpin, 2014). For example, McCarren (1998) notes that during the 19<sup>th</sup> and 20<sup>th</sup> centuries, (predominantly female) dancing bodies were often considered sick, and dance performances were “symptomatic of cultural tensions surrounding women, the body, and the body’s relation to the mind” (p. 13). Specifically examining *Giselle*, this author suggests that the ballet stages hysteria as an individualized gendered disease, while at the same time highlighting social tensions related to promiscuity, prostitution, and the medico-moral panic about the proliferation of syphilis. The complex interplays of madness with gender, sexuality and medicine are prevalent in the metaphorical use of madness in performance.

### **Performing Madness Against and Beyond Medicalization/Psychiatrization**

I am interested in how Mad performances can move against and/or beyond medicalization and pathologization of madness, while offering a political critique and cultivating Mad aesthetics. Wallin (2013) asks whether it is possible to address the ecological, social and political aspects of madness as an abject subject position — within performance — without interpolating oneself into medicalizing discourses of mental illness. Performances dealing with madness tend to ignore or discount perspectives that “assert that such experiences have intrinsic worth, despite or even because of the pain associated with such moments” (Wallin, 2013, unpaginated). This view of madness, as a potential site of valuable and worthwhile experience, is undoubtedly overshadowed by the predominance of medicalized, individualizing representations of madness in performance.

However, several scholars have argued that madness can be a site of creative, generative and artistic potential (Barnes & Schellenberg, 2014; Cvetkovich, 2007, 2012; Reville, 2013). This perspective is reflected in the mission statement put forth by The Icarus Project (n.d.), an

online community of Mad artists and activists:

The Icarus Project helps us overcome alienation and tap into the true potential that lies between brilliance and madness. We are members of a group that has been misunderstood and persecuted throughout history, but has also been responsible for some of the world's most extraordinary creations. Sensitivities, visions, and inspirations are not necessarily symptoms of illness, they are gifts needing cultivation and care. When honoured and nurtured, these gifts can lay the foundation for a wiser and more compassionate society. As a mutual aid community, we intertwine threads of madness and creativity to inspire hope and transformation in an oppressive and damaged world. (Vision, para. 2)

Politicized Mad performances, in other words, hold the potential to transform: to move beyond oppressive medical engagements with madness, addressing the difficulties, complexities and beauty of Mad subjectivities. However, Reid (2017) argues that:

often what is happening—with Mad art in particular—is that in the various place and spaces that engage with it, that nurture it, that program it and curate it and exhibit it, and take it up and take it back and appropriate it, is that the aesthetic value that is being highlighted time and time again is one of transformation. And this transformation is happening at a very surface level which just presents and re-presents mental illness to us. Specifically mental illness and not madness. So as a project, this Mad art, or Mad artists, are being positioned as a project to beautify, to clean up, and at best to address on an individual level, which really just continues to oppress Mad artists, because we're diagnosing, we're looking at treating, we're also policing and socially controlling them. And this disregards the histories of organizing and cultural production that are so vital to understand if we are going to actually move forward in a way to think through the

structural level and systemic level issues that Mad art and Mad artists can, and do, and are, engaging with. (final thoughts)

Centering an aesthetic of transformation, in and of itself, is not necessarily an act of radical Mad politics. It may, in effect, serve to reify psychiatric notions of mental illness and ‘recovery.’ However, with a mind to structural and systemic issues, and Mad politics, and Mad cultural production, and anti-sanist praxis, perhaps we can revel in aesthetics of Mad transformation(s). Much of this research-creation project aims to do just this.

A growing number of explicitly political performances by and about Mad subjects are being documented (see, for example, Canadian Broadcast Corporation (CBC) Radio, 2014; CBC Player, 2018; Diamond, n.d.; Johnston, 2010; Kuppers, 2003, 2005; Microscope Gallery, 2014; Tighe, 2014). I will detail four examples of such Mad performance— one about theatre practitioners, one about a performance artist, one about dancers, and one about a theatre artist/comedian — and discuss the tensions and possibilities within these performances that highlight important issues for my project regarding Mad politics and aesthetics. I have witnessed in person only one of these performances, so first three that I will discuss are based on writings about Mad-related performances.

**Joy. A Musical. About Depression.** Johnston (2010) highlights the development of *Joy. A Musical. About Depression.* by Toronto’s Workman Theatre Project (WTP). WTP has mounted numerous mental-illness related productions over the past twenty-five years, with this performance being their largest. This musical was produced in collaboration with WTP artists, many of whom have experienced psychiatrization, as well as with theatre professionals and consultants who have not been psychiatrized. The artists involved with WTP have diverse political perspectives, however many share a critique of medicalized notions of mental illness.

The intention of the musical was to “challenge stigma of mental illness, respect the voices of people who have experienced mental illness, innovate with new strategies for representing mental illness on stage, and engage the public in mental health issues and concerns” (p. 208).

WTP centers the perspectives of people who have experience with mental illness, but also sought to create a production that was targeted to mainstream audiences. Johnston (2010) notes that within this creation process, there existed “a series of tensions: an activist theatre seeking to reach the mainstream, a musical about depression which could not be depressing, and [the musical] theatrical form that created possibilities and challenges for the WTP’s artistry and public education aims” (p. 207). The artists intended to communicate activist perspectives, but desired to reach mainstream audiences, and thus sacrificed some of their situated knowledges. For example, Johnston notes that the artists were concerned that in one section of the musical they had introduced “gallows humour - a type of humour that they felt relied too much on personal depression experience to appeal to mainstream audiences” (p. 214). This begs the question: who is Mad art and culture for? I am also intrigued by the artists’ assertion that the musical not be depressing. Does Mad art need to avoid difficult affect in order to be palatable? Who are we protecting, and at what cost?

*Joy. A Musical. About Depression.* initially was written with multiple story lines which came to center around one doctor. This choice was rejected in the creation process, as artists found the multiple story lines confusing and were uncomfortable with forefronting the role of medical intervention in the experience of depression. Another aspect of this creation process by WTP is the early focus on the “prototypical ‘journey’” of taking psychiatric medications that framed the trajectory of the musical, which is said to have several discrete phases including personal crisis, accessing medication, side effects, extra-personal crisis in relation to how other

perceive you, and then a decision to stay on or stop the medication (p. 212). Examining three contemporary theatre texts (not related to this musical), Harpin (2014) argues that madness is also frequently represented in performance through spatial metaphor, such as those of journeys and dislocation. Mad scholar Tam (2013) similarly suggests that the metaphor of journey and dislocation are employed, beyond performance, within medical contexts (e.g., the journey to recovery) and even activist resources (e.g., “the off-road map to wellness” (p. 288)). Tam (2013) ties these spatial metaphors to colonial narratives of owning, traversing and mastering the land, suggesting that Mad activists (and I would argue scholars exploring madness in performance) need to be conscious of the ways that the metaphors they employ are complicit with colonizing practices.

Ultimately, the WTP musical came to center on a character who is a heterosexual, white, middle aged, upper-middle class woman experiencing depression. The production also included three additional sub-characters dealing with mental illness, each of whom represented a side-effect of anti-depressant medication experienced by the main character; fatigue, headache, and anxiety. “What appealed to company members... about this focus on an affluent character was that it reminded audiences of the prevalence of the illness and its disregard for class boundaries” (Johnston, 2010, p. 216). This choice should be examined critically, given Gorman’s (2013) critiques of the ways in which Mad movements tend towards forefronting essentialized White Mad subjectivities, as well as given the calls by Mad scholars to recognize how racialized, colonized, queer, trans, impoverished, and disabled Mad subjects are unequally subjected to psychiatric violence (Daley, 2013; Kirby, 2014; Tam, 2013; Withers, 2014).

Despite the centering of White upper-middle class subjectivity, Johnston (2010) suggests that the representational strategies used to stage madness in *Joy. A Musical. About Depression.*

are effective at offering a complex and nuanced look at mental illness. Johnston (2010) argues:

From more naturalistic representations of depression experience to... hyper-visual, hyper-present and hyper-embodied forms, the production mobilized a broad range of representational strategies, locating Joy's experience not in a single note, register, or colour but in this much broader range... Each of the individual representational choices in *Joy* may seem merely to reiterate longstanding madness clichés such as erratic behaviour, diminished affect, or slowed movement. However, by enlarging some elements and minimizing others, the effect was to destabilize any single representation and suggest greater complexity in depression experience. (p. 218)

In other words, by staging visual, aural, and affective registers that were complex, shifting, excessive and minimalist, WTP offers new ways — grounded in a form of Mad politics — of performing Mad aesthetics. Johnston's (2010) (re)presentation of this performance invites a number of considerations that informed my dissertation project, including: creating Mad performance that might be accessible to mainstream audiences (which was more so an element of my autoethnographic performances than of the collaborative creation of *Mad Home*), but without sacrificing Mad affects to make the work more palatable; engaging with intersectionality in Mad performance; and (re)presenting multiplicity and complexity in Mad performance work.

**Mad Meds.** Another interesting example of Mad performance is one by Marni Kotak. Kotak is a performance artist who embarked, in July 2014, on a six-week installation performance art piece entitled *Mad Meds*. Within this performance art work, Kotak withdrew from her psychiatric medication in a gallery setting. In an interview, she shares her experience of being hospitalized in a psychiatric ward postpartum, and being refused the opportunity to pump breast milk for her still-nursing child (Clifford, 2014). Kotak speaks of finding the Icarus Project,

and a number of other resources that suggest that psychiatric medication might be the problem — that they have iatrogenic effects that are more harmful than the experience of madness itself (Clifford, 2014). She notes that “our society has created this kind of medicalization of human existence where you feel a pain, or you have a bad thought - you immediately go to a pill” (Kotak, quoted in CBC Radio, 2014). In order to interrogate this hyper-medicalization, Kotak set up an installation that included video, photographs, sculpture, and mixed media works (including a cabinet of prescription bottles of all the meds she took, and an egg encasing all the meds she did not take). The installation also included a furnished bedroom with an elliptical trainer, as well as a doctor’s office waiting room, all coloured gold (Microscope Gallery, 2014). She also had a small collection of Mad Studies and anti-psychiatry books on display (Schwendener, 2014). As a part of this installation, she weaned herself off of her cocktail of psychiatric meds and spent the majority of her days journaling, working out, and meeting visitors in the installation space (Squier, 2014).

Kotak articulates that she regularly met audience members who attended her performance and who shared their own experiences with mental illness. She states:

close to 90 percent of the people who have come into this exhibition have sat on my bed, and I feel like I’m holding some kind of confessional. People are telling me about their own experiences with mental health struggles and medication (quoted in Squier, 2014, para. 10).

Both news article authors and Kotak frame this performance therapeutically, suggesting performance art has therapeutic benefits, and that there is therapeutic intention behind the performance (Clifford, 2014; Squier, 2014). Kotak states that:

part of this project is that I want to get other women who have had other experiences with

mental health issues to share their stories... Because I just feel like the world needs to hear these stories. And people need to be able to tell them and it needs to be safe. (quoted in Clifford, 2014, para. 14-15)

Drawing from a Foucauldian Mad Studies perspective, I am cautious of performances that necessitate or compel people to confess the ‘truth’ of their Mad experience, potentially essentializing madness and Mad subjectivity. One question that I ask is whether the intentionally therapeutic act of inducing people to share their stories of madness, within this performance work, is fixing (both in the senses of normalizing and stabilizing) Mad and sane subjectivities.

There have certainly been critical receptions of Kotak’s performance of *Mad Meds*. For example, numerous news articles on *Mad Meds* articulate a relationship between the performance and spectacle (CBC Radio, 2014; Munro, 2014; Squier, 2014). The authors argue that the performance may be sensationalizing and spectacularizing madness. CBC Radio (2014) writes that:

while there are concerns that *Mad Meds* may increase the stigma surrounding mental illness by making a curiosity out of it, or that it may be taken as a form of entertainment, Kotak says her intent is in fact the opposite. (para. 8)

Kotak argues that her desire is to open up dialogue on psychiatric medication, the psychiatric industry, and destigmatizing mental health issues, which she certainly did in the media about her performance at the very least.

At the same time, she notes a desire to “change people’s perceptions about what they expect when they hear that somebody has a mental illness” by presenting a “calm, and centered” way of engaging rather than presenting a spectacle (Kotak, quoted in CBC Radio, 2014). ‘Calm and centered’ is an interesting choice of words, words that are indicative of sanist assumptions

about what makes performance, and Mad performers, legible and valuable. Does a ‘calm and centered’ performance of coming off psychiatric medication destigmatize madness and critique psychiatry, as Kotak intends? Does it destigmatize madness, or perform sanity: destigmatizing madness only for those who can perform closest to a sanist ideal? Like the Workman Theatre Project’s desire to make a musical about depression that was not depressing, Kotak’s assertion about the importance of being calm and centered in her performance seems to support the notion that Mad performance must be palatable to sanist audiences to be capable of destigmatizing madness. This tendency is an example of Reid’s (2017) argument that efforts are made to “beautify, clean up, and at best address on an individual level” the experiences of ‘mental illness’ in art and performance. This move is also precisely counter to Gorman’s (as cited in Decottignies, 2016) “non-normalizing” disability aesthetics (which includes Mad and Deaf aesthetics). What gets lost when we work to clean up and normalize our Mad lives and Mad living? Big and weighty pieces of our selves, and our world-making, are at stake.

While I am cautious of some aspects of Kotak’s performance, she does offer a significantly politicized work, gaining media attention that forefronts antipsychiatry critiques. Further, while I am wary of the way that her audience members felt compelled to ‘confess’ their stories to potentially essentializing ends, I am also interested in how these acts (and the performance space itself) may have sparked politicized Mad community-building. Some of the research-creation practices for my own dissertation project are informed by Kotak’s performance, including: creating politicized participatory Mad performance; centering ‘Mad life-as-art’ practices; questioning the role of medication, psychiatry and therapeutic engagements within performance; and building Mad community through performance.

**Traces.** Petra Kupperts' (2003, 2005) performance installation *Traces* is also relevant to my project. Over four years, Kupperts worked with members of "Mental Health Day Care Services" in the United Kingdom, exploring dance, movement and theatre exercises in sessions held weekly for two hours (Kupperts, 2003). The primary aim of these sessions was not intended to be therapeutic, but rather artistic, although the movement practices explored did draw off movement therapy. Kupperts (2003) states that "at their core, our sessions had an *artistic* impetus that involved sharing the work, bringing the individual expression into the social arena, providing alternative visions of mental illness for society" (p. 124, emphasis in text). The author links the artistic practice of exploring Mad movement to a political practice of making the individual social, and offering alternative representations of madness.

Kupperts (2003) describes the creative process as being, in part, about recognizing how "the representational and social aspects of madness had affected the sense of embodiment of people diagnosed with mental health difficulties" (p. 125). The author clarifies:

By working with people in mental health settings, I soon realized ... many of my performers' physical experiences seemed to mirror their representational silence or distortion in the media. Some were people who found no space for themselves, their bodies, their movements in their social and physical environments. They were excluded from living alone, getting an apartment, leading a life free from constant contact with medical practitioners.... Their bodies could be invaded, as the law allows them to be drugged against their will.... This lack of physical and mental privacy had undermined many people's ability to be confident in their use of space. (p. 125)

In other words, the ways in which the psychiatrized people in this group experienced their bodies, their movement, and their capacity to take up space was significantly shaped by social

and medical discourses and practices surrounding madness.

Kuppers (2003, 2005) notes that considering these embodied experiences, many of the participants involved had a difficult time engaging in “centering exercises” — such as relaxation, visualization, and breathing exercises that are often explored during movement classes. She argues that this is because “some had fundamental difficulties asserting their physical space: standing still, breathing deeply, or allowing their voice to resonate” (Kuppers, 2003, p. 125). Following the discovery of this point of friction for many of the participants, the group embarked on an intensive investigation of meditation, visualization and relaxation exercises to explore and expand participants’ embodied experience of their own inner space. Kuppers notes that:

in these movement sessions, the political impetus consisted not of claiming roles in traditional theatrical formats but rather of claiming inner space. Work that happens at this initial level can eventually change the participants’ sense of themselves and, through this, power relations and representations in the larger social sphere. This appropriation and habitation of inner space is a way toward being wholly in the shared, social space. (p. 127)

In other words, coming to take up more inner space is a political act for Kuppers, in the context of this project.

Ultimately, Kuppers’ (2003, 2005) project resulted in *Traces*, an installation that was created over two years with the participants in the mental health day program sessions that Kuppers facilitated. This installation consisted of three video screens in a dark room, where spectators were invited to sit or lay down anywhere in the room. The audience had to navigate the space, finding that wherever they positioned themselves, their bodies were silhouetted on the screens. Projected on the video screens was footage of the project participants doing meditation

and relaxation exercises, their focus drawing intensely inwards. The choice to do a video installation for *Traces*, rather than a live performance, was made in part because of a situated concern from the members of the group. Kupperts (2005) notes:

my performers were aware of the social status of their specific physicality, and they do not wish to expose themselves to stressful situations that can induce and exacerbate these ‘symptoms’ [of partial limb paralysis, speech disturbances, vomiting, dissociation], including conventional live performances. Having been taught that these behaviors are unsightly, they do not wish to be seen in ways that allow their bodies to be read for ‘symptoms’ of mental health issues. (p. 153)

Instead, the performers were presented in disjointed video footage, some footage tracing limbs, or hands, or torsos. A voiceover spoke a relaxation journey, inviting the audience into the experience of exploring inner space. The choice, in *Traces*, to represent movement through a video installation that mediated the performers bodies in time and space demonstrates an important way that this project navigated the concerns expressed by performers. These concerns about live performance, and the performers’ reservations about how their bodies would be read for signs of madness, are important considerations for my project as well.

What is particularly interesting to me is that Kupperts’ movement-based work on madness does not overtly or explicitly relate to people’s involvement with, and resistance to, psychiatric systems (in comparison to the Workman Theatre Project or Marni Kotak’s work). It focuses instead on embodied movement experience. I am excited by this performance work on madness, which explore ideas and experiences beyond that of interactions with psychiatric systems. At the same time, Kupperts’ work has some inflections of therapeutic engagement within the movement practices described that are less present in the other works. Does movement-based work

exploring Mad embodiment need to be about self-improvement? Can political work be done around Mad embodiments without falling into the trap of therapeutic engagement or personal development? As I will discuss in my *Mad Home* chapter, my collaborators challenged and complicated these questions as a part of our own research-creation work. Further, Kupperts' (2003, 2005) work invited additional considerations for this dissertation project, including: centering Mad embodied experiences, encounters and expressions in and through performance; thinking of Mad performance beyond physical presence onstage; forefronting collaborators' desires regarding how they would like to embody performance; and taking up space as a political act.

**CERTIFIED.** I have had the fortune of working with JD Derbyshire for the past two years, and have had the pleasure/pain of witnessing their solo show CERTIFIED in Calgary in March 2018. Among many other things, JD is a comedian, playwright, and multi-disciplinary theatre artist who works in the realm of inclusive design and co-created participatory performances. CERTIFIED invites us to:

join the irreverent fun in this hilarious & heart-aching romp, as comedian & certified insane person Jan Derbyshire turns the audience into a mental health review board to help determine her current state of sanity. Come humorously grapple with hefty questions like: What's crazy? What *isn't* crazy? Who decides? In this comic case, you do. (Global News, 2018, para. 1)

Weaving trauma, queerness, gender, gender-based violence, experiences of psychiatrization and mental distress, this work implicates the audience in the production of Mad subjects and destabilizes our relationship to questions about sanity and insanity. Derbyshire notes:

there are a lot of stories missing in the mental health canon and a few that really get told

over and over again, either the tragedy and/or how hard it is to love somebody with a mental illness – those are the two super overdone ones. Those stories exist, but so do many others. (Quoted in Watson, 2018, para. 7)

Derbyshire labours to tell other stories, and these stories are expansive, uncomfortable and exceptionally beautiful.

I sat in the audience, and while at times troubled by what the rest of the audience was making of this experience (we laughed at very different things, and the pitying groans and affective celebration of what some might read as an overcoming narrative were palpable at points), I also found a breath-taking, gut-wrenching home in the stories being told. I have never in my life experienced such exquisitely Mad performance, with depth and insight cultivated through intersectional analysis of interlocking systems of oppression, and it was absolutely world-making for me. Their work, to me, is proof that our Mad gallows-humour is vital to making home with Mad audiences, and can also be accessible to mainstream audiences, if done well. Derbyshire argues:

you have to have people that understand or even people who have gone through it themselves, some sense of community ... because part of the show is about reclaiming our full spectrum of emotions. All of our behaviours are getting pathologized: if you're too happy, if you're too sad, if you're too excited, if you're too full of grief it all gets put into a diagnosis now and it's like, 'Wait a minute, we've got to speak back to this because we are deeply feeling creatures.' (Quoted in Watson, 2018, para. 9)

Through this performance and our time working together, JD has taught me about crafting brave space, about the vital necessity of sharing our humour and pain, and about being a deeply feeling creature in the fullest sense, as a way of Mad artful living.

## **Additional Considerations in Creating Politicized Mad Performance**

Mad performance scholars chart some additional important considerations about what might contribute to a political engagement with madness in performance. These considerations include creating art that: multiplies subjectivities; undermines the necessity to visibilize a Mad symptomatology on the body; avoids realism and questions reality; and demonstrates the hard and the beautiful aspects of madness while forefronting collective and communal engagement with madness. Each of these considerations have contributed to framing this research-creation dissertation. In the following section I will discuss each of these considerations.

**Multiply subjectivities.** McCarren (1998) — discussed above — charts how, in the 19<sup>th</sup> and 20<sup>th</sup> centuries, dance reflected predominant medical understandings of madness. She also, however, highlights how one famous dancer enacted resistance to these understandings. The author argues that Lois Fuller employed techniques (such as hypnosis and electricity) — used medically to “collapse multiple identit[ies]” within the “hysteric” — to the radically different ends of creating “multiple, multivalent performance identit[ies]” through dance (p. 25). Kuppers (2005) also advocates for this multiplication of subjectivities in radical political performances of madness. The author argues that Mad performances hold the potential to spark “unknowability and generative uncertainty... multiplicity and manipulation of meaning” (p. 148). Multiplying subjectivities in Mad performance means avoiding the creation of an essentialized singular (and palatable?) Mad subject in favour of complicated, complex, conflicting, expansive and always shifting selves. As I detail in my Mad Home chapter, this consideration was explicitly articulated to be of vital importance for the collaborators involved in this project.

**Undermine necessity to visibilize symptomology.** Kuppers (2003) argues that “performance work with people diagnosed with mental health problems has to deal with a history

of bodily staging, of recognized and (potentially rehearsed) performances” (p. 124). Mad subjects have come to be recognizable (in psychiatric offices and popular culture) through staged performances where a symptomatology of madness is visibilized on their bodies. The author goes further to argue it is possible to stage invisible disability (including madness) in ways that undermine the necessity to visibilize a symptomatology on the body, and thereby challenge medical and popular perceptions of madness. She suggests that some ways to undermine the necessity to visibilize symptomatology include: situating spectators as participants and performers; using multi-media that plays with performer presence and absence; and documenting the work in a way that does not allow the spectator to “get the bigger picture” (p. 158).

**Avoid realism and question reality.** Harpin (2014) argues against the use of realism in Mad performance, suggesting that:

realism is limited in its ability to capture unusual states of mind. I would contend, moreover, that a realist framework readily invited a diagnostic gaze in so far as it replicates dominant categories of normal and abnormal behaviours. This is not to suggest that realism is incapable of more complex expression; rather it is to suggest that when it comes to the staging of mental distress realism is problematic unless it argues against the logic of its own form. (p. 190)

‘Realistic’ representations of madness necessarily assume a singular reality — one in which madness is othered — which closes down the generative potentials of madness to depart from, problematize, and madden notions of reality. On the work of three playwrights, the author argues that:

all three... share a concern to amplify the instability of notions of reality. Their concomitant interest in the impermanence and constructedness of realities is alive with

political potential in so far as it signals an acute awareness of the ambiguity that lies at the heart of current notions of mental illness... Their departure from, and implicit problematizing of, 'reality' is marked in their dismantling of static, demarcated notions of space, place and the role of illness. (p. 188)

Playing with the distortion, disruption and problematization of reality is one way that Mad artists undermine static binary notions of normal/abnormal and sane/insane.

**Demonstrate the hard and the beautiful, and forefront collective engagement with madness.** Wallin (2013) argues, in his discussion of madness in performance, that performance can positively impact stigma and complicate representations of madness if it: critiques the practices of psychiatry; moves beyond medical understandings of madness to include social, political and institutional dynamics; acknowledges the potential of community solutions to madness; and offers a representation of the experiences of madness that holds together both the hardships and generative possibilities that these experiences entail. Cvetkovich (2007) would concur, suggesting that we must hold the hard and the beautiful together, that they are inseparable. In exploring depression as a public feeling, Cvetkovich argues that:

with depression and...utopia, [we have] not necessarily shifted topics or even affective registers—the point would be to offer a vision of hope and possibility that doesn't foreclose despair and exhaustion. It's a profoundly queer sensibility and one that...can enable us to tackle the work that needs to be done and to create the pleasures that will sustain us. (p. 467)

In other words, holding together the hard and the beautiful of madness is a necessary act to do political work while surviving and thriving. Mad performances that are critical, collective, and acknowledging of the difficult yet generative possibilities of madness, are much needed.

## **Madness and Access to Movement and Physical Activity Practices and Environments**

In addition to exploring what madness and performance can do politically and aesthetically, I am interested in how to madden movement and physical activity practices and environments. This interest is born out of my research in the field of adapted physical activity, and my practice-based experience in fostering accessible movement programs and communities. How might movement and physical activity practices and environments be exclusionary of people experiencing mental distress? Importantly, what shifts to movement and physical activity practices and environments might make them more accessible? I consider these questions in depth in my two chapters on radical trauma-informed practice, but will set the stage here regarding how the literature in adapted physical activity approaches mental illness and trauma.

Physical activity, including dance, has been utilized extensively as a physical and psychosocial therapeutic tool for people diagnosed with a wide variety of ‘mental illnesses’ (Barton, 2011; Emck, 2014; Harrold et al., 2018; Hearon et al., 2018; Karkou, 2006; MacDonald, 2006; Rahman, El Werfalli & Lehmann-Waldau, 2017; Röhricht, 2015), and increasingly in relation to post traumatic stress as well (Bourn, Sexton, Porter, & Rauch, 2016; Martin, Dick, Scioli-Salter, & Mitchell, 2015; Oppizzi & Umberger, 2018; Rosenbaum et al., 2015). This parallels the breadth of research on dance and other physical activity used as a therapeutic tool for people experiencing disability (Bunce, 2006; Cluphf, O’Connor & Vanin, 2001; Halabchi, Alizadeh, Sahraian, & Abolhasani, 2017; Johnson, 2009; Marks, 2005; Scharoun, Reinders, Bryden & Fletcher, 2014; Skou, Pedersen, Abbott, Patterson, & Barton, 2018; Tsimaras et al., 2010). This therapeutic use of movement and physical activity is overwhelmingly imposed upon the bodies of Mad and disabled *subjects* by non-disabled and non-Mad *experts*. For example, many disability dance scholars have articulated their disinterest in, or outright rejection of, dance

as a therapy (Benjamin, 2002; Davies, 2008; Smith, 2005). They argue that the dominant cultural focus on movement as therapy devalues disabled dancers' artistic and cultural contributions, as well as perpetuating the medicalization and normalization of disabled people. Disability (and integrated) dance scholars are more interested in increasing access to artistic and educational practices and environments (Aujla & Redding, 2013, 2014; Whatley, 2007; Zitomer, 2013), as well as investigating what disability aesthetics can bring to dance (rather than enforcing a normalized aesthetic onto disability) (Davies, 2008; Koppers, 2003; Smith, 2005). Aligning myself with these disability dance scholars, as well as drawing from the critical Mad scholars discussed above (Diamond, 2013; Gorman, 2013), I am not interested in using this project to pathologize or therapize people experiencing mental distress. I am interested in how we might create movement and physical activity practices and environments that are safe(r), more accessible, and less pathologizing, especially when we are experiencing distress.

Adapted physical activity (APA) holds the potential to offer some insights, as it is a field concerned with developing and implementing activity and environmental “adaptations that could facilitate physical activity across a wide range of individual differences”<sup>4</sup> (Reid, 2003, p. 22). I am invested in making an intervention into the field of adapted physical activity, in part because it is a field in which I work, and in part because conversations about how to mobilize physical activity and mental illness are emerging in the field at an increasing pace (at conferences, if not yet in publication). Currently, within APA, there is little written about ‘mental illness’, madness, or trauma. In a search of *Adapted Physical Activity Quarterly*, the flagship journal of APA, as well as the *European Journal of Adapted Physical Activity*, *Quest*, and the *Journal of Physical Education, Recreation and Dance*, there are only five articles that deal explicitly with participants who experience madness or mental illness.<sup>5</sup>

Two of these articles focused on the correlation between psychiatric conditions and decreased motor skills. Gruber, Hall, McKay, Humphries, and Kryscio (1989) found that there were significant motor proficiency deficits for depressed adolescent inpatients. Similarly, Emck, Bosscher, van Wieringen, Doreleijers, and Beek (2012) found that children who were classified as having gross motor delays were at significantly more likely to be diagnosed with psychiatric conditions including anxiety, autism spectrum disorders, and attention deficit hyperactivity disorder.

Not unlike dance therapy, two articles in APA make a case for the use of physical activity as a form of therapy to improve psychiatric symptoms. A literature review on the relationship between mental health and physical activity by Van Andel and Austin (1984) puts forth physical activity as a therapeutic tool, suggesting that physical activity improves stress, somatic anxiety (but not cognitive anxiety), body image, and self-concept. Similarly, Van de Vliet, Van Coppenolle, and Knapen (1999) found that psychomotor therapy (including power and endurance training) influenced fitness levels, but also perceived physical ability and body acceptance, in a group of adult psychiatric patients. The focus in APA literature on physical activity as a therapeutic tool to remedy mental illness is also reflected in the predominant focus of conference presentations I have attended on mental illness in physical activity at both *The North American Federation of Adapted Physical Activity* conference in 2017 and the *Qualitative Research in Sport and Exercise* conference in 2018.

One example of research in APA that more closely aligns with my questions regarding Mad accessible and trauma-informed practices and environments is an article by Gomes et al. (2014). The article is titled “A contribution designing effective and enjoyable physical activity programs for individuals with schizophrenia.” While this study measured the physical activity

levels and heart rates of nine participants, they also focused on determining the preferred activities as defined by these participants. This is the first article in APA that centered perspectives of people diagnosed with mental illness, with the aim to find out what they would like to do. Walking was determined as the “most effective” form of activity included in the study (p. 24), because it impacted maximum heart rate most, and thereby “promote[d] health benefits of enhancing muscular fitness” (p. 28). However, walking was the least preferred activity. Dancing activities were regarded as fun, but sometimes too difficult. Participants reported enjoying the ‘small sided games’ session most, which “consisted of: stretching experiences, small-sided games... of handball and soccer as well as basic skills (shooting, passing, dribbling), abdominal exercises and, breathing exercises” (p. 27). This is an important article because it centers perspectives of those diagnosed with mental illness, a rare occurrence in the current available literature. However, the language used continues to perpetuate representations of tragedy and lack: “one of the most debilitating diseases” (p. 24); “high morbidity and mortality” (p. 25), “lack of motivation” (p. 28). Thus, all of these articles to date focus on mental illness as medical or psychiatric pathology.

A total of eight articles in the identified APA journals discussed trauma, but the vast major addressed ‘traumatic brain injury’ or concussions (Driver, 2007; Kish & Koutures, 2016; Schmies, 2014; Self, Driver, Stevens, & Warren, 2013; White & Robinson, 2018; Zittel, 2004), or ‘vocal trauma’ in physical education students and minimizing vocal pathology in physical education settings (McCull & Trout, 2011). One article considered traumatic responses resulting from natural disaster, and positioned physical activity programming for elementary school children as a therapeutic tool for coping, as well as reducing stress and anxiety (Wahl-Alexander & Sinelnikov, 2013). This article is the closest to considering trauma and mental distress within

the field of adapted physical activity, but does so from a therapeutic standpoint rather than considerations for designing more accessible programming.

Another article, which was not featured in the above journals of adapted physical activity, but which does important work in relation to trauma in the field of APA, is an article by Day (2013). This article discusses Paralympic athletes who have acquired “traumatic disability” (p. 2064), and have also experienced posttraumatic growth in relation to their initial experiences of physical activity post-injury. I discuss the findings of this article more in chapter five. What is particularly relevant about this article is it demonstrates a nuanced layering of the positive and negative aspects of trauma and mental distress, and how physical activity environments can hold together and make space to encounter both. It does not tout physical activity as a catch-all cure for negative traumatic reactions, although arguably flirts at the edges of therapeutic use. However, it does offer suggestions about elements of physical activity (such as control, meaning-making, and risk) that enhance the possibility of recognizing and honouring the generativity that can result from moving our bodies in and through trauma.

With the exception of this article by Day (2013), the field of APA continues to pathologize individuals with experiences of mental illness and trauma, predominantly focusing on using physical activity as therapy in relation to trauma and ‘mental illness’. The current work in this field focuses far less on the generativity of these experiences, and further how we need to change our physical activity practices and environments to be more safe and accessible to those who experience trauma and ‘mental illness’. Further, the field has thus far largely neglected any social or political conceptualizations of madness, mental distress or trauma, despite several APA scholars conceptualizing disability as a fundamentally social or political issue (Brittain, 2010; DePauw, 1997, 2000; Grenier, 2011; Goodwin & Peers, 2011; Shogan, 1998). Given this

growing focus of APA scholars on the socio-political nature of disability, as well as the predominant focus of the field on inclusion in physical activity contexts (Block & Obrusnikova, 2007; DePauw & Doll-Tepper, 2000; Goodwin & Watkinson, 2000; Seymour, Reid, & Bloom, 2009; Spencer-Cavaliere & Watkinson, 2010), APA holds significant potential to provide insights into creating physical activities and environments that are more inclusive of, and accessible to, people experiencing madness, mental distress or trauma. I also believe that this project has the potential to open up the field of inquiry in APA to include considerations about making physical activity spaces more inclusive: that is, safe(r), more accessible, and more meaningful for people experiencing madness, mental distress or trauma. However, as I will detail in my two chapters on trauma-informed practice in APA, we must be cautious of this move and its potential to further individualize and pathologize mental distress and trauma reactions.

### **Things to Come**

This dissertation is composed of seven chapters. The first chapter is an introduction that engages with scholarly and artistic literature around Mad studies, madness and performance, and approaches to ‘mental illness’ within the field of Adapted Physical Activity (APA). The second chapter outlines the overarching research-creation methodology that frames this project. The third chapter delves into my Mad autoethnography, which employs performance and performative writing, and is theorized as a series of episodes within a cycle. The fourth chapter is an ode to making *Mad Home*, a collaborative research-creation performance and website which deeply informed the following chapters on trauma. The fifth chapter considers trauma-informed practice in the field of adapted physical activity, arguing for radical anti-oppressive trauma-informed practices as an alternative to individualizing, pathologizing and therapeutically intervening into ‘mental illness’: practices that foster Mad and trauma-related access to

movement and physical activity. The sixth chapter builds on the fifth, detailing practice-based suggestions for implementing radical anti-oppressive trauma-informed movement and physical activity practices and environments. The seventh chapter is my ‘conclusion,’ which is really about beginnings, new episodes, and the sparks of new cycles: a discussion about the ways that the knowledges and practices, which have been crafted through this dissertation work, are being mobilized into the future.

## Chapter 2 - Research-Creation: Nesting Dolls and Love Stories

For this dissertation project, I engaged in autoethnographic and collaborative research-creation. This research-creation dissertation is a series of nesting dolls: a research-creation project composed of smaller ones, each hand-painted with different designs of a similar flavour. My autoethnographic research-creation project nests within my collaborative *Mad Home* research-creation project, nests within my trauma-informed practice research-creation project: each individual project joyfully present as you crack open another, but not the same without their companions.

Research-creation is a form of inquiry that centers the act of creation (artistic or otherwise) within the research process and outcomes. Thain (2008) argues that “priority falls not onto one term or another in the assemblage of research-creation, but to the ‘creative inbetween’” (p. 2). Canada’s Social Sciences and Humanities Research Council (2015) offers a specific stream of funding for research-creation works, and acknowledges research creation as a set of unique practices that weave artistic and scholarly research works. Research-creation draws from — or is sometimes alternatively referred to as — practice-led research, research-led practice, and arts-based research (Chapman & Sawchuk, 2012; Loveless, 2015; Sullivan, 2006). It has developed as a research form in part due to the (relatively) recent emergence of Fine Arts PhD programs worldwide, wherein the boundaries of artistic practice and research practice are being shifted and blurred (Loveless, 2012, 2015). Research-creation is relevant to my project in that I wanted to give weight to artistic practices as ways of knowing and acting otherwise: to learn about Mad performance through artistic practice; to move with Mad theory, politics and activism; and to develop practice-based possibilities for making more radical and accessible movement and physical activity practices and environments.

It is common for research-creation projects to take a cross-disciplinary or interdisciplinary approach to research problems or topics (Candlin, 2000). At the same time, research-creation offers the opportunity to reimagine and remake what interdisciplinarity means (Loveless, 2015). Loveless (2012) argues that while interdisciplinary research:

can and has been read as a situation that demands a set of ‘depth’ analyses from within discretely articulated disciplines that are then brought together, it can also be read as a structural dislocation of fixed loci of knowledge in favour of a situated imperative that engages in both a responsive and ‘response-able’ dialogue between sources, inspirations, discourses and stakes. (p. 98)

Borrowing from Loveless (2012), this project's interdisciplinarity is not only a drawing together of distinct disciplines, but also a thoughtful, playful, and fluid engagement at the boundaries and intersections of differing political commitments, fields of thought, means of making, and ways of knowing. I desired to engage in this kind of dialogue in exploring the “sources, inspirations, discourses and stakes” of madness and performance within my project (p. 98).

### **Opening Possibilities through “Creation-as-Research”: Playing, Making, Staging, Holding, and Crafting**

Because creation — that is, the development of something new — is so central to this research engagement, the road-map for conducting research-creation cannot (and/or should not) be entirely predetermined (Chapman & Sawchuk, 2012, 2015; Manning, 2008). Research-creation is a “form of play” in which researcher-creators engage in experimental, innovative, inductive and creative acts in order to access intuitive or tacit knowledges regarding their research topic (Chapman & Sawchuk, 2012, p. 12). In relation to disability, Chapman and Sawchuk (2015) argue that “it is by *making* performance, *staging* events, *holding* workshops,

*crafting* inclusive conferences, etc., that we have come to learn, profoundly, about the systemic pervasiveness of ableism throughout our society and culture” (p. 51, emphasis in text). The act of creating with and through Mad politics, aesthetics and practice-within and through performance-offered the potential to access similar insights. Sullivan (2006) concurs, arguing that “oftentimes what is known can limit the possibility of what is not and this requires a creative act to see things from a new view” (p. 20). Thus, as Chapman and Sawchuk (2012) also argue, there is not one way to do research creation work, but rather a vast array of possibilities that cannot fully be pre-determined because, “through research (i.e., interpretation, analysis), through creation (i.e., deployment, hands-on engagement), the very phenomena we seek to explore are brought into being in the first place” (p. 21). While I certainly came into my research-creation project with specific interests and theoretical leanings, as well as methodological desires and skill-sets in performance and collaborative creation, it is precisely this attunement to unexpected directions and new ways of knowing that artistic research-(co)creation undoubtedly brought to my process and project.

It is the open-endedness of this type of research process that offered me the opportunity to develop new (and access old) knowledges and “construct theories of ‘possibility’” (Sullivan, 2006, p. 19). For example, moving away from dance to consider performance more broadly opened up new possibilities for collective Mad meaning-making and artistic creation: I learned of Mad sensory worlds and making home and relating to my Mad ancestors through time and space. It was the permission, nay, the demand to be open to what was initially unimaginable that research-creation enabled within this project. Trauma is another example. I did not start with trauma, yet, through these research-creation processes, it has become a pivot point for this work and a site of possibilities for acting in the world otherwise.

Given this philosophy of exploring possibilities through and in research-creation, there are significantly diverse approaches to conducting research-creation (Piccini & Kershaw, 2003). Chapman and Sawchuk (2012, 2015) outline four broad forms of research-creation, and while not mutually exclusive and often co-constitutive, each form demands their own unique enactments and outcomes, as well as demanding distinctive quality assessment criteria. These forms are: “research-for-creation”; “research-from-creation”; “creative presentations of research”; and “creation-as-research” (2012, p. 7). While noting that these processes are not discrete and are iterative, Chapman and Sawchuk (2015) suggest that: “research-for-creation” involves conducting research early in a creative process in order to facilitate creation; “research-from-creation” involves embarking on a research project that has been sparked by a creative process; and that “creative presentations of research” involve using creative processes and/or products to translate and disseminate research knowledge.

My project aligns with the fourth form of research-creation outlined by Chapman and Sawchuk (2012): “creation-as-research” wherein “creation is required in order for research to emerge” (Chapman & Sawchuk, 2012, p. 19). These authors (2015) argue that “creation-as-research” involve aspects of all the above categories, as well as focusing on process, inviting creative output, and engaging ontologically with issues about what counts as research. Drawing from Chapman and Sawchuk’s (2015) quote articulated above, it is through “*making...staging...holding...crafting*” Mad dialogues, artistic practices, and performances that I have come to know more deeply and differently about my research questions and investments (p. 51). This dissertation writing reflects: making and staging Mad autoethnographic episodes, and our *Mad Home*; holding space, bodies, dialogue, our selves, and each other through hard and beautiful things; and crafting glitter jars, zines, origami games, twister boards, and practice-based

suggestions for radical anti-oppressive trauma-informed Mad accessible movement and physical activity spaces. Quite literally, “*making...staging...holding...crafting*” has become a crux of my methodological engagements within my autoethnographic and collaborative research-creation work, both of which made the emergence of my final chapters on radical trauma-informed practice possible.

**Embodied theory making through “creation-as-research.”** Creation-as-research “is a form of directed exploration through creative processes that includes experimentation, but also analysis, critique, and a profound engagement with theory and questions of method” (Chapman & Sawchuk, 2012, p. 19). These authors outline an example of Chapman’s own work of creation-as-research, wherein sound creation was done in tandem with interviews and collaborative processing of emerging knowledges. They highlight that “creation-as-research” involves specific attentiveness to intricately weaving theory and practice together. In research-creation, artistic and research acts are interdependently produced and inextricably linked, as are theory and practice. Artistic practice is considered to be embodied theory-making, and theory-making is considered to be an embodied, aesthetic practice (Loveless, 2012, 2015; Manning, 2008; Smith, 2009; Spry, 2011a, b). I chose research-creation for this project because this embodied aesthetic linking of theory and practice is a meaningful way that I both make (non)sense of my world, and come to act otherwise. Theory is critical to research-creation, but theory-making takes place in tandem with creation (Chapman & Sawchuk, 2012). As I will discuss in the following chapters, this approach has invited me to: theorize Mad autoethnography as episodic and cyclical by making and reflecting on Mad performance in episodes and cycles; engage theory in and through performance, most especially because myself and a number of my collaborators make sense of our worlds with and through queer, trans, disability and Mad theory every day; and theorize

trauma alongside Mad anti-oppressive practice, complicating both in the process. As I will demonstrate, theory leaks from our collaborative creation conversations, is mobilized to juxtapose sanist language in popular music with literature on gender-based violence and mental distress, is (de)composed through writing and performing myself Mad, and theory is an integral element woven into the tapestry of our *Mad Home*.

**Beyond the written document: Prioritizing other ways of knowing.** Certainly, the diverse and unconventional approaches fostered within research-creation work present challenges to the ways that knowledges are typically produced and valued within the University context (Candlin, 2000; Chapman & Sawchuk, 2012; Loveless, 2012). “In research-creation approaches, the theoretical, technical, and creative aspects of a research project are pursued in tandem, and quite often, scholarly form and decorum are broached and breeched in the name of experimentation” (Chapman & Sawchuk, 2012, p. 6). Research-creation asks us to call into question the taken-for-granted forms that academic research predominantly takes. For example, research-creation often challenges the primacy of the written research document as the hierarchized epitome of knowledge generation and representation (Candlin, 2000; Loveless, 2012). Throughout this project, I forefront a website, dialogue, photographs, video, material traces, ephemeral performances, workshops that have unfurled from this project, and tattoos on my skin as knowledges generated and (re)presented alongside this written dissertation. This written document is deflated without these other forms of knowledge, and is not the pinnacle of the “*making...staging...holding...crafting*” that this project has done (Chapman & Sawchuk, 2015, p. 51). For example, as I will share at the end of chapter four, the work we did in making *Mad Home* was enough for my collaborators and myself, even before an outside audience encountered it.

Research-creation invites us to stretch our imagination to consider alternative forms of knowledge generation and (re)presentation as valuable specifically for their alterity, and what this alterity does to our ways of being, thinking and knowing. It is this relationship to alternative forms of creating and sharing knowledge that “defines research-creation as an epistemological intervention on the level of academic methodology” (Chapman & Sawchuk, 2012, p. 23).

Research-creation challenges how and what we can know. In my autoethnographic episodes, and in the collaborative research-creation process that resulted in *Mad Home*, I take seriously the call for research-creation art work to be considered as equal texts to the written word. As such, in the following chapters I attempt to let these performances, performance traces and documents ‘speak for themselves,’ even as I speak some things about them: I could spend years analyzing and discussing elements of this project, and still some things are unwordable, and others take too many words. Instead, I write some love stories to and about these nesting dolls, highlighting some specificities of my autoethnography and the collaborative making of *Mad Home* in order to explicate some of my (and our) choices, and how these inform my movement practice.

### **Ontology, Epistemology, Axiology and Methodology**

Research-creation can be conducted by scholars working within many different research paradigms (Chapman & Sawchuk, 2012): that is, with many different sets of assumptions about what and how someone may know something about a given phenomenon (Donmoyer, 2008). This project involved a collaborative co-creation and thus was shaped by various differing world-views. Donmoyer (2008) notes that not all paradigms are incommensurable. Lincoln, Lynham and Guba (2011) agree, articulating that it may be more useful to consider “how paradigms exhibit confluence and where and how they exhibit differences, controversies and contradictions” (p. 97). Conrad and Beck (2015) suggest that understanding one’s own research

paradigm may facilitate conversations with others with different world-views. I have particular leanings towards the arts-based research paradigm outlined by these authors, partially because it takes into account the co-creation of knowledge across different world views and diverse ways of knowing, and also because it centers art as a way of knowing and doing research. Drawing on Heron and Reason's (1997) participatory paradigm, and on Wilson's (2008) indigenous research methods, Conrad and Beck (2015) explore some philosophical assumptions that may be held within arts-based research. For these authors, arts-based research projects include those that involve art "*in* a process of inquiry or meaning-making (generating, interpreting and/or representing material) or *as* a form of research (research-creation)" (Introduction: Growing Deeper section, para. 2). Considering that these authors draw on participatory and alternative research practices, and specifically address research-creation, I align this project with this arts-based research paradigm. Drawing on Conrad and Beck (2015), I will outline these assumptions here.

### **Ontological Assumptions: Art as Survival and Flourishing**

Paradigms consist of ontological, epistemological and methodological assumptions (Donmoyer, 2008). Ontology refers to assumptions regarding the nature of reality (Denzin & Lincoln, 2011). From within the arts-based research paradigm, one belief about reality is "that we are all, at a fundamental level, creative and aesthetic beings in intersubjective relation with each other and our environment" (Conrad & Beck, 2015, Ontological Considerations section, para. 1). Art is a way of meaning-making, and of engaging with ourselves, each other, and the wider world. In forefronting creativity, aesthetics, and cultural production processes, as Conrad and Beck do, an arts-based research paradigm dovetails precisely with my desires to explore Mad culture and aesthetics. Further, the focus on intersubjective relations within this paradigm is

reflected in my focus on community-based knowledge co-creation. These authors argue that art-making is life-sustaining: it is necessary for survival, and at the same time, in excess of survival. This has certainly been my experience: art has been (and is) one thing that has undoubtedly kept me alive, but also helped me flourish.

### **Epistemological Assumptions: Contextual, Relational and Aesthetic Beings**

Epistemology refers to assumptions regarding the “relationship between the inquirer and the known” (Denzin & Lincoln, 2011, p. 12). Put another way, it refers to how and what we can know. From within an arts-based research paradigm, Conrad and Beck (2015) argue that

as aesthetic beings we come to know more about our world; to relate to, organize, and impose meanings upon it through relational, aesthetic (sensory, perceptive, emotional) practices. An arts-based research paradigm acknowledges our multiple and diverse ways of coming to know through creating, embodiment, feelings, intuition, and spirit.

(Epistemological Considerations section, para. 2)

Knowledge is thus constructed experientially, emotionally, intuitively, presentationally, propositionally, practically, and always in collaboration (Heron & Reason, 1997; Lincoln, Lynham & Guba, 2011). Numerous research-creation scholars concur, suggesting further that knowledge and creation are both contextual and relational (Manning, 2008; McCormack, 2008; Piccini & Kershaw, 2003; Portanova, 2008). I argue that research-creation — from an arts-based research paradigm — is especially suited to exploring madness and performance because it can draw on and illuminate diverse, relational, contextual, embodied, unspeakable, non-linear, and emotional knowing.

### **Axiological Assumptions: Reflexivity, Relational Ethics and Social Activism**

Drawing on Heron and Reason (1997), Lincoln, Lynham and Guba (2011) argue that

paradigms also consist of axiological assumptions: assumptions relating to ethics and questions of what is valuable or worthwhile. Liamputtong and Rumbold (2008) state that ethical considerations include “actions (rules, codes and roles) ... character (based on values) and ... structures (where issues of justice and liberation arise)” (p. 7). Therefore, as research-creators in collaborative, relational engagements, we must consider how our actions, ways of being, and structural situatedness influence our research-creation throughout the entirety of the process. These authors demand that reflexivity and respect are central to ethical engagement in collaborative research. Further, considerations and practices of relational ethics are crucial to both autoethnographic and collaborative research and creation (Adams, Holman Jones & Ellis, 2015; Conrad & Beck, 2015; McCormack, 2008; Spry, 2011a, b). I discuss relational ethics in relation to my autoethnographic cycle in chapter three, and my collaborative creation in chapter four.

Conrad and Beck (2015) note that “openings, becoming-other, standing up against oppression, and bringing value to all aspects of human life — these are among the efforts that must be undertaken through the arts in/as research” (Axiological Considerations section, para. 4). Art as research holds the potential to open both ourselves and our worlds, to change us, and to make larger political change. These authors, drawing on Heron and Reason (1997), go further to argue that praxis and the active cultivation of flourishing is of worth and value within an arts-based research paradigm. Likewise, Chapman and Sawchuk (2012) argue that research-creation critically intervenes, it does something in the world. Research should draw together theory and practice, and make changes in the world for the better. Borrowing from Finley’s (2011) work on critical arts-based inquiry, my research-creation aims to be “both a mode of inquiry and a methodology for performing social activism” (p. 436). The works developed in my

autoethnographic and collaborative research-creation chapters are forms of social activism, and also inform the social activist aims of my fifth and sixth chapters: conceptualizing radical anti-oppressive trauma-informed practice and offering suggestions for practicing otherwise.

### **Methodology: Research-Creation, the Bricoleur, and Maddening Methodology**

In relation to methodology, an arts-based research paradigm requires that “primacy [be] given to interacting with and making art” (Conrad & Beck, 2015, Methodological Considerations section, para. 1). Within my methodological choices I work to honour this assertion, centering art in the research-creation process. In terms of methodology, Horowitz (2014) suggests that in research-creation, “the functions of research, creation, and dissemination are complexly iterative, intertwined, and reflexive” (p. 25). Research-creation processes blur, or disrupt altogether, the lines delineating the research act from the creation act from the dissemination act. These are not discrete and concrete phases of a research trajectory within a research-creation process. My nesting dolls speak to each other, their echoes resonating. Their bodies touch, rest against, envelop, hold each other.

Further, Thain (2008) argues that within research-creation the process itself holds the potential to be transformative (Thain, 2008; see also Smith, 2009). For me, forefronting process requires me to acknowledge that making social change occurs in my everyday relations and methodological choices as much as it does in the outcome or product of research-creation. Conrad and Beck (2015) note that “Denzin and Lincoln’s (1994) description of the qualitative researcher as *bricoleur* is an apt metaphor for the arts-based researcher as she/he responds to emergent opportunities for research-creation” (Methodological Considerations section, para. 1). For Denzin and Lincoln (2011), the researcher can be a political, theoretical, interpretive and/or methodological bricoleur by:

using the aesthetic and material tools of his or her craft, deploying whatever strategies, methods, or empirical materials are at hand... if new tools or techniques have to be invented or pieced together, then the researcher will do this. The choice of which interpretive practices to employ is not necessarily set out in advance. (p. 4)

The stories/problems/questions facing the researcher, the context within which these stories/problems/questions are present, and the unfolding of the research process itself, help to determine what tools and practices might be used. In other words, an important feature of research-creation methodology is its emergent nature (Chapman & Sawchuk, 2012; Conrad & Beck, 2015; Finley, 2011). Taking seriously the emergent nature of qualitative research, and most especially research-creation, I worked to employ different/new(-to-me)/invented tools in my research-creation process.

Theory is woven together with method throughout this research-creation project, just as Chapman and Sawchuk (2012) argue research-creation work must do. The methods I employ are maddened by engagements with Mad theory, and the embodied material conditions of research-creating madly. Citing Neil Marcus' famous statement, "disability is an art, it is an ingenious way to live" (Marcus, quoted in Price & Kerschbaum, 2016, p. 51), Price and Kerschbaum (2016) argue that disability, and critical disability studies, is a methodological intervention. They argue "disability cripps methodology" (p. 20). Prioritizing the presence of disability invites us to imagine and enact methodology otherwise, precisely because disability is generative of new ways of being, knowing, relating, and acting in the world. By extension, madness maddens methodology, and I have found research-creation enables this maddening in a way that has been intensely fruitful. This project has been one of methodologically maddening my world: and likewise, maddening of theory and methods has been made possible in this project because of the

fluid playful engagement, as well as the "responsive and 'response-able' dialogue between sources, inspirations, discourses and stakes," that is enabled by research-creation (Loveless, 2012, p. 98).

### **Nesting Dolls and Their Love Stories**

In the following chapter, I will detail some of the interwoven ontological, epistemological, axiological and methodological approaches I used to develop my autoethnography, including: performative writing; mash-ups of popular music; participatory-based and sensory-based performance invitations; and performance. Based on experimentation with these forms, and with Mad subjectivities, I will offer some research-creation performance traces of my autoethnographic episodes, and I will theorize autoethnography as episodic and cyclical. I will then follow with chapter four, explicating elements of my collaborative performance creation, which both constituted and resulted in the collaborative sensorio-political performance of *Mad Home*. This chapter also includes a link to a website that makes the conceptual underpinnings, and performance traces, from this event accessible to folks who could not attend in flesh form (for a myriad of reasons, Mad and otherwise). My fifth and sixth chapters are informed by these autoethnographic and collaborative processes. In these chapters, I mobilize discoveries, theories, and approaches devised from research-creating with Mad performance and politics. I do so in order to expand conceptualizations of trauma and Mad access, and to research-create new ways of making, staging, holding, and crafting physical activity practices and environments otherwise. I now hand you my nesting dolls, and invite you to encounter the love stories that echo inside.

### Chapter 3 - (De)composing Episodes in a Mad Autoethnographic Cycle

I began my research exploration of madness and performance by creating an autoethnography.

Pause.

Let the cursor blink.

This singular, tidy, chronological sentence doesn't do it.

The iterative (think: episodes, cycles).

The reflective (think: mirrors, prisms, crystals<sup>6</sup>, shiny things, my face in a handful of marbles).

The multiple (think: personalities, subjectivities<sup>7</sup>, stories, repetitions, perseverations, representations, personas<sup>8</sup>).

The overlapping (think: temporalities<sup>9</sup>, voices, skins<sup>10</sup>).

The interwoven (think: warp and weft weave together a new being, different from each individual string).

The mosaic (think: fragments<sup>11</sup>, shards, collage<sup>12</sup>, the *bricoleur*<sup>13</sup>, scratchy grout that rubs hands raw).

The contextual (think: who am I calling into this dialogic relationality<sup>14</sup>? reader, listener, witness, accomplice, fellow human, being Mad: who am I to me next to you? What does this space, time, relationship allow?)

The conflicting (think: desires, intentions, effects, the I's I want and the I's I don't, constructing new pasts, dismantling old futures).

The process-product-process-product-process-product-process-and-so-it-goes-until-they-are-the-same-but-not.

Dried glue peeled off my hand that takes my million skin cells with it.

This autoethnography is more than one. A series of episodes in a cycle: in different times and spaces, perseverating, looping, composing Mad flesh and selves and discourse.

### **Autoethnography**

As Ellis and Bochner (2000) argue, “we are inside what we are studying” (p. 743), and as such, it is incumbent upon me to investigate how I am situated within my research.

Autoethnography is “the process as well as the product of writing about the personal and its relationship to culture” (Scott-Hoy & Ellis, 2008, p. 130). Ellis and Bochner (2000) argue for “the necessity of exposing how the complex contingencies of race, class, sexuality, disability, and ethnicity are woven into the fabric of concrete, personal lived experiences,” which they suggest can be done through “reflexive, experimental, autobiographical and vulnerable texts” (p. 735).

Autoethnographies can be just such texts: texts that involve critically investigating one’s own subject position and experiences, making the personal political (Conrad, 2003; Ellis & Bochner, 2000; Mayan, 2009; Spry, 2011a, b). As Spry (2011b) writes:

It is the intentional and critically reflexive connection of [personal] narrative to larger social issues, to the politics, pleasure, and pain of other people, that distinguishes performative autoethnography as...grounded in forging knowledge with others to dismantle and transform the inequities of power structures. (p. 498)

Autoethnography, for me, plays seriously at the nexus of academic, activist, and artistic intervention into sociopolitical stories about madness by mobilizing personal, local, specific alter-na(rra)tives that disrupt dominant discourses.

Scott-Hoy and Ellis (2008) suggest that “autoethnographic texts appear in a variety of forms — short stories, poetry, fiction, novels, photographic essays, scripts, personal essays, journals, fragmented and layered writing, and social science prose” (p. 130). Beyond

representing autoethnography through art, these authors argue that art-*making* is another way of *doing* autoethnography. In relation to madness, Derby (2013) conducted an arts-based autoethnography, arguing that this form of research can bring complexity and nuance to representations of madness, while challenging medicalization and normalization.

While autoethnography is a vast, diverse, and divergent set of orientations and practices, Adams, Holman Jones, and Ellis (2015) argue that there are some commonalities in terms of the intentions, focus and scope of autoethnographic practice, including: centering personal experience as a site of critical interrogation and sense-making; committing to reflexive practice; exploring insider knowledge of specific and contextual cultural conditions; critiquing norms, power relations and experiences; and actively entering a purposeful relationship to an audience. Further, numerous authors argue that autoethnographic processes involve simultaneously moving inwards, to the personal, and outwards, to the socio-political (Ellis & Bochner, 2000; Scott-Hoy & Ellis, 2008). For example, Adams, Holman Jones, and Ellis (2015) note that:

The inside-out trajectory of autoethnography also describes how we begin a research project. Often, research projects begin with events that turn us—our thinking, feelings, sense of self and the world—and others—our friends and families, members of our social, political, and cultural communities, and others who are different from us—inside-out. Autoethnographies begin with the thoughts, feelings, identities, and experiences that make us uncertain—knocking us for sense-making loops—and that make us question, reconsider, and reorder our understandings of ourselves, others, and our worlds. (p. 47)

Certainly, in examining my experiences of madness through autoethnographic practices, I have been turned inside-out, knocking around in ‘sense-making loops.’ My autoethnography has certainly involved interrogation of my investments, my vulnerabilities, my messiness, and my

relationships (Conrad, 2003; Spry, 2011a). I have taken to heart Loveless' (2015) argument that research-creation work must “tell stories-that-matter” and forefront reflection upon “which stories animate us, and why” (p. 54). This has sparked my episodic and cyclical turning and (re)turning to the stories, conundrums and questions that animate me: questions about madness, performance, and accessible movement practices. However, rather than ‘reorder’ my understanding, as Adams, Holman Jones, and Ellis (2015) imply is an outcome of autoethnographic exploration, within this autoethnographic cycle I have worked to ‘dis-order’ myself, as I will discuss below.

### **Dis-ordering: Autoethnography as Episodic and Cyclical**

There are some interesting tensions in the autoethnographic literature relating to sanism and madness. On one hand, some articulate sanist valuations of rationality and coherency when discussing how to determine the quality of an autoethnography. For example, Adams, Holman Jones and Ellis (2015) propose narrative rationality as an important governing logic for autoethnography:

As autoethnographers interested in the symbiotic dance of self and culture, we must be mindful of the ways in which our stories—especially our characters, descriptions, dialogue, interpretations, and conclusions—illustrate narrative rationality. Even though our stories can and do change with time, space, and context; even though memory is fluid and fallible and revision is always possible, we must, to the best of our ability, create probable, trustworthy, and resonant autoethnographic tales. (p. 95-96)

Whose words, work, and living are most likely to be interpolated as probably or trustworthy? What if, perhaps, our autoethnographic selves both invoke and provoke experiences or relations that are neither rational, probable, nor trustworthy? What if this is the point—targeting the

sociopolitical valuation of these (never neutral) capacities, and the knowledges and lives made unworthy by these valuations? Similar to the above move by Adams, Holman Jones and Ellis (2015), Conrad and Beck (2015) argue for the need to “extract something consistent or coherent” within arts-based research practices (Ontological Considerations section, para. 6). This presumes a value-neutral orientation to coherence that some experiences of madness contradict, and that Mad authors may find alienating and ultimately unachievable (if not undesirable). This is not to say that all Mad experience is about a consistent lack of rationality, coherency, or trustworthiness, nor is it so say that quality and craft does not matter in Mad autoethnography. Rather I am calling into question how sanism is at work in social and scholarly demands to perform rationality, coherency, and trustworthiness: these being questionably achievable, performative thought/action qualities that have long been mobilized as foundations for psychiatric pathologization.

On the other hand, some authors argue for autoethnographic practices and performances that critically question and undermine rationality, trustworthiness and coherency as the bases for composing (and performing) our selves. For over twenty years, some authors have been alluding to the value of autoethnographic and autobiographical representations and techniques that I read as potentially crip and Mad (see hooks, 1999; Pollock, 1998; Smith, 1998). For example, Pollock (1998) argues that performative writing is “*nervous*. it anxiously crosses various stories, theories, texts, inter texts, and spheres of practice, unable to settle into a clear, linear course, neither willing nor able to stop moving, restless, transient and transitive, traversing spatial and temporal borders” (p. 90-91, emphasis in text). Spry (2011a) draws on Pollock in arguing that a “performative self... ‘is not merely multiple,’ it moves itself ‘forward...and between selves/structures’” (p. 59). There is a nervousness, a multiplicity, an instability, a non-linearity, to

composing and performing our autoethnographic selves that resonates greatly with my experience of madness and my readings of Mad theory. On performative autobiography, Smith (1998) writes that “the cultural injunction to be a deep, unified, coherent, autonomous ‘self’ produces necessary failure, for the auto-biographical subject is amnesiac, incoherent, heterogeneous, interactive” (p. 110). Further, Spry (2011a) writes:

In Smith’s concept of autobiographical performativity, the autobiographical subject is not an intact coherent self waiting within the body to be recorded through language; rather, she is a conflation of effects, a ‘constellation of resources’ created through a performative process of critical narration that resists notions of individual coherency; the performative-I disposition is a coupling of this sense of subjective incoherency with critical ethnographic reflexivity. (p. 64)

While these above authors, and others, have been using metaphors and images that reflect qualities of Mad experience or psychiatric diagnosis (nervous, anxious, incoherent, amnesiac, non-linear, multiple), only Spry (2011a) begins to more explicitly tie these (re)presentations of performative autoethnography to embodied experiences of madness. Spry (2011a) writes:

Although expressing passion and spirit within the communal narrative of academe seemed more like heresy than successful scholarly practice, in going mad, I had learned that heresy is greatly maligned and, when put to good use, can be the music that begins a robust dance of agency in one’s personal/political/professional life. (p. 98)

Are we maddening research by making space for multiple, non-linear, incoherent, nervous selves through critical performative autoethnography? I am nervously inclined to say it is a possibility, based on my own experience, and on Spry’s (2011a) articulations.

This reveling in the messiness of performative autoethnography calls me. It is a

generative Mad disruption, a push against the stories and narrations we are expected to perform within our interactions with psychiatry and psy knowledges: one that depathologizes non-linearity, one that derives pleasure in twisting twisted stories, one that hungers for subjugated knowledges, one that critically examines what is ‘trustworthy’<sup>15</sup> (and for whom), and one that honours the generative potential of complex (re)presentations of our selves beyond the sanist pulls to rationality, singularity, and confessional narrations of coherent(ly diagnosable) identity.

In an effort to madden research practices and performances for myself, and as an extension of this above work on performative autoethnography, I have come to conceptualize my own autoethnographic process as episodic and cyclical. “The autoethnographic ‘I,’ then, becomes a plural pronoun with the constant refraction of selves in disparate locations”<sup>16</sup> (Spry, 2011a, p. 93). Perhaps taking this too literally, this autoethnography has highlighted for me the vital utility of engaging with episodic, cyclical, plural refraction of my selves, across time and space and back again. Spry (2011a) shares a similar sentiment, noting that “through engaging knowledge as embodied, I began to experience rupture and fragmentation as a form and function of performative ethnographic representation” (p. 65). I want to take this rupture, fragmentation, and refraction seriously, and push at its limits. Here I am intentionally reclaiming terms that have formed the basis of some of my psychiatric diagnoses: My mind-heart-body working to soften, open, find warmth for my episodic existence, for my cyclical turning and (re)turning to things that matter to me, and things that make matter of me. Reiterated, obsessively cycled upon, wearing grooves into the ground beneath me. Finding the generative in the seasonal, the affective, the up and the down, the dark and the light.

To begin doing autoethnography, scholars often suggest taking time to notice, to register those moments of epiphany (Adams, Holman Jones & Ellis, 2015), to draw our attention to

transformative times and experiences and sensations (Spry, 2011a). At the same time, Spry (2011a) notes that “the transformative experience may have been *a series of smaller or gradual events* that had its effect over a period of time” (p. 123, emphasis in text). These transformative experiences, for me, are episodic and cyclical. Episodic: gaps and bumps; inconsistent; built in fits and starts; broken up by taking breaks; forgotten; accidentally erased; fragmented (Spry, 2011a); dis-ordered; decomposed (McRuer, 2006). Cyclical: drawn together and pulled apart and redrawn; rising and falling to rise again; trying new tools for old problems in new times; sticking sticking on something that ‘animates’ me (Loveless, 2015); bringing forward different voices on similar issues.

Here, I present to you some (re)presentations of my most recent autoethnographic cycle: a series of episodes cycling around madness, performance, and Mad-accessible movement practice. Below I will highlight some of the theoretical and methodological choices I have made in relation to some of the episodes that I consider to be a part of this larger cycle. I will also include performance traces, including photographs and videos, of some of these episodes. These traces—like the episodes themselves—are partial, incomplete, sometimes incoherent, varied, occasionally connecting by loose associations, and speaking to each other in tongues. What is crucial for me about the aesthetic of this episodic Mad autoethnography cycle is that it is not intended to make me more diagnosable (although psy knowledge is incredibly limber and always flexible enough to enable never-ending diagnostic potential). Rather, it is intended to diagnose social and cultural conditions that make living Mad a more difficult and dangerous feat, and to prescribe alternative Mad possibilities for flourishing.

## **Composing the Fragments: Gathering Together Sensations, Experiences, Critiques and Selves for the Development of Autoethnographic Episodes**

To begin an autoethnographic process, Spry (2011a) encourages us to “begin thinking and writing in *fragments of experience*” (p. 141, emphasis in text). The first fragmented loops of this autoethnographic cycle began to emerge as early as 2011, where my very first embodied and textual Mad explorations were supported in my coursework on arts-based research (with Diane Conrad, 2011), sensory anthropology (with Helen Vallianatos in 2013), and contemporary performance and movement (with Piet Defraeye and Lin Snelling in 2014). I was not studying madness at the time, and had never heard of Mad theory or Mad aesthetics. However, sensory writing exercises, invitations to build my own autoethnography in class (which turned into an experiential sensory-based participatory performance installation), and my Masters’ work drawing together arts-based research and critical disability studies, all offered popping sparks and hot bubbling mud puddles. I did not know yet this was going to produce a new cycle for me, but the record needle was skipping around before finding a groove to play out. Some of the writing, the movement, the thoughts, I never went back to. Most of the performance installation elements are now long lost: lost in the process of divorce; and lost in queering my life; and lost because they were made of Lucky Charms cereal and lavender and white cheddar popcorn, all of which degrade significantly with age. At the same time, I undoubtedly found, as Spry’s (2011a) articulates:

What is written from the body changes the body and vice-versa; what is performed turns back upon itself, changing word and body. In performative autoethnography, body/performatives, paper/word, and stage/performance are in flux, in process, in progress as they continually (re)generate one another...none existing as fixed or static,

none positioned as authority. (p. 28-29)

I learned felt senses of how my body writes just as my writing embodies (with Celeste Snowber in 2012). I have wrestled with thinking theory that I could not feel, and feeling theory that I could not think. Courses on participatory research (with Diane Conrad in 2014) and performance studies (with Natalie Loveless in 2015) pushed my interconnected relations with my Mad “body/paper/stage” further (Spry, 2011a), bringing madness to the tip of my tongue after years of practice shaping my mouth and throat and gut around it.

Wait, did this cycle start earlier? It did. Yes. In the days of navigating (c)overt sanism when I’ll-pull-you-into-my-office-to-tell-you-that-it’s-okay-if-you-are-not-cut-out-to-be-an-occupational-therapist-because-our-professional-program-refuses-to-accomodate-madness-such-that-you-will-need-to-appeal-your-“forced-to-withdraw”-status-through-an-ombudsperson-and-disability-support-services-on-campus. I didn’t yet have the politicized language around ‘mental illness’. I didn’t have access to Mad art, or Mad community. However, my guts and throat and mouth all knew that something was off. The mud bubbles and sparks were in my belly and on my retinas and bouncing around my skull, making the insides of my wrists and the backs of my knees raw and tingling, long before they were in words or images or critical insights.

This autoethnographic cycle is indebted to many of these moments, but also importantly to many people. In composing autoethnography, Adams, Holman Jones and Ellis (2015) highlight the methodological necessity and the value of “talking with others” (p. 52), “listening out loud” (p. 53), “interviewing others” (p. 54) and “collaborative witnessing” (p. 56).

Autoethnography is relational, both in process and in product (Adams, Holman Jones & Ellis, 2015; Spry, 2011a). Fragments were built over eleven years in moments when my integrated dance community, and my peers, and my supervisors/instructors/mentors, made sanist jokes or

remarks, and I didn't know how to respond. Others were built when my community offered an eye-roll and a check-in because they too knew the sanist jokes were not funny. A number of fragments, including *Noise Cancellation* (version 1.0), were built on exchange at UBC Okanagan (with Matt Rader, but also importantly with the vital witnessing of Aimee Louw and Katie Jung, in 2016). My first embodied performance fragment of my performative written text, *Loose Leaf*, in front of an audience was an uncomfortably productive mess (Performance and Oralities Conference, Bogota, Columbia in 2015). More fragments were built by finding Mad mentors and playmates, of which I have had the fortunate of meeting more and more each year: Michele Decottignies, JD Derbyshire, Nathan Fawaz, Sarah Hamill, Alexis, Rebecca John, dales laing.

Hindsight offers me perspective. In reflecting, I am reminded that this cycle relies on my continued weaving of sensory, tactile, embodied, experiential and participatory strings. I have literally and figuratively added to, and sculpted, the flesh on my frame through Mad performance (*Swallowed the Fly* in 2014; *Other than Freddie Mercury, why are all my neuroqueer crushes so white?* with Rebecca John in 2017; in a psychiatrist's office, for over a decade). Pounds of new and used muscle, sinew, bone, fat: nourished, and indulged, and medicated. All marked with blushes and shadows, and bruises from Danielle's wheelchair on my thighs. All while my lips pursed, then opened, then my tongue tapped the roof of my mouth to form the word 'Mad' for the first time in public performance (Disability and Material Culture conference in 2013; repeated, out loud, at the Differential Mobilities Conference in 2013). A lipstick alphabet written on my body, making me contort to spell out all that is expected of me (at UBC Okanagan with the support of Erin Scott in 2016). Dancing to expel the affect at my fathers' death (living room, with my ex's shoulder bruising up from knocking down the door, in 2007). These are some of the fragments of this cycle on Mad performance and access. Spry (2011a) writes:

The process of critical reflection is seldom linear. Speaking from my own experience, fragments, pieces of self, spirit, whathaveyou, do not eventually coalesce into a coherent subject. Rather, they recognize one another in breakage, remaking alternate ways of being. Yes, messy, argumentative, compassionate, and comforting. (p. 152)

I take seriously that “the aesthetic crafting of autoethnography is a sociocultural and political action” (Spry, 2011a, p. 106). This intentional commitment to sociocultural and political action has certainly been paramount in shaping the (de)composition of my the autoethnographic episodes within this cycle. Specifically, I want to honour hooks’ (1999) assertion that, in critical aesthetic writing praxis:

it becomes ruthlessly apparent that unless we are able to speak and write in many different voices, using a variety of styles and forms, allowing the work to change and be changed by specific settings, there is no way to converse across borders, to speak to and with diverse communities” (p. 41).

I have chosen to (de)compose the episodes in this cycle specifically to honour and make space for different voices, styles, and forms to be employed in specific contexts, such that they may ‘speak’ most intimately to and with diverse communities.

### **A Mad Cycle in (At Least) Three Autoethnographic Episodes**

In selecting episodes for this chapter, given all of the fragments I have gathered, I was struck by the question ‘what constitutes an episode?’ In the spirit of reclaiming, I am pulled to pull apart the diagnostic criteria for bipolar episodes (both manic and depressed, see Bressert, 2018; Grohol, 2017), and would argue that I need to enact elements of each in order to name an episode as such. Episodes typically involve a shift in mood, thought, and behaviour, that is sustained over a relatively extended period of time. By definition, they also mark distinctive

shifts in functioning in the context of school, work or leisure. If we can critically question the pathologization of these shifts, we might come to notice what is generative about them.

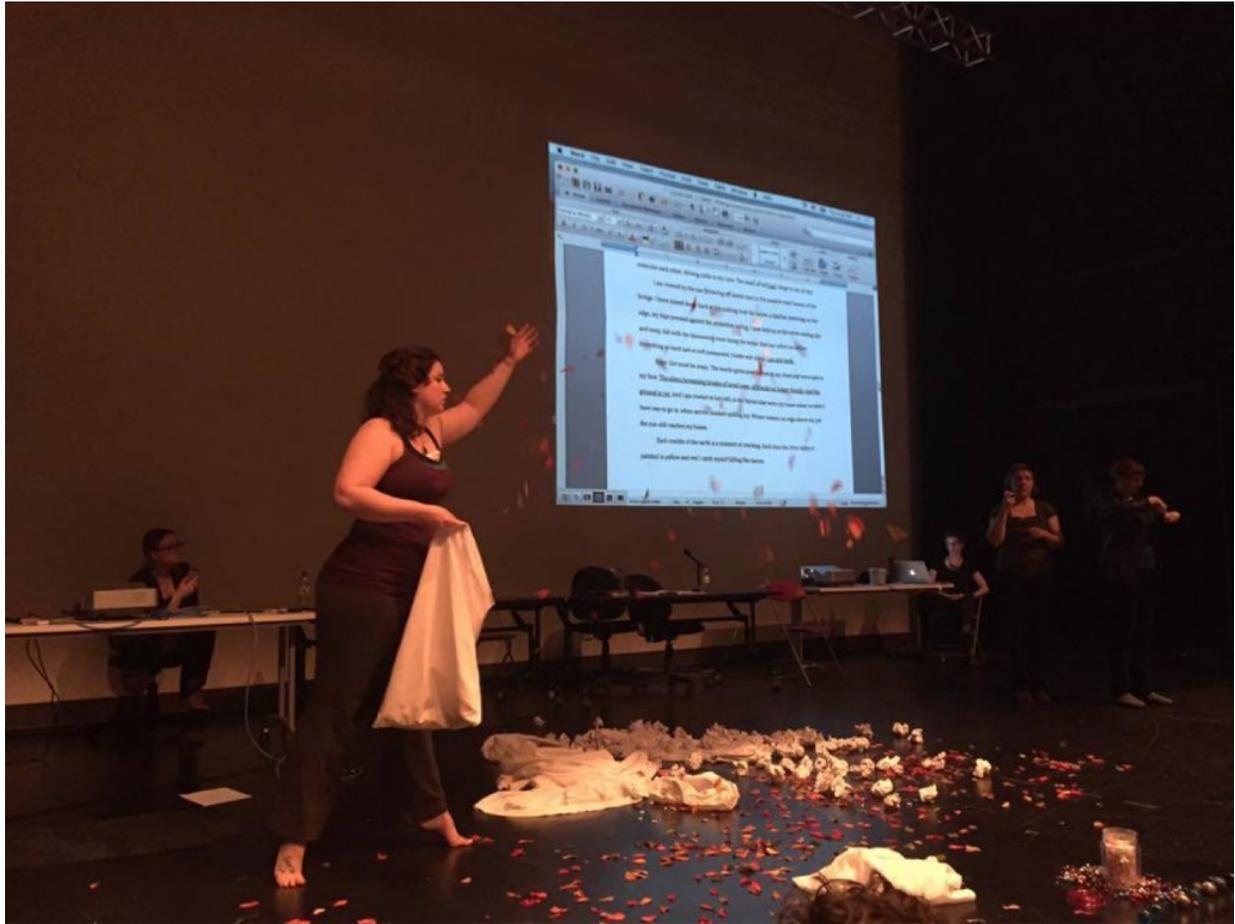
For me, my autoethnographic episodes involve deeply feeling into hopelessness, unworthiness, and my guilt for small/large and real/imagined misgivings. Reflexivity, for me, involves all of these feelings, and they are important even if sometimes undesirable.<sup>17</sup> I also need to ride manic waves if they grow.<sup>18</sup> I have turned autoethnographic fragments into an episode on the wings of phoenix-like-flights of ideas, lifted by the pressure to talk-talk-talk-keep-talking about what is itching me. However, I also need to lose interest, for days/weeks/months at a time, in order to know which fragments to drop and which to hold dear. Alternatively, attending intensely to “unimportant or irrelevant items” (Bressert, 2018, unpaginated) means that I can question who decides importance or relevance, and that I can wonder about how the unimportant or irrelevant in our lives are perhaps vital too. I also need to get my boots stuck, the brain swamp that makes concentration difficult (if not impossible). Sometimes finding myself knee-deep in swamp-filled boots is the only time I look up at the stars. I need to be reminded why I cut off my bootstraps years ago, especially when I phantom reach to pull them up. Perhaps my periods of “inflated self-esteem and grandiosity” (Bressert, 2018, unpaginated) translate to an inflated sensing of my selves, where I can (re)make past, present and future me(s)? Additionally, I need to let my energy ebb, ebb, ebb, creating a glugging whirlpool from the sucking vacuum, before it can flow. And I do need to think and talk about death, and about suicide. Sometimes it’s just really necessary to know there is a way out. Sometimes not caring about living makes life livable.

Ultimately, spending time and energy fixating on “significant goal-directed activity beyond [my] normal activities” (Bressert, 2018, unpaginated) means shit gets done. The vast

major of episodes I have made in this autoethnographic cycle have needed an intensive final push of goal-directed activity. They are episodes because they have resulted in a significant discharging of theoretical, affective, aesthetic and/or ethical energies. They have come to satiate my desire to dwell with madness,<sup>19</sup> within a specific context, at a specific time, with a specific audience. They are crafted to the point that I am satisfied: until I am not, and a new episode is conceived.

Adams, Holman Jones and Ellis (2015) argue that “because autoethnography is the study of culture through the lens of the self, separating the content of the text from the form of its representation is not desirable or possible” (p. 83). In this autoethnographic cycle I will offer three episodes that have been composed based on the above fragments, each with specific (though sometimes overlapping or derivative) content, form, context and intention in mind. These episodes are not totally chronological as they are deeply intertwined with one another, having been composed and decomposed alongside each other, and in conversation with the larger body of work in this dissertation. The episodes I will highlight include: 1) Mad Dance; 2) *Loose Leaf*; and 3) The Mad Dance of Grad School.

## 1. Mad Dance: Mad Politics, Aesthetics and Mad-Accessible Movement Communities



*Figure 1.* Mad Dance. This photograph is a still image from an episode of Mad autoethnographic performance. In this photograph, Lindsay is on the tips of her toes as her arm extends to throw red and orange leaves on a black stage floor. In the background, a page of text from Loose Leaf is project, and two ASL interpreters are translating in the corner. (Photo credit: Laurence Parent)

This episode was a conference performance for a critical disability studies audience. It was performed at the Inviting Movements: Emerging Critical Disability and Deaf Perspectives and Practices Symposium, held on May 5, 2016. The symposium was hosted by the Critical Disability Studies Working Group at Concordia University in Montreal, QC.

Autoethnography can take numerous forms, which, as Adams, Holman Jones and Ellis

(2015) argue, include:

temporal, sensory, and physical accounts, which explore personal/cultural experiences through the lenses of time, the senses, and the physical body. These texts seek to immerse readers in the sights, sounds, smells, and textures of the experience related in the account.

(p. 86)

In this performance-based episode I played with embodying text, movement, and Mad sensorial excess (littering the floor with leaves and candy and pillow cases and pages). Crafting the work for an audience attuned to critical disability studies—a field with significant parallels and overlaps to Mad studies—meant that I could play harder with Mad theory, while at the same time mobilizing dance to aesthetically call for both sensual and political engagements with embodiment in Mad studies.

Gingrich-Philbrook (2005) highlights two important tensions within performance-based autoethnography: tensions between “a demand to create knowledge (the epistemic) and a demand to create art (the aesthetic)” (p. 303). Spry (2011a) links these tensions in noting that “if autoethnography is epistemic, then the evidence of how we know what we know must reside in the aesthetic crafting of critical reflexion upon the body as evidence” (p. 19). This performance was, for me, just this: an aesthetic critical reflection on the Mad bodymind, in sensorio-political terms. It was also an experiential exemplar for me of the iterative nature of performative autoethnography, highlighting the productive possibilities in cycling between the body, the page, and the stage, and back again (Spry, 2011a). “The composition and performance process continually forms and reforms the body, the body of the text, the text of the body. In other words, the literary and performative collaborate in autoethnographic epistemology” (Spry, 2011a, p. 29). This performance was one iteration of paper-based text-meeting-body-meeting-stage which

informed all other episodes in this cycle, and specifically the final composition of *Loose Leaf*.

## 2. Loose Leaf.

Eales, L. (2016). Loose Leaf. *Canadian Journal of Disability Studies*, 5(3), 58-76.

<http://dx.doi.org/10.15353/cjds.v5i3.297> (see Appendix A).

One form of research-creation that is central to this autoethnographic cycle is performative writing; making my writing a performance in and of itself. For Adams, Holman Jones and Ellis (2015):

Performative writing, in which the writing itself approximates—performs—the experience(s) and culture(s) being discussed. Performative writing is ‘writing as doing,’ rather than ‘writing as meaning.’ In performative autoethnographies, the idea, concept, experience and/or culture under consideration guides the form and structure of the work.

(p. 89)

*Loose Leaf* is a performative writing piece, which began as fragments of writing from previous coursework, and which was included in my dissertation proposal as an early example of my autoethnographic research-creation work (see Appendix A). In *Loose Leaf*, my intention was to craft a Mad text that invited the reader to: madden their reading practice; perform non-linear engagement with the text; notice and disrupt the normative embodied practice of reading; think critically about “mental illness;” and to be affected by, and build meaning from, incoherency and loose association and chance. This takes its shape first in the performative invitation that begins the work (print off the pages, shuffle them, and read), and is developed throughout the piece in terms of both form and content.

*Loose Leaf* was later published as a part of a special issue of the *Canadian Journal of Disability Studies* entitled “Telling Ourselves Sideways, Crooked and Crip.”<sup>20</sup> St. Pierre and

Peers (2016), the co-editors for this special issue, write that:

Telling our individual and communal selves otherwise has been a pivotal move for many Mad, Deaf, neurodiverse, disability, sick, and crip activists and communities over the last century (*Charlton 1998; Clare 1999; Gannon 2011; Sins Invalid 2016*). Doing so makes a bold epistemological claim about the value of experiential, embodied, and community-created knowledges in a context where medical, charitable, eugenic, inspirational, and colonial discourses attempt to straighten us, and our stories, out...drawing on this history, for this special issue, we have chosen works that mobilize experience methodologically: in order to critique and challenge and disrupt entire fields of knowledge about us; and in order to crip and create new ways of knowing, performing, desiring, experiencing, and researching our 'selves.' (Introduction section, para. 3, emphasis in text)

Of *Loose Leaf*, these authors write:

Eales draws on various formats of performative writing, crip and Mad theory, and personal experience to de-compose the acts of living and writing madness. This evocative work engages not only with psychiatrized aspects of her queer-Mad life, but also with how madness (in)forms important relationships, life events, affects, and desires. (Introduction section, para. 5)

In reading the work of Adams, Holman Jones and Ellis (2015) I came to find a term that resonated for the kind of work I am cycling on. These authors argue that performative writing, insider texts, and critical autoethnographies can be forms employed in *conceptual* autoethnography. Adams, Holman Jones and Ellis (2015) elaborate:

In conceptualist art, ideas dominate; they become the 'machine that makes the art.'...Conceptualist texts question the role and purpose of research and writing, the

formality of research texts, the role of the author as artist, and the lessons that autoethnographies can offer writers and readers. In conceptualist texts, interpretation and analysis are the inspiration for story; showing and interpreting are tightly coupled. Conceptualism also emphasizes the importance of audiences in creating and completing texts, thus making a variety of collaborative readings possible. (p. 88-89)

Given this definition (and most especially the point about audiences creating and completing texts), I would argue that this episode (and cycle) of autoethnography is, among other things, a conceptual one.

### 3. The Mad Dance of Grad School: A Choose Your Own Adventure



Figure 2. The Mad Dance of Grad School origami game. This is a photograph of the origami

game that invited participation from the audience. It was used to randomly sequencing the order of content performed in this Mad performance episode. In the photo, a hand holds a bright orange square origami game, with fingers in each of four flaps. The words “scholar’ ‘activist’ ‘teacher’ and ‘dancer’ are written, one on each flap. Smaller writing on the inner flaps read ‘agitated’ ‘depressed’ ‘anxious’ and ‘distracted’. (Photo credit: Danielle Peers)

This episode involved a participatory performance for the Rod Murray Memorial Address, an annual peer-reviewed keynote lecture that I was selected to give. It was featured at the RECON Graduate Students’ Conference for kinesiology, sport, and recreation graduate students. It was held in Canmore, AB, on September 3, 2016, and was hosted by the Faculty of Kinesiology, Sport, and Recreation at University of Alberta. A video link to this performance is available here<sup>21</sup>: <https://vimeo.com/279889462>. This episode involved focusing a collection of my autoethnographic fragments towards examining Mad exclusion and Mad access in academic and sporting contexts.

Performance-based autoethnographers are responsible to epistemic (research-based knowledge claims) and aesthetic (creative or artistic craft) elements, as well as ethical considerations, within the practice of autoethnography (Conrad & Beck, 2015; Gingrich-Philbrook, 2005; Spry, 2011a, b). This performance episode employs a similar conceptual approach as the one I was crafting for *Loose Leaf*: one that invites multiple non-linear embodied performances to facilitate sensory, affective, theoretical, epistemic, aesthetic and ethical engagements with madness. Fragments for this episode of performative autoethnography were drawn from a number of places: my performance studies class with Natalie Loveless (conceptually and in terms of content from *Loose Leaf*); my very first autoethnographic performance installation in Diane Conrad’s arts-based research class; a multi-ethnography on

affect and physical activity (Avner et al., 2014); and from my time on exchange at UBC Okanagan, where I created the beginnings of *Noise Cancellation* (the ‘crazy’ song mash-up that demands noise cancelling eye and ear protection) and got a collective ‘killjoy’ tattoo with Aimee and Katie (a crip survival response to our shared experiences of ableism and sanism).

Given that the theme of the conference was “Choose Your Own Adventure,” I delved deeper in embodied and participatory elements within this performance presentation. I wanted to play seriously with both the possibilities, and especially the limits, of ‘choosing my own adventure’ as a Mad grad student and physical activity practitioner. I used an origami paper game (often played in grade school) to support the randomization of sections of this performance (see *Figure 2*), thereby placing the ‘choice’ and limit on audience members to determine the story I would be telling. I also included “Grad School Twister”, taking elements of the game which I have been playing in my autoethnographic performance installations since 2011 and relating them to experiences and barriers regarding mental distress for graduate students. Audience members were invited up to play Grad School Twister, an embodied exploration of these experiences and barriers which ended when one of the participants’ ‘broke down,’ but which also highlighted the value of community supports in sustaining the contorted positions we are made to hold in academic and professional life.

Another example of a performative fragment I developed more deeply for inclusion within this performance is *Noise cancellation* (see video from 19:20 to 24:25). Specifically, after creating the ‘crazy’ song mash-up and performing with it once in Kelowna, I came to realize how many of the songs not only used sanist words, phrases and sentiments, but also how they almost simultaneously enacted gender-based violence and supported rape culture. This is when I went to the literature on gender-based violence and rape culture in the academy. Spry (2011a) notes that

“research is used to support and expand upon the critical reflection, analysis, and representations explicated in your autoethnography. *Think of research as a voice in the conversation of your work*” (Spry, 2011a, p. 145, emphasis in text). In *Noise Cancellation*, I had done precisely this. I re-edited and captioning the audio file to put the lyrics of popular songs in conversation with quotations from academic literature, in order to highlight the ways sanism, gender-based violence and rape culture work in concert.

### **Maddened Autoethnography: (De)Constructing Selves, Constructing Possibilities**

Barbour (2012) argues for creating and performing autoethnographic dance, which holds the potential to be a politicized and embodied form of inquiry. However, Spry (2011a) cautions us that just because dance and other forms of performance often explore embodied knowledge, employing performance does not necessarily mean it is inherently politicized. We must constantly critically reflect upon how storying our embodied knowledge, both on stage and in text, is an act of constructing our bodies, our selves, our relations, and our worlds. How we story our bodies, our embodied experiences, and our embodiments, has political implications, including the potential danger of apoliticizing privilege and oppression (Spry, 2011a). Spry (2011a) writes that “in postmodern research, we sometimes like to think of the body as inherently ‘knowing’ things without remembering that *the body knows what language constructs*” (Spry, 2011a, p. 107, emphasis in text). In this cycle, I wanted to come to know more about madness by (de)constructing, in front of and with others, multiple maddened bodies through my words, and likewise, multiple maddened words through my body. I also wanted to playfully implicate the audience (differently in the case of each episode), as they are also tasked with (de)constructing me through their own processes of sense-making. Throughout the creation of this autoethnographic cycle (which is still ongoing), I find myself continually returning to ask,

“what are the consequences my story produces?” but also “what kind of a person does it shape me into? What new possibilities does it introduce for living my life?” (Ellis & Bochner, 2000, p. 746). For me, a radically shifted relation to the episodes and cycles of my being/thinking/doing offers me exciting new possibilities for living, even in the (not so) simple act being gentler to my process and my selves.

## Chapter Four - *Mad Home*

Feminism is homework... When feminism is understood as homework, it is not an assignment you have been given by a teacher, even though you have feminist teachers. If feminism is an assignment, it is a self-assignment. We give ourselves this task. By homework, I am not suggesting we all feel at home in feminism in the sense of feeling safe or secure. Some of us might find a home here; some of us might not. Rather, I am suggesting feminism is homework because *we have much to work out from not being at home in a world*. In other words, *homework is work on as well as at our homes*. We do housework. Feminist housework does not simply clean and maintain a home. *Feminist housework aims to transform the house, to rebuild the master's residence*. (Ahmed, 2017, p. 7, emphasis added)

*Invitation: Join us in our Mad Home*

We wanted and needed Mad home, so we made one. Below is a collaboratively crafted invitation welcoming a select audience to our performance of *Mad Home*, which was posted on a private Facebook event page:

*Mad Home* is a research-creation performance installation by Lindsay Eales, Nathan Fawaz, Sarah Hamill, Alexis, and dales laing. Through this immersive participatory performance, we invite you into a *Mad Home* of our own making. It is a place of darkness and light, a site of intense sensory experiences, and a space of caring for ourselves in pieces. We share food, we turn soil, we paint, we craft, we lie face down on the floor, we talk to bananas, we say it out loud, we shape space, and we work to bring more of ourselves more of the time.

In our *Mad Home*, we invite you to:

- Take opportunities for taste, smell, touch, and movement sensory exploration
  - Communicate your boundaries, desires and needs, and respect those of others.
- For example, ask if folks would like company or to be alone, share if you would like company or to be alone, pay attention to folks' name tags, make yourself multiple name tags, etc.

- Practice explicit consent to touch or interact with others in the space
- Choose how you want to participate in any, all, or none of the performance offerings
- Be in the space as a witness
- Have any, all, or none of the feels
- Feel free to bring all of your bodies, minds, and coping mechanisms with you (if you want to smoke, please take a walk down the block)
- Danielle is available to talk something through, support your needs, answer any questions, tell you where something is, or help you navigate the home.
- Come and go (and come back) as you please

It is meaningful that you all are joining us, in person or in spirit. A quick note - feel free to bring and wear your headphones/music devices if you want!

If you can't make it out in physical form for whatever reason -- over the next few months we will be translating the installation into performative invitations, so you can take an experiential piece or two of *Mad Home* with you wherever you go.

*Invitation: Enter Mad Home*

### **Collaborative Mad Research-Creation**

In chapter two, I outlined research-creation as an overarching methodology that frames my dissertation, and as set of nesting dolls that hold the layers of this work in relation to each other. As I detailed, my approach to research-creation in this project gives weight to artistic “creation-as-research” (Chapman & Sawchuk, 2012, p. 19). For this research-creation project, I draw on ontological, epistemological, axiological and methodological assumptions that align with an arts-based research paradigm, which I also outlined in chapter two (Conrad & Beck, 2015). These assumptions include that we are relational aesthetic beings who survive, make meaning, and intervene in our worlds through art (Conrad & Beck, 2015). Further, building on Price and Kerschbaum (2016), this work gives weight to the ways that madness maddens methodology: our methodology for creation is shaped by relating madly to ourselves, each other, and the world.

Research-creation enables embodied aesthetic theory-making that is intimately interwoven with practice (Loveless, 2012, 2015; Manning, 2008; Smith, 2009). As I stated earlier, I chose research-creation because an embodied aesthetic linking of theory and practice is a meaningful way that I both make (non)sense of my world, and come to act in the world otherwise. Research-creation works challenge our notions of what constitutes research, and ask us to recognize creation as the work of research, rather than the work of research being an analysis of a creative work. “In research-creation approaches, the theoretical, technical, and creative aspects of a research project are pursued in tandem, and quite often, scholarly form and decorum are broached and breeched in the name of experimentation” (Chapman & Sawchuk, 2012, p. 6). As such, this chapter, which focuses on the collaborative research-creation nesting doll in this larger research-creation set, is not an analysis of a performance. It does not adhere to a linear trajectory from ‘data’ collection process-to-analysis-to-performance outcomes. Rather, it is a form of serious play that inseparably weaves analysis, critique, theory and methods (2012), wherein “*making...staging...holding...crafting*” is a means of learning about social, cultural and political circumstances and possibilities (Chapman & Sawchuk, 2015, p. 51). This chapter will focus on some of the collaborative processes, discussions, descriptions of our creative work, and learnings from this creation-as-research project, with a mindbody to privileging the messy performance-based creation itself rather than a linear coherent written text-based analysis of it alone.

The collaborative research-creation portion of my dissertation project, one in this set of research-creation nesting dolls, was sparked by a number of intentions. Initially, my intention was: to learn through the embodied creation of Mad dance performance; to create performance by and for people with experiences of psychiatrization and mental distress; to learn more, and

come to know differently, about how Mad politics, aesthetics and practices intertwine; and to honour the needs and desires of my collaborators and the people who I interviewed. As I will discuss below, my initial focus on dance was shifted by my commitment to these other intentions, as it became apparent within our collaboration process that dance was not necessarily the primary medium that my collaborators and I connected around. Instead, we collectively followed our Mad desires and intuitions, and generated a collaborative, participatory, site-specific, sensorio-political performance entitled *Mad Home*.

In this chapter, I will discuss some of the choices and learnings that make up our *Mad Home*. These choices and learnings play at and blur the boundaries of theory, methods, analysis, critique, processes, outcomes, and practices. I use description, reflection, as well as transcriptions of some of our conversations to share about these choices and learnings. These transcriptions are not ‘data’ that was then analyzed to create the performance. Rather, they are a form of (re)presentation of the creation itself that share about the weaving of our theories, methods, critiques, and actions, as well as our creative decision-making and analysis being done in-situ.

I will begin by discussing the collaborators involved in this project. I will then share some elements of making *Mad Home*, which included: being in relation; dialogue; discomfort; anti-pathologization; memory; and sensory experiencing. I will also reflect on documenting *Mad Home*, as well as how we are mobilizing this research-creation work.

### **Collaborators and Collaborations**

I obtained ethics approval from the University of Alberta’s Research Ethics Board to conduct interviews and a collaborative creation process with people who have lived experience with psychiatric systems and/or mental distress. As I discussed in my introduction, the knowledges generated by psychiatrized people are often subjugated ones (Foucault, 1969; 1976),

and Mad studies projects prioritize the perspectives and experiences of those who experience mental distress and psychiatrization (Menzies, LeFrançois, & Reaume, 2013). As such, it was important to offer the opportunity for my collaborators' ideas and words to be credited by name. Issues of confidentiality and anonymity were discussed, in the context of semi-public performance as well as written documentation. Collaborators were invited to use their own name or a pseudonym, and all collaborators determined how they wished to be named in our Facebook invitation to *Mad Home*, within the written document of this project, as well as on the website.

**Interview with Ruth Ruth Stackhouse.** I sought out interviews with Mad scholars, artists and activists from across the country who would not be able to participate directly in the collaborative creation process due to geographic distance. I sought interviews with artists and academics in Canada doing intersectional work around madness and mental distress, as well as race, poverty, queerness and trauma. This request was sent out by email to four individuals with whom I did not have ongoing personal relationships with, but who's work I have read and been in conversation with. I received one response, and conducted an interview with Ruth Ruth Stackhouse in Toronto on March 9, 2017.

Ruth Ruth is a theatre artist, the director of the Friendly Spike Theatre Band, and an activist and organizer of Toronto Mad Pride. She has been working in Mad theatre and organizing since 1989, engaging these personal and community practices as forms of protest and celebration. She has previously written a Masters' thesis titled *The Friendly Spike Theatre Band and Mad/Disability Peoples' Theatre in Toronto* that has been a great source of insight for me as I move through this project (Stackhouse, 2013). I met her at her artists' loft, a whimsical office with an overhead walkway packed with vibrant visual art, and we spoke together in person for approximately one hour. This interview was unstructured and open-ended in nature (Mayan,

2009), and was loosely focused on the experiences and generative possibilities of madness, Mad community, Mad organizing and Mad art-making. This interview was conducted before I began working with the group of collaborators in Edmonton. With consent from Ruth Ruth, I shared the content of this interview with those involved in the collaborative creation process. Ruth Ruth explicitly stated that she was not interested in reviewing transcripts, because she is busy and didn't feel a need to. She did state: "I just hope that you do a good job, and trust that you will...and I'm glad that you are doing what you are doing." I hope I have lived up to her trust and support.

***Learnings from Ruth Ruth that informed Mad Home.*** Much of my discussion with Ruth Ruth resonated with me, and with the rest of the collaborators. When we began, I did not know how this interview would be integrated into our collaborative creation, but it undoubtedly sparked initial conversations that shaped some *Mad Home* content and processes. For example, Mad performance, Mad organizing and Mad living, for Ruth Ruth, are deeply individual as well as collective and political:

what we do in our theatre is we try to express the barriers that we come up against on a routine basis. Many of the barriers are linked with poverty. And are systemic. There's a lot of barriers like within the pension system... Many of the actors in our group are on ODSP [Ontario Disability Support Program], and experience the same barriers because of that, so it's not because they're labeled 'schizophrenic' it's... the barriers. So, we work on that. And then also the individuals have an opportunity to express themselves personally. And, again, there's a lot of commonalities, there's a lot of people have had loss in their lives, a lot of people struggle with addictions. So, it's just, it's interesting but we're in like, as far as political...it's almost as if ... we've all been spit out by the whale and

we're on the other side and we're able to sight the oppressors.

For Ruth Ruth, Mad art making and performance is used to interrogate the systemic barriers encountered by this community, to foster a communal space for connection and reflection, and to express the specific experiences and imaginaries of those involved. These elements of Mad art making described by Ruth Ruth were woven throughout our process. Our work in *Mad Home* not only interrogated the barriers we encounter, but also celebrated the magnificent, deeply embodied, collaborative and relational survival tools we have gathered through being 'spit out by the whale.'

Ruth Ruth also turned and returned to the use of madness as a noun, verb, adverb, or adjective rather than a specific identity or relationship to psychiatry. She stated:

Madness, to me, madness is not an isolated thing. Madness is 'madly in love' or 'mad at the system' so it fluctuates all over the place... when you say, 'how's madness acted out on stage,' well, in a million different ways. Because it needs to be tagged with something. Like, 'madness against the system' or 'Christian madness' or 'madly in love' or 'mad for this tremendous food that we're eating'! Or, you know, whatever.

Learning from Ruth Ruth, the term "Mad" has taken on expansive and deeply contextual meanings: a descriptor, a sensation, an emotion, a spark, a motivation, an action, a site of community collaboration. This sentiment is evident in our own 'tagging' of 'Mad' to 'home' in this project.

Further, the value of food, and connection, and other practices of living were central to Ruth Ruth's articulations of Mad processes. She notes that Mad organizing and art-making practices include "anything that involves expression... you can take that in and develop it. So, food. Food is a big thing. So, food preparation, community kitchens. The breaking of bread

together. Gardening.” As I will discuss below, these encounters with life-as-art, sparked by both Ruth Ruth’s articulations and by our own histories of creation and collaboration, became vital components of *Mad Home*.

**Collaborative creation with dales laing, Alexis, Sarah Hamill and Nathan Fawaz.** I recruited four collaborators from within my Mad, queer, anti-racist, and disability artist/activist/scholar circles through purposive sampling (Mayan, 2009). I specifically recruited collaborators who: have experience with madness, mental illness or mental health systems; have made art or shared publicly before about experiences of madness (or mental illness); and have a creative practice in dance or another art form. At the request of the ethics review board, the collaborator recruitment request was sent out by someone who was more ‘arms-length,’ with the intention to mitigate some of the potential for coercion that could have resulted from me requesting participation from my friends directly. I chose Kelsie Acton, the co-artistic director of CRIPSiE<sup>22</sup>, who was known by my collaborators, but did not have as close a relationship with the collaborators as I did. I received six responses from people interested in collaborating or being interviewed, but due to scheduling, life commitments and health needs, four collaborators were involved in the creation of *Mad Home*.

As soon as collaborators joined the creation process, we engaged in a series of sharing and planning sessions to collaboratively determine what the overarching intention and structure of this project would be (I will discuss these sessions in more detail below). Based on the needs and desires of myself and the collaborators, this creation process took place over two months: the schedule for creation work was collaboratively determined. dales laing, Alexis and Sarah Hamill live in Edmonton, and attended group creation meetings in my living room. We met twice in March 2017, twice in April, and once in early May, for two hours each time, to dream, discuss,

plan, and create together. Nathan Fawaz, who lives in Calgary, connected with me via email, text, and then Skype for one-on-one dialogue, and then Skyped into a group meeting in April. The collaborators also choose to do a significant amount of labour in preparation on their own time, including: offering poetry and creative writing, developing participatory activities, curating content, imagining how to hold space and minimize harm in facilitating sensoria-political encounters, as well as being with and thinking deeply about discussions, needs, desires, and creative possibilities for this project.

As a part of our creation process, we decided to each specifically invited four to six of our people to witness and engage in *Mad Home*. We specifically wanted to invite a small select group of people to attend: in part because it is a small house, in part because we did not want to be overwhelmed by a large number of people, and in part because *Mad Home* is an intimate and vulnerable sharing of our world that we wanted to be handled with care. We chose people to attend who could hold our madness with this care, as well as people who might be in need of a *Mad Home* like we are. We invited people via a private Facebook event page, whether or not these folks could attend in person. We did this because we wanted to acknowledge that our Mad survival and thriving depends on webs of people across time and space, and that attending in spirit is as valuable as attending in person. We all shared who we would like to invite with each other, and mobilized our consent-based decision-making practice (discussed below) to collectively consent to everyone that was invited. We wanted to consent to who was attending, because we hoped to minimize the possibility of inviting people who are implicated in our experiences of harm or trauma.

Nathan travelled to Edmonton on May 6<sup>th</sup>, 2017, and I met up with them to chat and collage together for an hour. We then all gathered together as a group, for the first time in person,

and spent three hours preparing to welcome outside audience members into our *Mad Home*. On May 7, 2017 from 1-4 pm, we opened the doors of our *Mad Home* to these select people. This participatory performance on Mad living took place on the main floor and backyard of the home that I share with my partner Danielle (and my friend Kelsie who lives in the basement).

Documentation of our creation process was collaboratively negotiated. I took audio recordings of our creation meetings, and shared a google doc that included transcripts of these meetings, and a transcript of my interview with Ruth Ruth Stackhouse (with her consent). These transcripts were (re)presentations of our conversations, which I transcribed; trying to translate words and sounds and silences and multiple embodied contacts, dissociations, and love unspeakable, into written language. All transcripts contain recurring inaudible talk-over-laughter and mumbles and burps and farts and non-sequiturs and non-linear flights of Mad conversation, as well as deep care, brilliant thought, and being-together.

Our documentation also included another shared google doc that hosted content ideas, reflections, and pragmatic planning details. Collaborators read, edited, or added to these different google docs, interacting with them in ways that were meaningful at the time, at a pace that was self-determined. These google docs were used as planning devices, but also as memory tools. This was important because, born out of trauma and mental distress, forgetting is a tool for survival. At the same time, we *cared* to remember our creative process, the mundane and magical exchanges in our conversations, and the wisdom of those around us. Therefore, sharing transcripts and planning documents in this format was desired by the group. All collaborators were invited to review transcripts of our meetings, our process notes, and practical ‘to-do’ lists, and to make any changes they so desired. Given the 400 pages of transcripts, I did not expect everyone (or anyone) to review them, although one collaborator did clarify some names that

were misspelled in earlier transcripts. No substantive changes were requested, but some collaborators did comment on how lovely it was to encounter our conversations again through these transcriptions.

We also took some photos from one of our creation meetings, and created a box of index cards documenting our performative invitations (in the Fluxus style, which I discuss in more detail below; see also Friedman & Smith, 2002), which were featured throughout our *Mad Home*. We also chose to video, in time-lapse form, part of the *Mad Home* space that featured collaborators and audience members creating a giant painted mural on the wall. Additionally, we had an audio recorder set up to ‘talk to a banana’ in the washroom, which some audience members elected to record messages on. Collaborators also took photographs of the performance space before, during and after audience attendance. For confidentiality, we chose to ensure that no faces (other than those of the collaborators) were identifiable in the photos we took. Signage was clearly posted about these forms of documentation taking place in *Mad Home*, including at the front door, which read:

Don't feed the bears (or do so at your own risk). If you want someone to speak the content of these posters to you verbally, please ask.

There will be discussions of psychiatrization, medicalization, psychiatric medications, pain, trauma, queerness, suicide, among other things.

There is one camera in the space (above the bookshelf). If you do not want to be on camera, please put your name down on the list at the front door and we will ensure you are not recognizable in any shots that will be shared publicly. Footage may be hosted (likely in time-lapse form) on a webpage about *Mad Home*.

There is one audio recorder in the bathroom so you can talk to bananas. There is another

audio recorder in the bedroom with Nathan - they will ask consent to record with you.

We ask that you ask people for their preferred gender pronouns (e.g., if people use they/them, she/her, he/him) before you assume their pronouns.

There are invitations around the home that outline some of the ways you can participate.

If you don't know what they mean, feel free to ask.

If the number of people in the home feels overwhelming we may ask you to spend some time in the yard if needed.

There is a tent outdoors if you want some dark quiet space. Noise cancelling headphones are available if you need noise alteration/reduction.

We also posted signage next to any recording devices within the space, and had an 'opt out of video' sign-up sheet, which no audience member elected to sign. Some of the documentation from making and doing *Mad Home* is featured on the companion website (<https://madhomeproject.weebly.com/>), and I have included links to specific pages of this companion website for reference throughout this chapter.

Collaborators were invited to review the website and read this chapter, to consent to how their words and ideas are (re)presented herein, and to offer any feedback or make additions/edits/deletions of any content. I chose a process of consent and feedback over 'member-checking,' as my intention was not to determine the credibility, trustworthiness or validity of my findings, or to prove I had made 'correct' meaning of our collaborative work (for critiques of member-checking, see Birt, Scott, Cavers, Campbell, & Walter, 2016; Braun & Clark, 2013; Smith & McGannon, 2018). Rather, I chose to obtain consent or non-consent from my collaborators to use the words and ideas as they are contextualized within this written document. I highlighted each collaborator's words and ideas in this chapter and sent it to them,

requesting their consent or non-consent, and any feedback they would like to offer. I chose to ask after consent or non-consent because I cared that my collaborators were okay with how I discussed their ideas and words. It was also a way of offering the least labour-intensive means of confirming this content was acceptable to them as presented, given that each collaborator had committed a significant amount of time and effort to make *Mad Home* possible. Along with requesting consent or non-consent, I invited additional feedback as well, with the intention to offer a range of choices regarding how collaborators could interact with this written text. I received enthusiastic consent from all collaborators involved in the collective creation process, to include their words and ideas as presented here. The only edit requested was from one collaborator who requested that to decapitalize the wording of their tattoo, which I have. Along with my collaborators' consent, the feedback I received was in the form of moving love notes of appreciation and support. These love notes, to me, suggest that this written document meaningfully resonates with their encounters in *Mad Home*.

***Rummaging through our selves and practices.*** I collected self-identification information and communication preferences via a demographics form, which also included three main questions. First: "Is there anything you would like to share about other personal information or identifications relating to race, class, sexuality, gender identity, disability, mental illness experience or diagnosis, or any other information you find relevant or important to this research process?" Responses included: "non-binary trans, childhood trauma survivor with CPTSD [complex post-traumatic stress disorder], panic disorder, white middle class, bananahead, queer"; "gay! Major depressive disorder! i love to love! stump! OCD! [obsessive compulsive disorder] self harm!"; "queer, nonbinary, invisible physical disability"; and "I am a queer non-binary transmasculine being. I experience disability. Bipolar is the most front and centre of my brain

pathologies”. I would add my own response to include: white, Mad, bipolar-diagnosed, cis queer femme who grew up living mostly below the poverty line. Additionally, we have all completed post-secondary degrees, each encountering different institutional barriers, and some accessing varying levels of accommodation.

It’s worth noting here that every collaborator identified with experiences related to multiple (at least two) axes of oppression, such as gender identity, sexuality, or disability alongside various diagnostic and other relations to mental distress. Most of us did not avoid using diagnostic language here (which is undoubtedly partly structured by the question being asked). However, this language was infrequently used in our conversations throughout the process of making *Mad Home*, which indicates that it is one of the ways we name our experiences, but is not a primary way of identifying when relating to the specific others involved in this project. Resonating with Ruth Ruth’s comments above, how we name ourselves in relation to ‘madness’ is contextual and shifting.

Collaborators also responded to the question: “Do you have an artistic practice, or artistic experience? If yes, is there anything you would like to share about it?” Responses included: “love making zines, jock, love to do tactile things that makes things, finding words for feelings”; “sing + create music! ukulele! vocal improvisation! Cooking!!! feeding people! aligning bodies + diets + food + needs”; “occasionally painting, writing, gardening, putting rainbows in my home, making things”; and “I am a writer and enjoy creating online installations dedicated to my work in healing”. My own response includes dance choreography, dance performance, performance art, as well as weaving, knitting and painting (to varying degrees of speed and ‘success’).

The other main question I asked on this form was: “Do you have experience in dance or

movement-based performance? If yes, is there anything you would like to share about it? If no, is there anything you'd like to share in response to this question?" Four of us referred to past childhood training in formal dance technique, such as highland dance and tap dance. Alexis also mentioned dancing recently in a CRIPSiE integrated dance piece titled "Fix You." Nathan noted having nothing to share for this question. dales also included "bodybuilding", "EMDR therapy"<sup>23</sup>, and "Hakomi" (a body-based somatic psychotherapeutic technique).

I was taken by the vast array of practices that my fellow collaborators listed as a part of their artistic experience; I read these practices as intimate and alive and life-sustaining and world-making. They are also expansive, and qualitatively different from responses to the dance-related questions, which tended to reflect past experience in formal training settings. Given Ruth's appreciation of the art of preparing food, eating together and gardening, along with early conversations with Nathan that led me to question the accessibility and relevance of dance as the primary medium for this project, as well as these above responses, I was invited (and compelled) to reimagine what the modality of this collaborative creation could be. dales' responses to the last question also sparked a recognition that we have performance practices, beyond what we might consider 'dance,' which are connected to movement and are self-determined engagements with healing modalities that center our embodi-mind-ments. These appreciations, nudges, reimaginings, and sparks all set the stage for our *Mad Home*-making, which I will describe in more detail below.

*Invitation: Stroll Mad Home*

(<https://madhomeproject.weebly.com/>)

### **Making Mad Home**

We snuggle. Pet a dog. Dissociate. Dream. Eat 100% chocolate with mint, a taste

sensation we affectionately term ‘butt blood.’ Laugh (tired-abs, cheek-aching, involuntary-tears kind of laugh). dales brings memes about robot furnaces, poetry and zine-making, and sweet tales and tips on queer glute workouts. We challenge one another, stating needs and desires and dislikes and no-go’s: apologizing, shifting our actions and relations. Nathan crafts monologues that make the hairs on my body stand in praise, populating a whole world in my bedroom with projects that are (and make us come) undone. We actively negotiate not ‘shoulding’ on ourselves or each other. Sticky hands, flappy hands. Nathan and I Mad collaging on their hotel bed, layering and gluing together timelines of now and the moments that have been carefully collected over the past fifteen years. We massage knots out of each other’s shoulders. Sing songs to each other: “I wish it was Christmas Day” (dales) and “hello darkness my old friend” (Alexis) and “mmbop” (Lindsay). Alexis leads us in a sensory encounter with food: we cover our limbs in chocolate sauce, mix garlic and smoked paprika and dates, take bites out of an onion, touch smooth wood cutting boards and sharp knives, eat combos that make us cringe, and love the cringing. “I get to make a sparkly jar, I get to put avocado on my body, I get to paint people I love. Like, what the fuck, man?! This is amazing” (Alexis). Sarah grows plant babies for potting (black pansy and lavender and other scent-rich herbs), and teaches us to make glitter jars with a lusciously loose recipe. We pour too much glitter and then pour some more, “making it worse,” which is sometimes better. Create swirling cosmos, and a toy dinosaur graveyard. Sharpie sharpie sharpie, potato potato potato. We like dogs and succulents more than most humans. Swing on a porch swing. We talk about bell hooks’ notions of love (2001) and Alison Bechdel’s *Fun home: A family tragicomedy* (2007), and Sarah Ahmed’s feminist survival toolkit (2017). We bring our favourite books to litter the home: Star Trek aliens and Eva Hesse who used caustic materials to make magnificent sculptures and went “a little like us” (dales). I collect pots and

papers and paint, glue and glitter, soil and snacks, bananas and tents. Alexis makes us waffles while we share our wants and needs with each other before we opened the doors to our *Mad Home*. We challenge our perfectionism, reminding ourselves that this can't be 'done,' and that "perfection harms me 24/7" (dales). We invite Danielle in to help us hold space, for us and for others, so we can be in our *Mad Home* without being forced to perform as 'host.' We work to hold both physical and psychic space for our differences, our distance, our specific needs and desires, and our unique artistic practices.

Some elements that shape our *Mad Home* include: becoming affected by friends and ancestors across time and space; decorating our walls with the stories we want to tell; finding home through dialogue; honouring our needs and desires in collaboration; inviting into discomfort and distress; curating for anti-pathologization, access, and support; curating for memory and breaking-as-resilience; curating *Mad* sensory worlds; and sharing *Mad Home* beyond these walls. I will discuss each of these elements of *Mad Home*'s making here.

### **Think-with-do-with-be-with: Becoming Affected by Friends and Ancestors Across Time and Space**

research-creation involves an ethical commitment to learning to become affected...by the relational movement of bodies, and a political [commitment] borne of the claim that we can never determine in advance the kinds of relational matrices of which bodies are capable of becoming involved. (McCormack, 2008, p. 9)

In research-creation we must value, and open ourselves up to the possibilities inherent in, relational engagements that cannot be predetermined or predefined. This call to center unpredictable relational engagements encouraged me to (re)consider what the constellation of humans involved in this project could make possible. This kind of relationality invited

divergence from my initial intent to create ‘dance,’ in order to think Mad making more broadly.

Adams, Holman Jones, and Ellis (2015) argue that “one approach researchers use to enact relational ethics is ‘friendship as method’” (p. 61). This involves prioritizing and nurturing relationships, continuing relationships beyond the scope of the research, explicitly addressing potential conflicts, and the ongoing negotiation of issues including “confidentiality, loyalty, and critique in ways that meet both the demands of the friendship and the demands of research” (p. 61). Margaret Price, with Leah (Phinnia) Meredith, Cal Montgomery, and Tynan Power, (2011) use friendship-as-method in the context of conducting research with diverse Mad, neurodiverse, and disabled folks. These authors discuss friendship-as-method as both a practice of, and a way of learning about, in/ter/dependent scholarship. Further, they discuss it as a practice that both imposes and demands mutual vulnerability, deep reciprocity, and specificity in relational practices (for example, what one friend needs will never be the same as what another does).

This project, in many ways, began out of friendship. Eight years ago, and very early on in our burgeoning friendship, my now-partner Danielle introduced me to Cvetkovich (2007) and the idea that depression is political. Mad theory, Mad community, and Mad living may have very likely otherwise eluded me. Together we practice interwoven enactments of crip and Mad politics, ethics, and aesthetics every single day: fumbling, fucking up, reveling in the sexy, and holding each other in the devastating. Although Danielle was not an official research participant, my collaborators called them into a vital role within the performance of *Mad Home*, as someone available to hold space and debrief with anyone who was in attendance (including audience members and performers alike). Danielle was chosen for this role in part because they already had existing friendships with many of the collaborators involved.

Nathan, a long-time friend of Danielle’s, was truly my first Mad life-line. They have

brought me magic, and reflection, and resonance, and healing in so many forms. We have dreamed together for years about art and life projects that are too numerous to count, some traces of which were present in *Mad Home*. Most of these, as Nathan so beautifully puts it, are “undone” (not half-done!). In the “undone” lies a sustained bubbling of magnetic creative energy, newly imagined pasts and futures, a commitment to growing old together, and deep tenderness for our affectionately (and seriously) termed difficulties living in “earth-time” (a term I learned from Nathan that is an intensely affirming reminder that time is constructed, often to our exclusion).

Beyond admiring dales’ activist practices for many years, I was fortunate enough to spend summers with them in 2016 and 2017. We’d dig in the dirt, plant nourishment, share about how sanist violence has played out in our lives, and dream about affirming spaces for existing with mental distress. We imagined together about non-traditional holistic healing centers that do not pathologize, a place to go for support without threat of institutionalization, an accessible way for someone to come and sit with you when you want to die. dales’ self and community healing practices, enacted through intimate conversations, dance party DJing, space crafting (both earthly and stellar), and online provocations to name a few, have moved me immeasurably and offered vital scaffolding for the construction of *Mad Home* even before we knew what we were building.

Alexis and I have shared a stage, and we work together with CRIPSiE’s board, but it was her gift for crafting community through food that was one of the more intimate ways that we connected before *Mad Home*. She graced our kitchen for weekly vegan gluten-free brunches that were designed with deep care for two different (and somewhat conflicting) medical-related diets that Danielle and I were attempting at the time. Our time together was a nourishing reprieve, an island of possible in what felt impossible. We came together messy and hopeless and giggly and

honest, floating in and out of conversations on crip and Mad living and loving, and filling our bellies with wonderful easy feasts. Her approach to crip world-making through food, using her stump and her heart and her joy, brought me to a deep valuation of how making and eating together can be a vital political act.

I have learned of Sarah's wonder in part through dancing, in part through support work that she has provided with CRIPSiE, and in part through our shared experiences of navigating the completion of an occupational therapy degree with experiences of mental distress. Her thoughtful, generous, and intensely collaborative ways of being with disability, in work and play and friendship, have long been a model for the ways in which I hope to exist. Her celebration of the critical importance of personal experiences of disability in occupational therapy practice remains an exemplar and an engine for my own continued engagement with the field. Her labours of love in bringing plant babies to life, and divining home with her community, and attending to sensory needs and pleasures and possibilities, are parts of Sarah's artful ways of living that have sparked me, and are also central to many of the elements that make up *Mad Home*.

Each of these people also had various connections to each other before the project started, either through queer community, activist organizing, single degrees of separation that included "you must meet this person!", or online admiration of each other's work and ways of living. Working with these friends on this project makes space to honour the notion that thought is always already co-created (Manning, 2008; McCormack, 2008; Portanova, 2008). If we take the co-created nature of knowledge seriously, collaborative research is a valuable tool for co-creating and sharing embodied, experiential, presentational, and practical knowledge (Heron & Reason, 1997; Liamputtong & Rumbold, 2008). As Manning (2008) argues, "movements of thought are

thinkings-with as much as thinkings-about” (p. 17). Undoubtedly, even before its official inception, this project was already a “thinking-with” (Manning, 2008, p. 17), as well as a making-with, doing-with, and being-with.

This ‘thinking-with’ also calls upon an expansive web that connects us to ancestors across time and space. Also critical in the web of relations that enable our thinking-with-doing-with-being-with in *Mad Home* is the land we occupy. Being white and white-passing settlers, it is vital that we acknowledge that we make our home on stolen land. As settlers with white and white-passing privilege, our capacity to make home in Amiskwacîwâskahikan is enabled by structural violences enacted through histories and presents of colonialism, eugenics, and cultural genocide.

*Invitation: Acknowledge our home is on stolen land. Acknowledge our ancestors, and those in attendance across space and time.*

Below is a transcription of collaboratively developed signage posted inside *Mad Home*:

We acknowledge that the land we gather on is Amiskwacîwâskahikan, a traditional meeting ground and home for many Indigenous Peoples, including Papaschase, Cree, Dene, Saulteaux, Blackfoot, Métis, Ojibwe, and Nakota Sioux.

We acknowledge and hold space in our home for those of us who could not be here in physical form today.

We acknowledge our peers across time and space - who did, are doing, or are desiring this work, who may be or have been prevented from doing it, and those who will do it in the future.

This was a particularly important point of reflection for us, as we talked through how to acknowledge those who we are in relation with in this kind of artful living. Our work is in

conversation, for example, with past and present (and future) artists, and academics, and the other Mad folks that Ruth Ruth importantly insisted we recognize. Ruth Ruth stated that:

we are descendants [of Mad ancestors] ... so a hundred years ago we would have been locked up, but now we are able to pursue higher education! And have meaningful lives, and make social change. We are duty bound to make social change because we come from the margins.

Notwithstanding the fact that many people are still locked up around the world, differentially based on race and class and gender and sexual orientation and disability, I resonate with Ruth Ruth's call to acknowledge our ancestors and to mobilize both our privilege and our marginality.

We also create our *Mad Home* in relation with theorists, and for me, Ahmed's (2017) work echoes off the walls of *Mad Home*. Certainly, Ahmed dances with madness throughout *Living a Feminist Life* (2017). She writes on "shattering experience" (p. 12) and personal and collective "breaking points" (p. 187) and "losing it" (p. 194) and the feminist "snap: when she can't take it anymore" (p. 190). She writes of the killjoy, "one who does not make the happiness of others her cause. When she is not willing to make their happiness her cause, she causes unhappiness" (p. 74-75). She goes further, stating:

We can be made ill by a diagnosis of being ill. So many feminist women lived their lives at the border of sanity. Feminists have paid a high price for the failure to give up their will and their desire. A feminist history is thus hard to disentangle from a diagnostic history, a mad history, or a history of madness. Not only have feminists been agitators, many have, in agitating, crossed the border between sane and mad, a crossing that has led to confinement and death. Many feminists became what Shayda Kafai (2013) calls astutely 'mad border bodies,' bodies that expose the instability of the distinction between

sanity and madness in how they travel through time and space. (p. 76)

In this project, we are in conversation with Mad, and feminist, and anti-racist, and queer, and trans being-and-thinking-and-doing. We are also in conversation with: site specific art practices (Kwon, 2002); dialogic art practices (Kester, 2004); art centering labour and care and support and ‘social practice’ (Jackson, 2011); life-as-art and sensorial art and food-based art practices (Kirshenblatt-Gimblett, 1999); crip art that makes space for pleasure in pain and harm, such as Bob Flanagan’s work (see McRuer, 2006); and Mad performance like Marni Kotak’s *Mad Meds* (see Schwendener, 2014) and Kupper’s *Traces* (2004). These are some of the ancestors, the agitators, the “mad border bodies” (Kafai, 2013) of pasts, presents and futures, who we hope to think-with-do-with-be-with in our *Mad Home* work.

### **Decorating Our Walls with the Stories We Want to Tell**

For the collaborators on this project, settler privilege, white and white-passing privilege, as well as class privilege, interact with precarious employment, psychiatrization, government-enforced poverty, and omnipresent micro- and macro-aggressions to structure our varying access to secure and stable housing. Access to the literal materiality of a home—four walls and a roof, locking doors—*matters*, and is more precarious for some of us than others.

Ahmed (2017) writes about walls as a complex metaphor and as hard-felt materiality. She points out that “**walls are how some bodies are not encountered in the first place. Walls are how other bodies are stopped by an encounter**” (p. 145, emphasis in text). She writes of border walls, institutional walls, and asylum walls. We are locked up, locked in, locked out differentially depending on how our bodies are marked. She writes of “diversity work as a ‘banging your head against a brick wall job’” (p. 135) and unpacks “what these walls teach us about the materiality of power” (p. 91). She highlights that:

those who don't come up against walls experience those who talk about walls as wall makers...the feminist killjoy is understood as a wall maker...the one who makes things harder than they need to be; she makes things hard for herself. (p. 141-142)

When we are 'too flaky' or 'too attention-seeking' or 'too demanding' or 'too negative' or 'too much,' our Mad existence is cast as a wall of our own making, and a justification for the threat of locked up in a mad house, or our unequal access to spaces where we can find home. Mad ruckus makes wall-makers of us.

Ahmed (2017) also calls out "heterogender as wall" (p. 214). Speaking of what I would consider micro-aggressions (and certainly sometimes macro-aggressions), she notes:

a history can become concrete through the repetition of...encounters that require you to put the whole of your body, as well as your arms, behind an action. Maybe these actions seem small. Maybe they are small. But they accumulate over time. They can feel like a hammering, a chip, chip, chip against your being, so that eventually you begin to feel smaller... **Actions that seem small can also become wall.** (p. 217, emphasis in text)

Micro-aggressions, be they borne of heterogender, racism, and/or psychiatrization, are wall-makers too. Living queer, and non-binary, and trans, as well as Mad, and disabled, our bodies bear the weight of this concrete, slathered daily by the insidious violence of a word, a glance, a noise, a non-consensual touch.

Further, "**a wall is a catalog. A history of what comes up**" (Ahmed, 2017, p. 149, emphasis in text). Nathan's work on "Undone," confined to the walls of my bedroom, featured their Mad-making history literally scribbled over walls. It was a catalog of brilliantly undone projects and sensations and reminders and experiences and encounters with madness and art and the art of Mad living, in sharpie markers of the past and sticky-notes of the present. Like

Nathan's work in *Mad Home*, Ahmed asks, "**if the walls could talk, what would they say? We need the walls to talk. What a story**" (p. 220, emphasis in text).

The *Mad Home* walls were filled with stories: "NOPE" taped across the front window; Mad paintings of rainbows and trees and pill bottles and shattered faces; hand-written posters with stories that invite various ways to participate; drawn maps of the *Mad Home* floor plan; recipes for glitter jars and sensory food play; photos of Mad tattoos inked into our skin; magnets holding survival tools on the fridge. Sparked by dales' poem "deep dark blue," an invitation to wade into our darkest waters, we also created a collective wall mural in our *Mad Home*, painting a collaborative story that our living room wall could tell. Each collaborator chose a paint color to reflect their own 'deep dark blue.' We labeled each of our paint tins with instructions, such as "please use with Lindsay's consent" or "for use by [a specific set of people]", and included an additional color of deep dark blue that could be used by anyone. We used fingers and brushes and our bodies to craft an evolving, swirling, textured and winged invitation to "Stay Mad". This work is reflected in a time-lapse video hosted on the *Mad Home* website:

<https://madhomeproject.weebly.com/stay-mad-mural.html>

Ahmed (2017) insists that:

we have to keep trying. We want the walls to come down. Or, if they stay up, we want the walls to talk, to tell our story. A story too can shatter: a thousand tiny little pieces, strewn all over the place... in making an ordinary out of the shattered pieces of a dwelling, we dwell. **We dwell, we tell. How telling.** (p. 222)

I experience *Mad Home* as both a story that can shatter, written all over our walls, as well as a site of complex collective self-care. Throughout our collaboration, many of us spoke of caring for ourselves in pieces, or caring for others when we can't care for ourselves. Ahmed (2017)

draws on Audre Lorde's articulation that "caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare" (1988, p. 131). Ahmed (2017) writes that:

in queer, feminist, and antiracist work, self-care is about the creation of community, fragile communities... assembled out of the experiences of being shattered. We reassemble ourselves through the ordinary, everyday and often painstaking work of looking after ourselves; looking after each other. We need a handle when we lose it. A killjoy survival kit is about finding a handle at the very moment one seems to lose it, when things seem to fly out of hand; a way of holding on when the possibility you were reaching for seems to be slipping away. Feminist killjoys: even when things fly out of hand, even when we fly out of hand, we need a handle on things. (p. 240)

For Ahmed, these 'handles,' which compose her feminist survival toolkit, include books, things, tools, time, life, permission notes, other killjoys, humour, feelings, and bodies. She writes:

**"wiggling is in my survival kit. Dancing, too"** (p. 247). What moves me is how each of these above 'handles' were featured, in an intensely literal sense, so prominently throughout the home we made together. *Mad Home*, in all of its iterations, is an enactment of a queer Mad survival kit "assembled out of the experiences of being shattered" and the stories we want our walls to tell (p. 240). I will tell some of these stories here.

### **Finding Home Through Dialogue**

Meaning-making through dialogue and art creation was an integral part of this collaborative creation process, in line with the tenets of participatory research, and an arts-based research paradigm, which I discussed in chapter two (Conrad & Beck, 2015; Conrad & Campbell, 2008). We engaged in dialogue, both through, and in addition to, art-making. For example, we began by talking together about what we imagined this research-creation project

could be. Drawing inspiration from my conversation with Ruth Ruth, and conversations that span years with my other collaborators about dreams and desires for being together madly, I threw out an idea to play with the notion of “mad house” versus “Mad home.” Here is some of the dialogue that ensued:

Alexis: Thinking about my own relationship with madness and mental illness and all that stuff, and thinking about the home, it just, at first, I’m like, yeah the house! It’s so warm and awesome. And then, with madness I hate being home and I love being home all at the same time. I can’t escape it but it’s the only place I can be all of me... so I think that there’s a lot of, for me anyway, a lot of potential to be in a space like a home or a house kind of thing because there are rooms that are so full of darkness and then there are, you know, great places of solitude. So, there’s, I think, a lot there.

Sarah: A thing that kind of came into mind for me when you were talking about this is sort of the idea of... trying to imagine I guess what a society could look like, what a place could look like that embraces madness. And so, something like trying to, in some small way, create a little pocket of an experience, that lets people come and participate and bring their own ideas and their own madness to it, and just sort of what could society look like, in this small, I want to say the word microcosm, but I don’t have a sentence for it, so.

dales: Yeah, I think being able to capture the multiplicity of what a home is, you know. Cause for me sometimes, I gauge my sanity by if I have gone out of the house or not. Like I did that today, I was like, I have to just, you saw me at Earth’s [General Store]. I was like, we have to go for a walk because I haven’t left the house and if I don’t leave the house today that means that I’m insane.

Group: [laughs]

dales: Right? Like, that's just it, check the box, good! Doesn't matter what's going on, doo doo doo doo doo, I went out! That's literally,

Sarah: I have done that before, I have totally done that before. Like, I just need to get outside.

dales: Like I want a door that when I open it, it just goes "WOOOOOO!!!! You went outside!" and then you can go back in. And with like horns, and like confetti going. And I'm like "I did it! I'm going back to bed!" [laughs].

Group: [so much laughing]

*Invitation [dales']:* Make your front door celebrate your leaving,  
and rain confetti when you return

Through this dialogue, we spoke of home, as Nathan articulated, in terms of "the complexity of it being a haven but also sometimes a hole." Alexis noted that, for her, home shrinks and expands with mood cycles. Sarah and I, and Nathan and I, talked of our relationships to home being shifted by medication—the ones that make us get up and go, and the ones that make us sink deeper into the body-shaped indent in our bed.

*Invitation [Nathan's]:* "Seroquel Face, Ativan Face, Seroquel Face, Ativan Face..."

We traced the borders of our home, sometimes marked by the bed frame and the toilet. Envisioning their participation in *Mad Home* as a participatory performance that took place within the boundaries of the bedroom, Nathan noted:

I just thought about being in the [bed]room, because then, you know I can talk about how frequently the only thing that gets me out of bed is having to go to the bathroom. But then, I really wanted to have a space where, also, there was no permission to leave. And not just by my mind, but you know, being a formal patient, for example. I have a whole thing about that, and it just feels like it's nice to try to leave and not be able to.

Crafting *Mad Home* offered a chance to (re)present Mad commitment, of both the involuntary and the voluntary kind.

We also discussed home as marked by ritual, born out of trauma-survival tactics. We spoke of rituals of control, rituals of choice, rituals of protection, rituals of isolation and connection, rituals of care, rituals of pleasure and pain (sometimes together). We shared of the importance of impenetrable walls, where locking doors can be a ritual of safety from harm, especially in the context of histories of trauma. Sometimes we need walls. Ritual resonated deeply for Sarah in her past experiences of living abroad. Ritual was also vital for dales as they embark on “operation hermit crab,” shifting geographical spaces and making home on their back.

We chatted about how we invite people into our home, cautiously, and the value of being social without leaving our home. Both Sarah and Alexis commented on the importance of mad-relating with roommates. Alexis shared:

It was my first beautiful experience living with people I’d known for a while, like past friends and stuff, who all had different relationships with mental health, and had really diverse needs, and I was like, oh fuck. It was actually kind of a bit what we’re talking about, what it felt like to live in a Mad home. Because, we just had, you know, shit didn’t get done. We didn’t make eye contact if we didn’t want to, we were alone in our rooms for 47 hours and nobody, you know. We would just be like ‘do you want some water?!’ ... the way that we would check in with each other, looking back on it, was so queer and awesome. I don’t know, it was just a neat lesson, and so different than any other relationship in a house that I’ve ever had.

In sharing about our relationships to home, and to Mad home, we began to learn from each other about the specificities of how we would like to relate in *Mad Home*.

Through this dialogue we dreamed. We dreamed and dreamed and imagined and schemed and dreamed. We need to be able to dream together. We dreamed of what our perfect home would be: an apartment building or commune with shared outdoor space and private indoor space. We dreamed of what a radical Mad house would be: a respite, a community gathering space for Mad doula-ing and collective care. dales shared the image of a “Polly Pocket” clamshell, where someone else could carry you for a while, because “sometimes home isn’t the right home.” We made space for dreaming in *Mad Home*, including Sarah’s idea for ‘wanted ads’ placed on the fridge alongside a collectively generated Mad survival toolkit: a site of nourishing possibilities for stating what we are dreaming of, and maybe finding some ways to fulfill these dreams. Some of these wanted ads were hauntingly beautiful: “I want to move freely, without pain”; “I want to have confidence in my choices and thinking”; “I want to be good enough”; “I want to know I am not a monster”; and “I want a father who wants me alive.” Queer crip Mad dreaming is a powerful, difficult and beautiful thing. We also dreamed of more time together, more time after we opened our *Mad Home* doors to others, to work and play and commune and co-exist.

Crafting *Mad Home* became in part, as Sarah articulated above, a space for utopic dreaming that “in some small way, create a little pocket of an experience, that lets people come and participate and bring their own ideas and their own madness to it, and just sort of what could society look like.”

Through our dialogue, we also turned and (re)turned to the vital importance of non-linearity, multiplicity, complexity in relation to madness and to home and to performance and to ourselves and to each other. We are complex, multiple, non-linear beings, and wanted to prioritize holding space for this in our *Mad Home*.

dales: The idea of operating in a home is more comfortable for me. Like having it be a really solid thing that...doesn't necessarily have a beginning/end temporality, which to me is stressful. Linear lines of progress really fuck with my head, so the fact that it wouldn't operate in the way that I traditionally think of performance as, like, 'here's the intro, and then you do the thing, and then there's the big finale' right?

Sarah: 'And you have to do this thing at this exact time'

dales: Right?

Lindsay: 'And this is where the audience sits [mimes a proscenium stage] and that's where you are'

dales: Yeah, and even just the idea that, I think there's value in discipline, but the disciplining can be something really different in creating this piece. Yeah, because the linearity of other ways of maybe doing it is very uncomfortable for me. So even just using home as the base from which we explore on, I think, works really well for me, because it creates a certain level of comfort while at the same time...there's a LOT that comes out of it as a starting point for me.

Lindsay: Awesome

Sarah: Yeah, I really like what you said about home having space for a lot of other things too, so that even if we do decide to pull in other aspects, it's not even necessarily other. It can still fit within home.

Alexis: Mmhmm

dales: Cause my idea of home is all of it, right? Like, and I don't think that I would necessarily call it home, but when I'm in a situation when I'm asked to articulate my politics, it's so more people can bring more of themselves more of the time. Right?

Group: Mmhmm

dales: And so, like, involution, which is a theoretical big word, but means to make more complex, and that's my underlying ethic as a Mad person, is for there to always be more space for more complexity. And so, that's what a dream home would be, it would hold everything. And not even in a way, like, the idea of holding is even limited, but

Alexis: You know, it's interesting you say that because, like, I didn't think about it in relation to this at all, but my secret dream with Stump Kitchen and stuff is to maybe, maybe, one day, whatever! I'm dreaming! I will have a restaurant, it will be tiny, it will be called Stump Kitchen. It will be universally accessible, and you will sit on stumps for chairs that are fucking comfortable, and all of the chefs will have limb difference, and...you can eat whatever the fuck you want, and it will all be vegan and gluten free, and nobody will need to feel bad or guilty that they can't have soy, or like 'please put the peanuts on the side' and it's not like your fault. Like, it would be...as inclusive and complex space for outside food eating as possible. Just because, from working with CRIPSiE and working with Brailletones and different things that I've worked on throughout my life, and being in those spaces that feel so close to that ideal, or that ideal, it's like 'ah, fuck, yeah! How do I take that into all aspects of our lives?' So, anyway, dream-time done. That would be a good.

Sarah: NOT DONE!

Group: No!

Alexis: Dream-talk done. But, still alive in my head. Definitely.

From this discussion, I take away the vital role that complexity, non-linearity, multiplicity, and dreams played in our *Mad Home* making. Fostering complexity, non-linearity, multiplicity and

dreaming in this project supported us to, as dales articulated in the above discussion, “bring more of ourselves more of the time.”

Other people found home here too. Danielle reflected, after holding space for folks who attended *Mad Home* in person, that they experienced people floating through our participatory performance “until they found home:” that each person who entered appeared to have found home in different places, precisely because it was complex, non-linear, multiple. For example, some people wandered, picking up books or tasting food, until they landed in an hour-long conversation with Nathan in the bedroom. Some hung back and witnessed us paint a wall mural, checked out photos of our Mad tattoos in the hallway, and then gravitated to the kitchens and spent significant amounts of time crafting “wanted ads” and posting them on the fridge. One person entered, scanning zine-makings and touching glitter, until they found a copy of *Loose Leaf*, which they then sat with and read from end-to-end. I experienced similar floatings and landings, scanning the curated chaos and then diving into paint, followed by dirt, followed by glitter. The complexity and multiplicity of our non-prescriptive participatory invitations meant that each of us could follow our whims and pulls, and find a place or two (or more) to call home.

### **Honouring Our Needs and Desires in Collaboration: Control, Separation, Parallel Play, and Flaky Pie**

Our Mad collaboration was not one of equality. This is important. We are not the same. Our capacities to offer presence and resources and connection often shifted, ebbed and flowed. I think that we gave what we could, did our best to ask for what we wanted, and took some of the things we needed. We did this in part by prioritizing the practice of articulating our needs and wants, which included control, separation, parallel play, and flakey pie.

We shared about our needs for control, and how that manifests in relation to home. dales

shared their need for control in terms of the materiality of their socks: “I live by myself, I have my own home, my socks don’t move. Like moving socks actually causes me a lot of feels.

[laughs].” Sarah later reiterated the importance of control:

Sarah: I’m smiling a little bit, like, what you were saying about control, I’m like yeah! I just have my things that I control in my home, and everybody just goes with it.

Group: [laughs]

dales: It’s like actually becoming kind about my needs.

Sarah: Yeah!

dales: Like, alright, I had no power and so like, I’m obsessed with being separate. I’m *obsessed with being separate*. Cause, being connected is like, not very safe for me.

Group: Mmmm

dales: And I, like, really love having a sense of control. because I didn’t for a really long time, both interpersonally, and then surviving. I had no idea what was going on, so I didn’t feel like I had any control over myself. Yeah, so just being like, those drives are so legitimate, and those needs and wants are so legitimate.

Group: Mmhmmm

dales: And I’m still, like, responsible in the world for how I meet them.

Group: Mmhmm

dales: Which, for a long time I couldn’t even fathom. I was like ‘no! I just have to do them.’ And I just like did a lot of harm that way. Um, so, yeah. Just realizing, you know.

dales’ beautifully articulated reminders about the importance of validating our needs and wants—especially those that take root in the ashes of trauma— while still working to hold ourselves accountable for harm that may stem from them, became a new ethic for me that I feel

into in fleshy ways daily. We worked to honour our needs for control by each taking on specific tasks or rooms or experiences in creating our *Mad Home*, and by considering how we could enable the participation of others in this space while having the capacity to engage or disengage throughout the time that we spent together (with and without an audience).

Our group's collaboration often included being separate together: dissociating; cancelling; opting out of activities; co-existing in *Mad Home* by jumping from corners to tents to conversations to bedrooms to wall murals to books to bathroom talks with bananas. Throughout the process, we spent different amounts of time together, virtually and in person. We worked alone, and together, and alone together. dales' articulation of the importance of being separate also resonated within my conversations with Nathan, and invited me to (re)consider what collaboration means. Nathan shares:

In terms of collaboration in this thing, I was thinking about how, there's a thing about parallel play<sup>24</sup> here for me that's really important. I'm introverted, I don't want to be around most people at any time...and I was just thinking about, again, this question of interdependence for non-extroverts. It didn't occur to me that I could need interdependence and still be an introvert, that there's a way for that. Because I do the most and best work in the company of particular people.

Art-making through parallel play created space for the introverts (and introverted extroverts) we are. This way of making invites quiet co-existence. For us, it also invites the possibility of gentle conversation that meanders and babbles through laughter and darkness, often together. We float in and out of talking, and are buoyed by interdependent relating that makes space for us to be, as dales puts it, "separate" but not necessarily alone. It also offers (at least me) the opportunity to negotiate anxiety by being able to check in about the sticky points, the stuck points, and find new

ways to flow.

We also spoke together about valuing friends (including each other) who cancel at the last minute, who ‘flake’ on us, and the important work this does for our sense of possibility and connection and love. On cancelling with friends, we shared:

dales: I always say, I love flaky, pie is flaky, I LOVE PIE! Flaky like pie! And like, who doesn’t love a good flaky pie!

Group: [laughs]

dales: You know?!

Lindsay: Truth! Right?!

dales: It’s just like, you’re just like pie! And I love Saskatoon pie! Yeah!

Alexis: I guess, just for information, I read something that we haven’t, like it’s just such a new thing, right? that... if I do that for you, it gives you more permission to do that for me, and it’s like you’re actually giving yourself and others more space to have their needs met in a safe way, and with love, rather than be like I’m such a bad friend I have to cancel.

Fuck that! like, you are awesome because you are being kind to them and you, and

dales: Yeah, you said the word love, and I feel like, it’s very theoretical of me but it changed my life. So, bell hooks has a book on love, *all about love*, and if anyone...has experienced any harm in their families, cause...like, who hasn’t?

Lindsay: Mmhmm

Alexis: No kidding

dales: ...For me, as someone who experienced a lot of harm from people who were defined as people who loved me, it really undid me in many ways. But she defines love very specifically, and she makes a difference between, like, affection and kindness and all of,

intimacy, are all different things, and the way that I understand her definition of love is [that] love is like taking the risk and doing the work of helping each other grow.

Group: Mmmmm

dales: That's what love is.

Alexis: Yep. For sure

dales: ...So for me that's what that is, and to me that's a very queer crip idea, right? It's like I'm not telling you where to go, it's not about control, it's not staying the same, it's actually about growth. Spiritual and emotional wellbeing.

Lindsay: And not needing you to be 'better' in that

Alexis: Give you space

Lindsay: Where like, you need to be

dales: ... So that, for me, the idea of 'how do you greet each other and like support each other with love?' For me, like, I love my flaky friends. And I love being able to be like 'no!' ...I have one friend who I am the only person who shares that ethic with them, and they are always in such turmoil with their, like even just being clear with boundaries, and all of these things that I think you are more engaged with when you're Mad,

Group: Mmmhmmm

dales: And just being like, 'no, every time you do that, it actually helps me grow.' Like, every time you do the thing that you need, not just do what I need, it helps me grow.

Alexis: Mmhmm

dales: Because I need to see other people do it. And I need to have it modelled in front of me.

Sarah: Well, and if you show me that you'll do it, I'll trust that you can do it, cause otherwise I'll just be second guessing all the time, and be like 'are you sure you want to do this thing?'

Cause people so often say things that they don't mean, and I can't tell the difference.

Lindsay: Hmmm

Sarah: So I'm always questioning.

Alexis: Yeah, and it makes it so uncomfortable. [pauses, takes some guacamole]. Ah! I hate it when the chip breaks!

Group: [laughs]

dales: Oh, but then you get to double dip!

We trust people who model flakiness, who live Mad and tell us. Trusting our Mad choices, and by extension the choices of others within the context of our *Mad Home*,<sup>25</sup> matters to us, especially when there are many other things we can't necessarily trust: memory, other people, 'safety,' suicide hotlines, therapeutic professionals, 'reality.' We worked, through *Mad Home*, to model (for ourselves and for others) how we can honour our needs and desires for control, and separation, and parallel play, and flakiness, as radical acts of growth and love.

### **Invitations into Discomfort and Distress**

Sometimes we felt uncomfortable. For example, Nathan and I talk about the precarity and discomfort of joining a group of humans that they admire but had not yet met in person. This project is intimate and this particular set of complex relations—shaped by geography and earth-time and new people in close quarters—was a brave dive for Nathan to take, even if they were jumping into open arms. I danced with my own discomfort as well, wanting to make everything feel safe and good (such a contradictory sentiment for a Mad process that hopes to honour complexity and diverse affects). I imagine others dabbled with discomfort as well. We certainly all, at some point, shared anxiety, and panic attacks, and being triggered to frozen: all whirlpools that swirl *Mad Home* into relation with our other living feelingscapes.

What is interesting about this discomfort, is, in part, that we invited each other into it. This is not something that is easy for me, yet in this process I found myself exposing those things that I hid before. It seems that others did too. Alexis shared about her panic attack that resulted in projectile vomiting. We laughed and celebrated the wonders of a panic-body that can produce such volatile and magnificent reactions. We shared what we look like when we are triggered, dissociated—rocking or repetitive body movements, blinking or searching eyes—and specifically about how we would like to be approached in these moments, including that we may very well want to float away, and that that is a welcomed possibility. We also shared about the value of being able to ask for what we need in our discomfort, if we can articulate it. Sarah shared:

I think that's the thing, is being around people where you can ask for you what you need, and that's okay. Or like, if somebody doesn't react the way you need them to, you can just be like 'whoa! Let's try that again, I need some care for this, I need some more sympathy here, try again!'

dales also noted that it is okay to sometimes not have the words, and shared a strategy that works for them. They added:

Don't get unsettled by not having words for it either, I think is important for me... I think everyone has experienced people who, when you lose it and you can't use words and you can't do it, they don't know what to do, you know? Which is my only thing I negotiate with people is like, if I get triggered, can you just not leave the room unless I ask you to? You don't have to do anything else, just please don't leave the room because that will not end well for me.

Being together in our discomfort and our distress, and sharing ways that we might invite others

into co-existing with these experiences, was a vital practice we developed together in *Mad Home*. It is a vital practice because it makes living, and being there for each other, possible on our own terms. It is a way out of the isolation of feeling scary or difficult things alone. It is a way of being recognized and held without needing to be fixed. Nathan shared a story, that was also composed as a monologue for performance in the bedroom space, to describe their invitation to relate in and through discomfort:

Nathan: I'm in a very stuck moment, which is fine. I realize the project that's happening [in the bedroom] is sort of collapsing my office and my bedroom into a single space...what I am realizing about this, though, is that I made this little world so I don't have to ever leave that room, which is how my bedroom is, and also my apartment, and also my block, and also the five-block radius, like I have these options. And, but also that's very lonely, and I'm not interested in most people, like I like succulent plants more than most people, but I'm very interested in you...And, I think, I'm just really trying to be curious. However, my social anxiety is extremely enormous, and it's much enormous-er around people I admire, so, if I seem withdrawn or closed or I look at you and I can't say words, it's not you. And also, okay, can I explain with a story? It's easier with a story.

Group: Mmhmm!

Nathan: So, my ex-husband's grandfather had Parkinson's' Disease, and he got to a place where he could walk until he reached the doorway, and then he could not, he *could not* walk through a doorway. And, you know, for years, there's all this therapy, all this stuff, he couldn't get through a doorway. And, okay, fine, they figured out ways to sort of deal with this in the place that he was living, and anyway one day my ex-husband visited and, [whispers] I hate that word. Anyway, this person visited his grandfather, and his

grandfather had these magazine holsters on either side of his walker. Many many magazines, right? So, he looks at his granddad and is like ‘um, that looks really heavy, is that helping you? What about that?’ And his granddad...just kept walking down the hall, and they kept walking down the hall, and they were approaching the door, and he was about to help him turn, and the grandfather raised his hand and he threw the magazine in the door. He could not walk through the doorway, but he could step over a magazine.

Group: Mmmm!

Nathan: And so, I’m similar to that. If I get in the freeze-up, I can’t initiate much myself, but I invite you to toss a magazine, whatever that might look like for you. And I will endeavor to step over it.

We reveled in this story of *crip generativity*<sup>26</sup>: that is, we reveled in this story of accessing and honouring the brilliant new ways of moving through the world that disability creates. And we threw magazines down for each other: giving space, making space, eye contact and smiles and gentle confirmations that we want each other, here, in our *Mad Home*, however we are. And we did the stepping too: these magazines as bridges, minding the gaps, and bringing us places we desired to go, with support.

There are many different tools that we used when deciding where we wanted to go together with this project. Our decision-making was largely collaborative, though not necessarily about consensus (see Eales & Goodwin, 2015). Within this process, we didn’t all have to agree, or want to agree, but worked to honour multiplicity instead. We used many different decision-making tools. One tool was consent: ‘Can Nathan take over the bedroom with their work?’ All enthusiastically consented!; ‘Will throwing dishes out the window make the yard unsafe for our puppy?’ Possibly, so... no consent. Another tool was ‘yes lets!’ (cover ourselves and one wall in

chocolate sauce and paint). Yet another tool was asking ‘what is the potential for harm here?’: we asked this, for example, when crafting ‘content FYIs’ about suicide and trauma and other hard things. Invited by dales’ articulation of the importance of validating our needs and wants, we also made decisions by asking: ‘what are our needs and desires and passions?’ (e.g., making zines, sharing our poetry, digging in dirt, eating chips); and ‘what do we keep returning to?’ (e.g., the sensory, the living, accessibility, and radically (re)imagining how to expand our practices of participation).<sup>27</sup> Further, we asked ‘do we have the skills and resources to pull this off in the time that we have?’ (e.g., none of us know how to make a confetti canon, so a couple of signs that celebrate our arrivals and departures will have to do). Sometimes we decided not to decide. And sometimes we decided through durational engagement with each other, in tiny fragments of moments, through changing our minds then deciding again, anew, by being attentive to each other, and to ourselves.

### **Curating for Anti-Pathologization, Access, and Support**

We also made decisions by sharing worries and questions and talking and listening. For example, early on, Alexis shared some anxiety about not knowing the direction of the project. She asked whether we “want specific things that are like ‘I do this to help me feel better’ or ‘this is how I do this as a Mad person’ or random and less specific ‘this is the way that I am in the world?’” I responded that one of the questions rolling around for me was whether this was a ‘therapeutic space,’ which tends to creep me out, and that I was thinking more of the work being about Mad access, which could include things that make us feel good to be there. Sarah pushed my thinking about this:

When you think of a space as being therapeutic, there’s sort of this expectation that you will feel better when you are here, and if you don’t, you’re doing it wrong... There’s also

the ‘therapeutic as a specific activity’ and that this is separate from ‘real life’. And so, there’s also just existing in a space and having things that generally make you feel good but there’s no expectation that you have to feel good, and that there may be techniques or items that are often used in therapeutic settings, but they are sort of just incorporated into the space, and so it’s not, it’s not therapy, it’s just life.

dales picked up on this complexity, adding:

Even just separating the things that are therapeutic out of life, are like, for me is like something that’s really hard, not something I’m interested in...it’s like thinking about...how care is professionalized in ways that actually make it separate...and so it becomes a thing on a list that you do, not an integrated something that’s actually about connection or otherwise, or to your life, to people, to everything. And it’s just this weird compartmentalizing that for me keeps me from the things that I want or need, or even myself, right? And so, when you said the word ‘access’ that really resonates with me, because like, I think for me it’s about spaces where you can bring more of yourself more of the time...for me it’s like, anything we do in this space can also, can have multiple meanings, depending on so many factors at different times and places and people and things. And so, yeah, I think it’s like making more space without a prescriptive notion of what it’s for, or a separating it like something that heals you from something that destroys you. Because the things that I undo myself with are often part of something that would also, you know, sometimes my destructive behaviours are exactly what I need in that moment, no matter what they are labeled as.

Sarah layered the conversation further, noting “sometimes I don’t do things to feel better, I do things to feel.” Alexis added “or feel different.” We wanted to bring all of these experiences and

ways of relating to our invitations and encounters in *Mad Home*: experiences of therapy, and destruction, and destruction as therapy; experiences of accessing and integrating healing and connection as not separate or separable from madness and Mad being. We wanted to hold space for the therapeutic and the destructive (which also can be one and the same) and the things that make us feel, feel different(ly).

We spoke of the vital and generative possibilities of embracing Mad thoughts and Mad existences and Mad coping strategies. For example, we spoke of incorporating suicidal ideation into our everyday existence, not as a thought distortion, but rather as a signal, a reflection.

dales: I'm really working how doing transition for the last two years has actually been about healing, and how having this separate idea of being mentally ill and being trans, and always having to hold them separately, and do one or the other depending on my mental illness, I've really like, transition has become something not just about gender. And just like, I really freaked people out because I was like, both of these things—being non-binary, and being Mad in the ways that I am—require that I get rid of the end goal that I'm going somewhere, right? Cause those are both unhealthy binaries, that I'm well or I'm not well. And the thing I really pushed them on, for me I've spent the last two years, like one of my victories is integrating suicidal ideation into my definition of well.

Group: YES! yes!

dales: It's like, I'm gonna wanna die for the rest of my life. Like I have a death drive tattoo now, I did it myself, and I'm like, and I know now what that means. I know that means, based on my little kid brain wiring, that something in my life is too much. Something in my life needs to stop and change, and that's what I'm actually communicating. Wanting to die means I need my life to not do this anymore. I need this to stop.

Group: Yes!

dales: And that's I think where those [Mad] houses always came into my mind, is like, when I need it to stop, it means I actually just need to stop completely myself, cause that's what I'm desiring. I need other, something else to pick it up and carry me through until I'm ready to turn the engine over again. But just like, people are really uncomfortable when you're like 'no, my own wellness includes wanting to die'. Quite often that's a communication tool for my body and my existence

Alexis: So simple but it's so true, because like, why, yeah! That idea is so, is pathologized the right word? I don't know, but like it's so bad like, to have those thoughts. Like, oh my god. But of course it's a normal part of a lot of people's

dales: Yeah

Alexis: Like, every day, so yeah.

Sarah: ... Well, and that's the other part of like, being...like it's not okay to feel like you want to die. Well, then nobody's gonna talk about it. So, in some ways just being able to be like 'yeah, I really want to die right now'

dales: Yeah

Sarah: ... just being able to have the freedom to be really open about that can keep you alive...not that that needs to be the goals, I don't want to make people the sense that you win if you don't die...I'm not meaning to set up a binary where there's a right choice, but just that yeah,

dales: Yeah

Lindsay: Well and I think for me part of the spark for this project was ...what kind of practices, movement practices and art spaces and communities, where we can go and we can be like

‘ya, I want to fucking die’ and I’m gonna sit in a corner with like a hood on and bead while everyone else is dancing, which is how I spent half the time with Alice Sheppard. But like, still be welcome in the space, valued in the space, but not have to *not* be like that, you know...where you can go and be like right crazy and that would be valued as adding something to the space even?

Group: Mmmhmmm

dales: ... And for me it’s like every time that someone feels like they can’t come, you reduce the connectivity and you reduce what’s produced in some way, not that it’s like ‘more is better’ but, for me, I think that transformation is about coming together.

Honouring our coping strategies, especially the ones that would be pathologized such as suicidal ideation or ‘non-participation,<sup>28</sup>’ was vital, and a means of coming together. We made performative invitations that involve what might be deemed as ‘self-harm,’ which are practices of self-soothing and control over our own bodies, and tracing and shifting the pain and pleasure we feel in them. We explicitly crafted instructions for those we invited into *Mad Home* to bring their coping mechanisms, and made space for ‘unhealthy’ coping such as smoking. Through these discussions and performative invitations, we worked to actively recognize that our coping strategies are also survival tools. This recognition was a means of affirming our Mad lives and Mad living. For example, thinking of suicidal ideation as integral to my definition of wellness, as dales suggests, invites me to be more gentle and generous with the ways that I survive. It supports me to exist in relation to suicidal ideation with pride and compassion rather than guilt and shame. Sharing about our pathologized coping strategies also offered a chance to multiply our available survival tools, and to story our lives differently.

We made space on the fridge to share our survival tools, alongside Ahmed’s killjoy

survival kit (a chapter of Ahmed's (2017) book which I discuss above, in which she articulates books, things, tools, time, life, permission notes, other killjoys, humour, feelings, and bodies as tools for feminist survival). We talked about our desire for sharing survival tools:

Alexis: ...I feel like that is somehow needed. Or like having a visual reminder of, you know, X  
Y and Z things that you can do, or whatever, so, I'm not really sure

Sarah: I think, this is only one, but like, I've personally had a really good experience with Jewish Family Services, and so they, they're something I that recommend for people...they're like queer friendly and poly friendly and a whole bunch of stuff, so that's the sort of thing that I would like to share with people, because also they have sliding scale, and so it's financially accessible, and that was the only therapist who actually ever helped me.

Lindsay: Totally. That's super interesting. And I think maybe, we even, I don't know if it's dangerous to leave it open, but also maybe we do leave it open,

Sarah: I was kind of thinking of that

Lindsay: Like, what supports and services have worked for you?

Sarah: Yeah. Somehow I'm still here, so something must have worked somehow.

Alexis: Yeah. It's the birds in the neighborhood. Are like the best support for me.

Lindsay: Totally. But I think that that's exactly, like, to me, what it would be

Sarah: Yeah, like a combination of

Alexis: Yes. yeah, the first time I moved my, this recent apartment, at my first boardwalk, I was the one, my family always has this race to see who sees the first robin every spring. And I saw the first one, and I just burst out crying because I was just like "this means I'm home' and it was just like,

Group: Mmmm!

Alexis: And so every time I go walking every day to see the woodpeckers and the robins and this morning I saw waxwings, and there are so many where I live, which is amazing, and they are just like, yeah. These are my people. My peeps! My peeps! I found my peeps! And Jezebel, my sisters dog. So, those are supports, but they are not going to be your typical supports

Lindsay: Which to me is like, totally, the thing

Alexis: Yeah, or like the day that dales supported me, and they didn't even know. I know that it was just conjuring your energy to have around. Stuff like that.

dales: This is when I wish, like the thing I was talking about earlier, about like not wanting to become someone who charges per hour.

Group: Mmmmm

dales: Like, 'oh, yeah yeah, you want to die? dales is the one you can call', cause I know how to sit with it.

Sarah: And somehow still be able to live

dales: Yeah, that means that we sustain each other, because we have different things to contribute.

Sharing and validating our survival tools and supports, and sharing the labour of Mad caring, was meaningful to us in our *Mad Home*. For me, it was meaningful because there are precious few spaces in my life where I can unashamedly ask for care, and share in care, without pathologization and normalization. Further, being able to take what I need and contribute what I can means that, as dales stated, "we sustain each other" without having to be anything more than I am. Sharing our survival tools also meant I could reimagine the breadth of possibilities for Mad flourishing to include relations to my selves, emotions, non-human animals, technology, books,

and spirits. Our Mad survival toolkit, collected during *Mad Home*, includes: “eat your feels. Question ur coping”; and “blame your dad. blame your abuser(s). blame your boss. blame your school. blame yourself.”; and “clench your teeth, avoid eye contact, stew about it, poison with sarcasm, AVOID! definitely don’t sleep”; and “livestreaming kittens”; and “Ursula LeGuin, Octavia Butler”; and “be around people who you can ask for what you need or want from—and who are also solid enough to be there when you don’t know what you NEED”; and “Find the people that you can say no to or cancel at the last minute”; and “pups”; and “each other”; and “Jewish Family Services”; and “Netflix”; and “cry. Or, don’t.”; and “birds in our neighbourhood”; and “conjuring the energy of those who love you”. We survive (and thrive) in many ways.

### **Curating for Memory and Breaking-as-Resilience**

*Mad Home* is curated to honour consent, and coping mechanisms that are pathologized in most other spaces. It is also curated to access memories that our bodies hold but do not readily share. And to honour resilience, and breaking (as resilience). This came up when Nathan and I talked about the difference between a ‘mad house’ and a ‘Mad home’:

Nathan: I think a Mad home is curated. Everything is intentional, not to prevent us from getting to a place where we need to stop, but allowing us consent in the go-go-go or the slow down. You know, because I was thinking about packing for this show, and I particularly am trying to recreate my bedroom, and, you know, I just brought this one tub of things and bag of crafts...It was really hard not to bring ‘oh, I need this crystal and I need this and I need this’...because, like, casting over those things, holding them, they allow me to access memory, in a way that my mind can’t remember without them...And actually the memories of the things that are in that room are, they are pieces of resilience, they are

pieces of vision, they are pieces of grounding, they are pieces of, you know. So, I can be anxiety brain, walk into that room, and still be anxiety brain, but even in anxiety brain I can access these memories.

Lindsay: yeah

Nathan: And so I think that the way that museums...are curated, and art galleries are curated, and I think the process of curation is about, you know, distilling an artist to their essential pieces, distilling a time period to, like, visual and tactile representations, and I think that's what a Mad home does. But a mad house can't,

Lindsay: Right

Nathan: Because it's so specific, your curation of yourself, your story or whatever, is so specific.

Lindsay: Well, it's interesting too, because I feel like also the artifacts in my home, a lot of the painting or visual art stuff is actually about moments of breaking too.

Nathan: Yes! Yes!

Lindsay: And the moments of breaking, I don't think, can be honoured and held and displayed in a mad house, because it's everything you need to get rid of, as opposed to those rememberings, of even the times of breaking

Nathan: Well, and that's what I mean when I talk about pieces of resilience. That's what I mean by resilience, is that: breaking in past tense is resilience, right?

Resilience is in the breaking itself, and the knitting bones and skin and hearts back together with artifacts and ideas and people: not in a 'recovery' sense, but a 'collecting sea glass from a deep dive into the break' sense. We curate our collection of sea glass for *Mad Home*, and invite others to touch it's smoothed and rough edges, and taste the salt, and bring their own.

## **“The Double Becoming of Affecting and Being Affected”: Curating Mad Sensory Worlds**

We also curated for sensation: encouraging embodied experiences that, as Sarah and Alexis noted, make us “feel” or “feel different.” Creating and accessing embodied knowledge is cited as the intention of numerous scholars working in performance-based research-creation (Piccini & Kershaw, 2003). Art as a means of inquiry can be especially useful when exploring embodied knowledge, and knowledge that cannot so easily be put into words (Liamputtong & Rumbold, 2008). Conquergood (1998) argues that performance is a more “sensitive register for the nonverbal dimensions and embodied dynamics that constitute meaningful human interaction” (p. 26). Performance can be attuned to, account for, and give weight to, non-verbal and embodied ways of knowing and sharing knowledge. Given my own experiences of the bodily natures of ‘mental illness,’ I wanted to know more, and learn from others, about how our bodies figure in.

We spent a lot of time curating sensory experience and enacting sensuous scholarship (Stoller, 1997), by experiencing and considering how taste, smell, deep pressure, movement, touch, sound and visuals could be Mad encounters in our home. We shared hurt in our bodies, of pain, and of injury that prevents movement and it’s triggering effects. We brought foam rollers, and weighted balls, and spikey sensory toys to love our bodies up. Alexis invited us to have rags lying around “if/when we need to weep on the floor - then we can clean the spot where our heads need to lay weeping.” We considered the sensorial discomfort of germs and sticky hands and scented wipes. We felt. We taped plastic to the baseboards and it stuck to our bare feet as we painted as high as our fingertips could stretch.

Folding and cutting and gluing. Laying down, cushioned by spongy yoga mats in the pink glow of the tent. Bending and reaching and ripping and reading. Dirt under fingernails from digging in soil. Gently holding tiny plants with their roots exposed.

Sometimes we invited sensation through the disruption or dislocation of physical spaces in our home. We shared about crossed brain wires, synesthesia: “orange is the color of three, and I hate threes” (dales). We played with synesthetic use of space: we spread food across the floor of the living room; the fridge was a site of nourishment, not of the food variety, but rather hosting our ‘wanted ads’ and ‘survival toolkit’; we collapsed bedrooms and offices; we talked to bananas in the bathroom; we displayed flowers in the dishwasher and invitations to shove dishes in the oven (to an audio-recorded proclamation of “shove it! good job!”). Born out of dragging mattresses into the kitchen, cooking naked, and having sick queer crip sex, we included a giant bean bag that took up the entire floor space of the kitchen. As we (want to) do every day, we maddened our physical space, existed madly in our bodies (or out of them), and shared about ourselves, each other, and our worlds from these madly embodi-minded encounters.

Emerging out of a conversation on how to document our *Mad Home*, dales brought up Fluxus<sup>29</sup>, and the use of “proposal pieces, propositions, or instructions” (Friedman & Smith, 2002, p. 1). Or, as we sometimes referred to them: invitations. We were excited about this practice specifically because it is an invitation to action, calling folks into Mad performance practice with us. I shared *the Fluxus Performance Workbook* (Friedman, Smith & Sawchyn, 2002) with the group. We talked about Yoko Ono’s (1964) *Grapefruit: A book of instructions and drawings*, Fluxus art practices, and this bit of performance art history. We all wrote out invitations in a number of our group meetings, and dales typed them up so we could scatter them around *Mad Home*, inviting people to choose ones that resonated and glue them into their own personalized “Recipe for a Mad Home” zine.

Inspired by this work from Fluxus, we crafted invitations to share in a Mad experience that is meaningful to us. Interestingly, roughly two thirds of these were deeply embodied

sensorial invitations. Some examples are:

“Lay in a hot bath right before the water cools, take out the drain and lay on the tub floor, letting  
the water drain around you”

“compression”

“crack a just frozen puddle”

“rock back and forth until everything settles, or forever, whichever comes first”

“be Jello (preferably lime)”

“get elbow deep in your deep dark blue”

“spin and wobble”

“echolalia”

“eat 100% dark chocolate with mint that tastes like blood and butts (then call Alexis and tell  
her)”

“itch your bones”

“rip up a piece of paper again and again”

“make hiccups”

“turn your body into water. Pour yourself across your bed, the floor, the ground”

“pug pant”

“converse with the voices”

“pluck your armpit hairs with tweezers, 1 by 1”

“wear headphones with or without music”

“dried white glue”

“mispronounce your words”

“spin in circles in the dark”

“throw. up.”

“Bubbles”

“put your hands in your pants”

“peel a clove of fresh garlic. Smell your limbs as much as you can before you sleep”

“hesitate under or inside doorways”

“hang upside down (‘possum’)”

“eat chips as loudly as you can”

“hold the pain spots on your body, say hello”

“stay home”

“STAY MAD”

“Mad recipe: darkness, avocado, maple syrup, smoked paprika, eat from a friend’s hand,”

“rip up these instructions and throw them into the river”

“fuck it.”

We discussed these invitations as a way of creating that could allow us to communicate what we would like in a Mad home (including all of the possibilities and impossibilities), even if we need to float away on the day we invited other people into our *Mad Home*. These invitations were also a way of sharing our work, and our sensual experiences, with folks who could not attend in person.

We shared a lot about our bodies, how we sense them and make sense of them. Thain (2008) argues that “the body as the ‘locus of research-creation’ is a recurrent theme... its creative potential understood as the double becoming of affecting and being affected” (p. 3). Through these performative invitations, I experienced this double becoming. I mean this in the sense of affecting myself and others through the intimacy of these invitations, and being affected

intensely by the similarities and specificities of our experiences. For example, a number of us were moved when we shared our various versions of picking (‘draw blood’ or ‘pluck your armpit hairs with tweezers, 1 by 1’ or ‘pick an ingrown hair until it bleeds’): something that for me held more shame before sharing than after, when I could deeply sense my experience echoed by others. We have ‘secret’ embodied experiences of being in and through madness, some of which became communal, a shared invitation to experience.

To me, the Mad sensory worlding done in *Mad Home* is what Ahmed (2017) calls a “sweaty concept: another way of being pulled out from a shattering experience” (p. 12-13).

Ahmed writes:

A concept is worldly, but it is also a reorientation to a world, a way of turning things around, a different slant on the same thing. More specifically, a sweaty concept is one that comes out of a description of *a body that is not at home in the world*. By this I mean description as angle or point of view: a description of how it feels not to be at home in a world, or a description of the world from the point of view of not being at home in it. Sweat is bodily; we might sweat more during more strenuous and muscular activity. A sweaty concept might come out of a bodily experience that is trying. The task is to stay with the difficulty, to keep exploring and exposing the difficulty...Sweaty concepts are also generated by the practical experience of coming up against a world, or the practical experience of trying to transform a world. (p. 13-14, emphasis added)

We got sweaty in our work transforming our world. We invited others we trusted to get sweaty with us. We worked to acknowledge that trauma, and ‘mental’ distress, is in our bodies, of our bodies. In some instances, creating with and for trauma became more central than creating with and for madness (if these are even separable). We worked to make home for our trauma bodies.

Nathan and I made a Mad collage, obscured behind “brain fog” (a humidifier pumping out clouds), and I sopped up the condensation from our brain fog while talking trauma in movement practices with my supervisor, Donna Goodwin. We invited sensory utopias that make space for trauma, and that sometimes offer embodied ways of being “pulled out from a shattering experience,” integrating healing and living through non-pathologizing and non-prescriptive sensory worlding (p. 12-13).

### **Sharing *Mad Home* Beyond These Walls**

Working to model the things we need and want through *Mad Home*, we invited people to participate in a myriad of ways, including in non-flesh form. Thereby, we made space for flakey pie, flakey people, as acts of radical Mad love. This was done in part by prioritizing the creation of the *Mad Home* website, an enactment of Mad access that mobilizes *Mad Home* knowledges through time and space. *Mad Home* and its companion website, as Horowitz (2014) suggests, are both art work, and documentation, of this research-creation project. As Piccini and Kershaw (2003) suggest, we put careful thought into what form the ‘document’ would take and what roles documentation would play in our work. The *Mad Home* companion website mobilizes elements of the sensorial, embodied, collaborative, complex, multi-voiced knowledges that we crafted. Its role is to facilitate access: an invitation on your own time, a virtual taste of how we wanted to perform madness together.

It is important to note that “the material translations of specific practices - in the form of documentation - can never wholly ‘stand in’ for the research although they can ‘speak’ alongside those research moments” (Piccini & Kershaw, 2003, p. 121). The documentation of a research-creation project is not the same as the live practices of research-creating. The way that *Mad Home* performs virtually, through the companion website, is not intended to be the same as the

audience-attended event nor the collaborative process, but invites encounters with each that traverse time and space. Auslander (2006) also points to “the performativity of documentation itself [wherein] *the act of documenting an event as a performance is what constitutes it as such*” (p. 5, italics in text). Is the *Mad Home* ‘performance’ made up of our group meetings, which were documented through audio-recordings and transcriptions? Is *Mad Home* the three-hour event attended by people outside the collaboration, from which we have photos and recordings and glitter and glue? Is *Mad Home* the website, where some of these traces are (re)presented? Is *Mad Home* how this knowledge is being mobilized right now, or how it will be mobilized in the future through workshops, emerging artistic practices, and publications? Is it all of these?

If we stick to chronological ‘earth-time,’ we might be tempted to read ‘process (before May 7, 2017) -> performance (May 7, 2017) -> website (after May 7, 2017)’. But this is too clean, too linear, too cohesive. It is missing the constellations and webs and tentacles, the present enactments, the future mobilizations, the pasts that still haunt. It is missing the ways that process and performance and website are nesting dolls, mud soup, rainbows. As dales put it “linear lines of progress really fuck with my head.” Nathan pointed to the problematic pull to “finish” a work in “the way that traditional narrative frameworks require a sane and able performance, even of madness, you know...and also to adhere to, like, cohesive narrative. [scoff] like, there’s nothing sticking me together, like I don’t have cohesion.” Is it possible to disrupt linear cohesive narrative trajectories? I would like to think of *Mad Home* as all of these things: process, performance, website, alive at once; still processing, still performing, still embodying.

I am still processing these *Mad Home*-generated knowledges as I write this dissertation chapter on *Mad Home*, and throughout the following two chapters on trauma-informed practice that were influenced by this collaborative process. I find myself still performing *Mad Home*

through a number of recent invited workshops that center anti-oppressive trauma informed practice, which I will discuss in my conclusion. I am still embodying *Mad Home*, and will for the rest of my life, through tattoos, which all of the group collaborators got done together after we presented *Mad Home* to our people. Each one is different, referencing our encounters with *Mad Home* in one way or another.

“stay mad” on an arm

“not all who wander are lost” on a foot

“mad home maker” next to lavender on an ankle

“mad home maker” in a writing quill with 10/6 Mad Hatter reference on forearm

“Nope. Not today” with an echidna on the back of a thigh

“Mad Home” on ribs next to a star

*Mad Home* is all over our bodies, nestled deep in our skins.

All of these mobilizations of *Mad Home* are fun-house mirrors, disproportionate and warped and strange-yet-playful-sometimes-not-always reflections that will never supplant our practices of embodied relating. They work to honour relating to ourselves and each other otherwise. I also find new *Mad Homes*, new sites of non-normalizing and anti-sanist praxis (Diamond, 2013) that I admire, enacted in current projects by my collaborators: dales’ affirming commitments to self/selves as vital political work through #reclaimingneedy and #selfsweetness; Nathan’s ritual offerings (in collaboration with others) to challenge binaries and foster tenderness in #100loveletters and #tenderyear; Alexis’ celebration of limb difference alongside accessible vegan and gluten-free cooking on Stump Kitchen; Sarah’s plant-baby-sharing, and brunch-hosting, and ways of practicing occupational therapy, and showing up to adjust a dancer’s wheelchair because *she can*. My collaborators continue to make *Mad Homes*, and these sustain

me.

## **Being the Twisty Tree is Enough**

*Invitation: Be (with) the Twisty Tree*

Sarah shared that our time together in *Mad Home* “is very grounding, in a weird way.”

This brings me back to my conversation with Ruth Ruth, where we spoke of sensuality, and nourishment, and the earth:

Lindsay: What is Mad beauty? What’s Mad, like, what does madness look like in ways that are satisfying to you, on stage or in life?

Ruth Ruth: Uncontrolled.

Lindsay: Yeah?

Ruth Ruth: Yeah. I like that... just free. Free. Wild. Like, wild... beautiful. Beautiful.

Lindsay: It’s, it’s not a traditional sense of beauty maybe? Or. Or is it?

Ruth Ruth: Look at my hands okay. [shows me her hands]. I have arthritis. I’m not in pain. My hands can do the things I need them to do.

Lindsay: Mmmhmm

Ruth Ruth: If you look in a garden and the twisty tree is the most beautiful, then why can’t my hands be the most beautiful?”

I hold the image of the twisty tree, and the weird kind of grounding that this group nurtured, very dear to my heart now. Nathan reflected similarly:

there’s a tenderness, and a desiring of care...Because it wasn’t a high that made this. And that’s what’s funny about this to me. For performance, for me, what happens is [whipping up sounds] and then I push way past every possible point, because you have to put it on, you have to do it...but this isn’t like that...I always come to you to make sense of me.

And this just felt like that. but it felt like that with everybody. I was so surprised at how much love I have for everybody.

I resonate with Nathan's past experience with performance: the need to perform 'well,' to perform 'sick' sanely, to push past breaking and then needing time to pick up the pieces. I also resonated with the relieving sense of love and nurturing that this collaboration fostered, the sense that we didn't need to push past ourselves, because we are enough. Before we welcomed others into our *Mad Home*, Alexis noted:

I also wish that the *Mad Home* could be just us talking on the floor, laughing about the weirdest fucking shit. I just really enjoy all of you so so much, and I just, I think I've laughed more safely [tearing up] and genuinely than I have in a long time, and it's been really nice. And so I think a *Mad Home* ideally would be like, ideally if I could drink alcohol right now, I think it'd be drinking wine with you all [group laughs], shooting the shit, just talking weird shit and making weird jokes and people could just like, I don't know how they would be a part of that, but that would be enough. It's already enough.

dales offered that we attend to this, specifically:

we'll make sure there's enough time, and if we're not ready, the doors don't open until we get this time, and that would be really valuable to me, to be like, this is already enough.

We did enough. We are enough. *Mad Home* is enough.

## Chapter Five - Trauma and Adapted Physical Activity

As I did in the introduction to this dissertation, I must again tell you about what I am writing about, so you can consent to reading it. I do this as intentional access practice, in line with calls for content or trigger warnings as a trauma-related access need, and a matter of consent, which I will discuss later on in this chapter (Carter, 2015; Clare, 2017; Kafer, 2016). I will be discussing trauma in a variety of forms, from a variety of different perspectives, including psychiatric, socio-political, and embodied perspectives on trauma. You or someone you know likely has experience with trauma. You or someone you know likely also has coping strategies to navigate trauma – I trust deeply that you know best how you take care of yourself. For the most part, you will not be asked to recall or recount your experiences, but this may happen anyways. If you need to stop reading at any time, please feel free to do so, and if you need to debrief this information with anyone, please do so as well.

This chapter is a love story. I am writing about what *I* need to learn and take to heart in order to build my own anti-oppressive trauma-informed practice. This writing is informed by my autoethnographic and collaborative research creation project that I discuss previously in this dissertation, wherein I found that trauma and mental distress were experiences I needed to learn more about, as they were intimately interwoven throughout our Mad art making. I am also writing so that I can be better for people in my community that I love and wish to make more space for. I am writing Mad: repetitively, cyclically, perseverating on similarities and differences in research and practices that hold potential for radical change. I am also writing this with my subject position in mind, working to acknowledge how moving through the world as a white cis Mad queer fat(ish) femme in intimate relations with disability and crip communities offers me experience born out of both privilege and oppression. This will resonate with some readers, and

alienate others. If you are alienated because of your privilege, I encourage you to do the difficult and important work called for by the activists and scholars I will highlight (see especially action domain 3, on recognizing privilege, in the practical resource section). If you are alienated because this work perpetuates or reinforces your experiences of oppression, I offer my sincerest apologies, and am also deeply desiring of learning if you are willing to share with me.

With that said, I invite you to join me in a necessary and dangerous conversation. It is about trauma. It is also about mental illness and oppression. It is about medicalizing and pathologizing our experiences, and our responses to those experiences. It is a necessary and dangerous conversation about bodies and harm. I am pulled toward a necessary and dangerous conversation about doing damage by doing what we do, and how we do it; about being damaged by what we do, and how we do it. I will begin by discussing three interrelated personal and professional experiences that sparked this conversation for me: I have done damage, I have been damaged, and I am damaged vicariously in my practice as a dance instructor, choreographer, organizer, researcher and Mad artist. These experiences have brought me to explore *trauma* and *physical activity*, and I will discuss why it is pertinent that these two things to be thought together. I will then introduce *trauma-informed practice* in relation to physical activity, and specifically to the field of Adapted Physical Activity (APA). I will highlight the limited amount of research that is currently available about trauma informed practice in physical activity, which focuses primarily on sport and yoga contexts. Building from the trends and gaps in this literature, and in an effort to enact the first key principle of trauma-informed practice (*trauma awareness*); I will detail a series of ways to conceptualization trauma. These conceptualizations will draw on a variety of perspectives, including psychiatric, social and political, as well as embodied orientations to trauma. I will then mobilize these conceptualizations to discuss how trauma is

differentially distributed, highlighting trauma in relation to disability justice, access, intersectionality, and intergenerational legacies. I will bring forward difficult questions about how we as ‘helping’ practitioners and researchers may be perpetuating or perpetrating harm. I will end by detailing a series of practical suggestions that can make our work in physical activity, and Adapted Physical Activity specifically, more trauma-informed. These suggestions include tips on how to build anti-oppressive—that is, anti-sanist, anti-ableist, anti-racist, anti-fatphobic, LGBTQ2I<sup>30</sup> and trans affirming—practices and environments for movement, sport, and physical activity.

### **Good Intentions, Dangerous Practices**

To be honest, I am fearful about burgeoning discussions of mental illness in the field of adapted physical activity: a field of research and practice relating to disability and physical activity. I have come to know this fear is an appropriate response to the damage that has been facilitated, perpetuated, or perpetrated by professionals with good intentions and dangerous practices. (Para)medical, health, and wellness professionals can (and do) cause iatrogenic trauma: bodily and psychic trauma created by these professionals in the course of practicing ‘health and wellness care’ (Burstow, 2003; Danieli, 1998a; Duran, Duran, Yellow Horse Brave Heart & Yellow Horse-Davis, 1998; Falot & Harris, 2009). Falot and Harris (2009) state that “trauma has often occurred in the service context itself. Involuntary and physically coercive practices, as well as other activities that trigger trauma-related reactions, are still too common in our centers of help and care” (p. 2). Likewise, physical activity practices, instructors, and contexts have also undoubtedly been sources of humiliation, trauma, marginalization and violence for many people experiencing disability and/or embodied difference (Biggs, Simpson & Gaus, 2010; Haegele, Sato, Zhu & Avery, 2017; Sykes & McPhail, 2008). As APA researchers

and practitioners—often working at the intersections of disability, wellness, and physical activity—we must genuinely wrestle with our likely complicity in systems and practices that not only trigger but also perpetrate harm and trauma...even, or especially if, all of this is done with good intentions.

I am afraid of further opening up the field of adapted physical activity to make interventions *on* people diagnosed with mental illness. I am afraid of more professionals believing they are ‘helping’ when often times this help is hurtful. While the move to address mental illness in and through adapted physical activity has been happening for some time now (see, for example, Gruber, Hall, McKay, Humphries, & Kryscio, 1989; Kelly, 2006; Sherrill, 2004; Van Andel and Austin, 1984; Van de Vliet, Van Coppenolle, and Knapen, 1999), I am noticing an increase in attention to mental illness or psychiatric conditions within the field (see, for example, Carless, Peacock, McKenna & Cooke, 2013; Carlier, Mainguet, & Delevoye-Turrell, 2016; Emck, Bosscher, van Wieringen, Doreleijers, & Beek, 2012; Gomes et al., 2014; Verret, Gardiner, & Béliveau, 2010). I am fearful that, in further opening this discussion, I am contributing to an increase in the scope of practice for adapted physical activity practitioners and researchers, extending our well-intended but potentially dangerous practices to further target people diagnosed with mental illness. Thus, I am compelled to demand we have a necessary and dangerous conversation about trauma, rather than directly about mental illness, although the two are deeply related. Trauma and mental illness create a mutually reinforcing cycle: people who have experienced trauma are more likely to be diagnosed with mental illness (Brownley, Falloot, Wolfson Berley, & Himelhoch, 2015; Vitriol et al., 2017) and people who are diagnosed with mental illness are more likely to experience some forms of trauma (O’Hare, Shen & Sherrer, 2014, 2017). Further, there are trauma-related mental illness diagnoses (American Psychiatric

Association, 2013), and trauma is a form of mental and embodied distress that affects many more people (including disabled, racialized, poor, substance using, queer, trans and/or non-binary folks) than those specifically diagnosed with mental illness. I am arguing that if the increase in scope of practice within APA is to continue to develop in relation to mental illness, it must be accompanied by deep reflection on, and accountability for, our current and ongoing complicity in perpetuating and perpetrating trauma and trauma responses within our practice.

My investment in this is three-fold, which I will unpack in the next three sections. I am one of those professionals who has done damage with good intentions and dangerous practices. I am one of those patients/clients/participants who has been damaged by good intentions and dangerous practices. I am also a student and a professional who has experienced trauma vicariously in my education and practice. As such, I feel compelled to spark a necessary and dangerous conversation about trauma in physical activity, and most especially in adapted physical activity contexts.

### **I Have Good Intentions and Dangerous Practices.**

Larsson and Quennerstedt (2012) challenge us to examine the normative assumptions that underlie our movement practices, and the potentially problematic impacts of these assumptions. I found out in my first year of instructing integrated dance that my work could have negative impacts—could trigger and cause further trauma—by uncritically instructing exercises based on normative (even evidence-based) assumptions about what is beneficial for our bodies in physical activity contexts. I was teaching an integrated dance class, and used a progressive muscle relaxation (PMR) exercise, which is commonly practiced in a variety of physical activity contexts (see Epelbaum, 2012; Hashim, 2011; Navaneethan & Soundara Raian, 2010) and has been shown to offer significant benefits in therapeutic, health and wellness contexts.<sup>31</sup>

*Find a comfortable position, lying or sitting, away from distractions.  
Focus your attention on only your body. If your attention or thoughts drift, draw your  
attention back to the exercise and your body.  
We will trace your body, tensing muscles and then releasing them, without straining, to  
experience relaxation.  
Now, to begin, imagine waves of relaxation rolling over you.  
Take a deep breath, filling your belly, and hold for a few seconds before you exhale.  
Notice the sensation of air filling your lungs, chest and abdomen.  
Feel your muscles relaxing with each breath, releasing tension every time you exhale.  
Inhale...  
and exhale.  
Inhale...  
and exhale.  
Throughout the remainder of the exercise, remind yourself to breath...*

---

Months later, after running this exercise several times, a dancer finally confided that this  
“relaxing” exercise was in fact triggering, traumatizing, and damaging for her.

---

*Find a comfortable position, lying or sitting, away from distractions.*  
Oh. Fuck. Here it comes.  
And if there is no comfortable position?  
*Focus your attention on only your body. If your attention or thoughts drift, draw your attention  
back to the exercise and your body.* I spend so much of my time avoiding this.  
It is how I cope with chronic or intense pain... precisely by having my mind  
on anything but my body.  
*We will trace your body, tensing muscles and then releasing them, without straining, to  
experience relaxation.* Please, no.  
Oh, please, no.  
*Now, to begin, imagine waves of relaxation rolling over you.* I can't.  
Maybe I can be the one rolling out of here?  
*Take a deep breath, filling your belly, and hold for a few seconds before you exhale.*  
I am drowning with each breath. My diaphragm threatens constant spasm.  
*Notice the sensation of air filling your lungs, chest and abdomen.*  
There is never enough oxygen.  
Just burning  
burning and drowning.  
Neither squelches the pain of the other.  
And this is supposed to make me relax?

*Feel your muscles relaxing with each breath, releasing tension every time you exhale.*  
I am crawling out of my skin.

*Inhale...*

*and exhale.* Think of something else....

*Inhale...*

*and exhale.* Anything else....

*Throughout the remainder of the exercise, remind yourself to breathe.*

Pain radiates with each breath,

panic creeps in.

*Now, tighten the muscles around your eyes. Squint your eyelids shut and furrow your brows.*

*Hold...* Okay, this I might be able to focus on.

*and abruptly release.* I can focus on my face.

*Feel the tension melt from around your eyes.* It is not such dangerous terrain.

Maybe a good distraction? Is it?

*Draw your attention to your mouth and jaw.*

My mouth?

I want to scream.

*Smile widely, tensing your cheeks and jaw.* But sure, I'll smile. A tight, strained smile.

*Hold...* Clench my jaw against the waves of stabbing and aching

that I have fought all day to hold at bay.

*and release.* But I am not sure I can release this clench.

*Notice the weightlessness in your face muscles.*

Lock jawed.

Tight lipped.

*Tense your neck muscles by gently pressing your head back as though you are looking at the ceiling. Hold...* Do you think I haven't heard this before?

Relax,

it will make your movement more fluid.

*and release,* Relax,

It will hurt less as I poke and prod you.

*letting go of the tension in your head and neck. Notice the weight of your head as the tension melts away.* Relax,

It will help with your rehab.

*Breath in...* Don't you want that?

*hold...*

*and out.* And if I don't care to move

*Clench your fists into tight balls,* like you want me to?

And, oh, I will clench my fists alright.

*and hold...* Do you know the memories that are held within these muscles?

Of doctors.

Of stares.

Of inaccessibility.

Of abuse.

*now release.* No.

*Feel the weightlessness of your hands.*

weightless and hopeless become sensory bedfellows.

*Breath in...* Can anyone even catch a breath?

*hold...* with this rhythm and pace?  
*and out.* Is this relaxing for you?  
*Breath in... hold... and out.* I choke swallow to slow down/keep up  
 Doesn't anyone else feel panic when someone else regulates their breathing?  
*Tighten your shoulder muscles by raising them up around your ears. Hold... And release.*  
 This exercise is not built for me.  
*Feel the weight of your shoulders and arms sinking.*  
 This exercise can't even imagine a body like mine.  
*Now draw your shoulders back so your shoulder blades are close to touching, tensing your upper back.*  
*Hold...* I can't breathe without the sore on my back throbbing, let alone tense my shoulders.  
*And release.* isolating. float away.  
*Let all the stress you hold in your shoulders melt.* Panic swells my belly,  
 rushes over me,  
 And then the loneliness.  
*Feel your chest expand like a balloon, tightening as it grows larger with your breath in.*  
 Tightening?  
 Yes. A vice grip around my ribs.  
*Hold...* And no release.  
*And blow out slowly, exhaling all that tension.* I do my best to ignore it.  
 Too late.  
 Panic.  
*Suck in your stomach, pulling your belly button to your spine.* I need to be somewhere else.  
*Hold...* Okay, shopping, I need to go shopping.  
*and release.* What do I need?  
 Avocados  
*Breath in...* Oh, I wish you could get a good avocado here!  
*hold...* Chicken, Bread  
*and out.* Milk, I am pretty sure the milk in the fridge is sour, it's smells pretty funky right now  
 Chocolate  
*Breath in...* Some good pizza (cause who wants bad pizza, right?)  
*hold...* Oh, yeah, toilet paper too.  
*and out.* If only I had a pen right now, I'd have a list.  
*Notice the lightness and relaxation of your upper body, and gently shake out any left-over tension.* There is no gentle shake, but a rattle and clashing cymbals.  
*Now, as we move to your lower body...*  
 Oh, the lower body.  
*Hold...* Who was this made for?  
*And release* I wonder how many other people in the room are making a shopping list?  
*And hold...* At least it's not such a total waste of time.  
*Release.* Ha.  
*Breath in...* How do I get out of here?  
*hold...* That'll be really awkward.  
*and out.* I have to get out.  
*Breath in...* I have to...  
*hold...* I have to...

<i>and out.</i>	I have to...
<i>Hold...</i>	I have to...
<i>And release.</i>	I have to...
	I have to...
<i>Notice the weight of your body sinking into the floor.</i>	Bathroom!
	I'll tell them I need to go to the bathroom.
<i>Now Breath in... and out.</i>	That'll work.
<i>Notice how softened and heavy you feel.</i>	Better than this.
<i>Feel relaxation spread through your body slowly, from your head to your toes.</i>	Is this the first time these instructions might land in my body?
<i>Breath in...</i>	Now don't release the bladder yet! ...
<i>out first.</i>	Get
<i>and out.</i>	Get out. <sup>32</sup>

PMR is, at its core, about tuning into bodily sensations. As Hinton, Pich, Chhean and Pollack (2006) note, the capacity for specific bodily sensations to trigger significant and traumatic reactions is immense. PMR may amplify pain in dancers because these exercises often demand heightened attentionality to sensations within a particular part of the body. As Throop (2008) argues, “there is growing recognition that the faculty of ‘attention’ plays a key role in configuring the texture of our subjective life as mediated through the senses” (p. 255). The explicit directions of PMR to focus attention on specific body parts impacts the dancers’ experiences of these body parts and can heighten some of the painful sensations in these locations.

Further, with bodily sensations come embodied memories. As Hinton, Howes, and Kirmayer (2008) argue: “we organize our attention to sensations in terms of expectations and memories, and these color the sensory and affective qualities of even the simplest sensory event. There are complex loops between sensation experience, language, and social interaction” (p. 140). For some of the integrated dancers I work with, the pain, panic and anxiety they feel during PMR is intricately linked to specific embodied memories (see Hinton, Howes, & Kirmayer, 2008; Seremetakis, 1994a, 1994b). The way that memory resides in our senses, and folds the

present on the past, may have significant implications for individuals who are surveying their bodies in an attempt to relax, particularly if those bodies have experienced trauma.

I also came to notice another problematic layer to this practice: in PMR we not only gain haptic awareness and knowledges of the body, but we also actively construct the body. Hinton, Howes, and Kirmayer (2008) suggest, “it is more accurate... to speak of our constructing rather than simply receiving images of the world and the body through the senses” (p. 140). So, rather than pre-discursively having a body that practices PMR, I argue, PMR is a sensory practice that constructs a specific kind of body. This bodily construction within typical practices of PMR is a prescriptive and normative one.<sup>33</sup> Peers (2015a), explicitly details the prescriptive and normative expectations of the body that are imposed through instructing typical PMR exercises, in relation to their own non-normative embodiment as well as the non-normative embodiments of their fellow para-athletes. About experiencing a PMR-type exercise, Peers (2015a) writes:

I feel my breath move into my chronically dislocated hip. I flinch and then regain composure.... I can't help but wonder how my teammates are doing. Do they breathe deeply into a painful, absent, unsensing, or prosthetic limb without flinching? (p. 5)

Peers' writing highlights the problematics of normative body construction within these exercises, their (unintended) painful consequences, and their alienating and normalizing effects. Within most PMR exercises, there are clearly articulated expectations of which bodily practices lead to relaxation (e.g., tensing muscles and then releasing them), and which bodily sensations result from these practices (e.g., weightlessness, softness, limpness, lightness, fluidity). There are also very specific assumptions about the body parts that participants have (e.g., tense and relax your hands or feet), as well as about the capacities of these body parts to sense, and to voluntarily contract and release. These expectations and assumptions may hold true for some normative

bodies, but may often prove both untrue and potentially problematic, alienating, or triggering for participants with diverse and non-normative embodiments. Yet we don't talk about this. Good intentions and dangerous practices.

And still, we have the capacity to practice differently, with critical reflection and with creativity. Peers (2015a) continues:

An idea emerges. My hands grasp the crutches at my sides and I guide my next breath deep into their rubbery tips. I feel an embodied sensation of my breath tracing their contours and density: aspects of my crutches that I have explored intimately through the repetitive sharing of weight and time. The muscles we have developed together, through our shared movement, twitch with the pleasure of this exploration. These sensations are more real and relaxing to me than the instructed movement of breath through my supposedly natural legs. (p. 5)

If creativity can inevitably creep into even the most normalizing and structured of PMR exercises, as Peers demonstrates here, then there must be expansive possibilities that can be derived from developing more consciously porous and non-normalizing PMR-type exercises. I am sparked by this opportunity to creatively imagine instructing otherwise. And I am also called to attend to the trauma I can cause by instructing uncritically.

### **I Have Been Damaged by Good Intentions and Dangerous Practices.**

I wake up at 8am, an ungodly hour for me, and wade through the thick psych med swamp with slow determination to get out the door on time. I am intrigued enough to push back against the sinking September day. A panel at a transcontinental conference on Adapted Physical Activity centers on mental illness-related papers. Yes, it is clear from the titles of the presentations that a medical/psychiatric model approach to madness frames each talk: diagnostic

categories abound, but there is also talk of leisure, and physical activity, and experiences of us diagnosable folk. Discussions about mental illness are increasingly happening in APA, and though I certainly steel myself for most likely encountering unidimensional medicalized perspectives on Mad lives and Mad living, I am excited. Dare I say hopeful?

My crip community and I get into the room (not without difficulty navigating physically inaccessible space). We seat ourselves. The presentations aim to do good. Good intentions. Some aim to resist the ever-present medicalizing current, but are pulled down by the real and swift undertow of impossibility to think Mad living outside of diagnostic systems. I work to witness this flailing resistance. It is jarring and awkward and misaligned and I can appreciate the effort it takes to move non-normatively in normalizing waters. And I love non-normative movement, so I am struck by moments of beauty.

And then... The joke.

A researcher quips that he showed up to a physical activity session with a group of diagnosed folks, looking particularly unkempt, and was approached by a participant who mistook him 'for one of them'.

The whole room bubbles laughter. I choke on mouthfuls.

How hilarious it was that an APA researcher be mistaken for one of those crazies.

How hilarious it is to imagine the life of a crazy being compared to yours.

How hilariously pathetic is was of that crazy to assume similarity.

How hilariously different we are, you and me.

He articulates that he did not correct this assumption for some time; it proved too 'useful' for gaining insider information from the participants.

“Like other representational forms and cultural practices dealing with psychiatric illness,

jokes and humour about mental distress carry historical weight framing our social relations with psychiatrically ill others” (Cross, 2013, p. 14, emphasis added).

It matters who is making the joke, and at who’s expense.

I gurgle spit out a ‘that’s not funny’, glaring directly in their laughing eyes.

I feel pelted with stares as I storm from the room.

Although, perhaps, no one even noticed...

Too busy drowning in laughter?

I chain smoke outside the front doors of the conference hotel

fill my lungs with anything other than the burn of drowning.

Such dangerous practices are bad for our health.

### **I am (Re)Traumatized Vicariously.**

I encounter trauma on a regular basis in relation to physical activity practices and contexts, both personally, but also through the experiences that my friends and fellow performers share. Hearing about the iatrogenic trauma of navigating medical and psychiatric systems that is pervasive and often sickeningly unavoidable if my friends, lovers, and community members want to stay alive and active. Witnessing the insidious trauma of being expected to answer the ‘what is wrong with you?’ question daily, in its many ableist iterations, both from strangers on the street and on intake forms before joining a class or facility. Noticing the non-consensual touch of a trainer, the thinly-veiled racist conversation of fellow group-fitness class participants, the fatphobic t-shirt of the runner in the river valley, the conspicuous presence of gender-specific bathrooms and change rooms alongside the absence of gender-neutral possibilities, the unpredictable and violent echoes of dropping dumbbells behind us in the gym.

## **Physical Activity, Trauma, and Mental Distress**

Exercise is often touted as critical to maintaining mental health and as beneficial to people diagnosed with mental illness (Zschucke, Gaudilitz, & Ströhle, 2013). As Lesley et al. (2013) argue, there is a need for physical activity programming that is attuned to the needs of people living with serious mental illness, not only to address the co-morbid conditions associated with mental illness, such as cardiovascular disease and diabetes, but also to develop strategies “to counteract the negative effects of antipsychotic medications that contribute to sedentary activities, low motivation to exercise, and weight gain” (p. 28). Exercise is often mobilized, by professionals and laypersons, as a kind of ‘cure-all’: where Mad folks are told categorically that if we just exercise we will ‘get better’. Unfortunately, it’s not that simple. There are a number of reasons that physical activity contexts and practices might not be experienced as accessible, desirable or safe for people diagnosed with mental illness or experiencing mental distress more broadly (that is, who are experiencing negative symptoms sometimes associated with mental illness or trauma).

First, sport and physical activity can induce or contribute to mental distress. For example, university athletes are stated to be at a higher risk of mental illness “because of the cumulative stresses related to competitive sport” in addition to the pressures of academic life (Kaier, Cromer, Johnson, Strunk, & Davis, 2015, p. 725). Additionally, some sports and physical activities are more likely to foster experiences of mental distress. For example, sport-induced brain injury can cause significant depression and lead to suicide (Abreu, Cromartie, & Spradley, 2016; Mars’ Hill, 2015), and some sports and physical activities are highly correlated to mental illness diagnoses such as body dysmorphia and eating disorders (Taylor & Estanol, 2015; Quatromoni, 2017). Further, athletes have significantly higher levels of perceived public stigma towards mental

illness in comparison to non-athlete peers, and as a result, athletes are significantly less likely to disclose or seek support (Kaier et al., 2015).

Second, for some people experiencing mental illness or distress, exercise may very well be contraindicated. For example, I am on psych meds that cause weight gain, and that also include a warning that “over-exercise” can lead to overheating and dehydration, alongside other side effects including weakness, dizziness, and difficulty moving (Food and Drug Administration, n.d., p. 3). But what counts as ‘over-exercising’? In my experience it does not take a lot of physical activity to experience negative effects from this medication. So how do I hold this together with the intense pressure from medical, social, and media-related insistence that I must exercise to be a good psych patient dedicated to my own ‘recovery’. In an extensive review of literature related to exercise interventions for people diagnosed with a wide range of mental illnesses, Zschucke, Gaudilitz, and Ströhle (2013) suggest that “although a number of studies have yielded positive results on the effectiveness of [exercise interventions] as an adjunct treatment, evidence is limited for most psychiatric disorders” (p. S17). Further, these authors state that one problem with exercise data is that “patients know that [exercise intervention] is supposed to make them feel better, resulting in a potential bias” and that “risks, adverse events and contraindications” to exercise interventions are understudied and need further research (p. S17). In other words, the intense social and medical pressure to exercise as someone diagnosed with mental illness is sometimes in conflict with potential, under-discussed, dangers.

Third, sport and physical activity can be structurally inaccessible to people experiencing mental distress. For example, many sport and physical activity programs are quite expensive, when many people with mental illness and intersectional experiences of trauma also live in poverty (Smoyer, 2016). Commitment expectations often do not allow for people to come in and

out of programming depending on their needs and states of being (Kingsley & Spencer-Cavaliere, 2015). Gender-based violence, which is linked to mental illness (Rees et al., 2014), is particularly present in some physical activity and sport contexts (Rulofs, 2015). As van Ingen (2011) puts it “gender-based violence is undeniably pervasive and is widely acknowledged as a major social and public health problem. However, the issue of violence *against* women and transgendered people remains largely overlooked by physical educators and sport and physical activity researchers” (p. 68). Non-consensual touch is a frequent practice in many sport and physical activity spaces, where, for example, an instructor will physically manipulate participants’ bodies without asking consent (Emerson, Sharma, Chaudhry, & Turner, 2009). There is often pressure to participate in physical activity and sports contexts, leaving little room for active consent or opting out (Emerson et al, 2009). Froshing, locker room behaviour, and some coaching approaches can amount to verbal, physical or sexual abuse (Krahn, 2016; Stefanac, 2016), which are associated with mental illness (Thurston, 2017). Certain activities, like yoga, may ask people to focus on sensations in specific body parts that are holding trauma, and people may actively work to dissociate as a coping mechanism (Levine, 1997). Aspects of the physical environment of sport contexts can be exclusive - for example, florescent lights are difficult for those experiencing light sensitivity, warm temperatures can lead to overheating, mirrors can amplify body image related triggers, gendered washrooms can make changing or bathroom breaks dangerous, and stairways can make entering a building or using a washroom impossible. Further, fear of stigma and social isolation, which is prevalent for people experiencing mental illness, often prevents participation (Lesley et al, 2013).

Fourth, physical activity is often mobilized in order to ‘remedy’ the ‘problem’ of mental illness (see, for example, Harrold et al., 2018; Hearon et al., 2018; Martin et al., 2015; Oppizzi &

Umberger, 2018; Rahman, El Werfalli & Lehmann-Waldau, 2017; Rosenbaum et al., 2015), constructing madness as an undesirable state that must be fixed. This is not my experience, nor my desire. I would like to have access to physical activity programs that are not intended as therapeutic, but rather that are actively working to make their practices and environments more inclusive of me in all of the states of my bodymind. This includes acknowledging that people have both positive and negative relationships to physical activity (Avner et al., 2014), as well as to our embodiments, especially when we have encountered trauma as well (Day, 2013). We must learn about and be attentive to these diverse responses to physical activity, embodiment and trauma in order to practice ethically. In the context of disability-related trauma and post-traumatic growth, Day (2013) argues that:

the negative and positive aspects of human experiences are seldom integrated.

Posttraumatic growth is often associated with stories of courage, meaning making and positive coping strategies. As a consequence, it may seem counterintuitive to consider that such individuals may also experience the negative impacts of trauma. In such ways, it is important to consider that growth can not only occur alongside trauma symptoms, but further, that the experience and acceptance of negative symptoms may even assist in the process of achieving positive growth. (p. 2070)

We must make space for negative encounters with our bodyminds, with our experiences of trauma, and within physical activity.

At the same time, Day (2013) argues that one way people who experience trauma-related disability might explore both positive and negative aspects of their trauma-related embodiment is *through* physical activity:

All participants in this study reported using physical activity either to test the boundaries

of their capabilities, or to deliberately push themselves beyond what was recommended... Thus while physical activity was recommended by healthcare professionals as a method of enhancing well-being it often also highlighted the limitations associated with disability. (p. 2070)

The negative psychosocial effects of participating in physical activity are infrequently discussed when physical activity is promoted within healthcare contexts. Discussions of physical contraindications abound (especially in relation to physical impairment), but considerations of trauma and its impacts within the practice of physical activity are not so easily accessible. At the same time, physical activity provides one context within which key principles of trauma-informed practice can be facilitated (these key principles will be discussed in more detail later). While Day (2013) does not directly address trauma-informed practice, key principles such as choice and control are highlighted as important elements that physical activity practice can foster:

in retrospect, participants acknowledged that understanding and testing the barriers of participation also allowed them to view the future possibilities. Yet it was not physical activity itself that was perceived as promoting growth, but the personal control, responsibility, and risk taking. Participants described a change from being passive recipients of choices made by others, to actively choosing the level of risk that they engaged in. (p. 2070)

Here, physical activity is noted to offer a 'playing field' for exploring active autonomy, control, choice, responsibility, meaning-(re)making, and risk; one valued for its capacity to support sketching new outlines for limitations and future possibilities. Day (2013) continues:

Despite the positive experiences highlighted, it is also important to recognize that such accomplishments were not achieved without extreme difficulties, feelings of depression,

hopelessness and loss... While physical activity may assist individuals in achieving growth, the complexities and difficulties associated with this process should not be ignored. (p. 2071)

Physical activity is not inherently good, pleasurable or healing, but is one way to engage with a breadth of complex, messy, difficult, potent, and generative effects of embodied trauma. It is also one way to foster experiences of autonomy, choice and control, if the focus is not solely on the therapeutic 'healing' capacities of physical activity, but rather on access to opportunities to explore both positive and negative aspects of trauma-related experience. Considering this complexity in depth, and making room for negative as well as positive relationships to physical activity and trauma, is a much-needed project that I am invested in.

I have previously highlighted how, as professionals, we can do damage with good intentions and dangerous practices. I have been damaged by good intentions and dangerous practices, and I do damage. I have also experienced vicarious trauma in my education and practice. I have also just outlined four major barriers in relation to mental distress, trauma, and physical activity: sport and physical activity can induce or contribute to mental distress; for some people experiencing mental illness or distress, exercise may very well be contraindicated; sport and physical activity can be structurally inaccessible to people experiencing mental distress; and physical activity is often mobilized in order to 'remedy' the 'problem' of mental illness, constructing madness as an undesirable state that must be fixed. These four major barriers regarding physical activity, trauma and mental distress, as well as the dangerous practices discussed in the previous section, are what has brought me to consider trauma-informed practice as a means of creating more accessible environments and programs.

## **Introducing Trauma-Informed Practice to Adapted Physical Activity**

Trauma-informed practice means two things for Harris and Fallot (2001). First, it means being aware of histories of past and current trauma for people we are working with. Second, and more importantly according to these authors, it is to:

understand the role that violence and victimization plays in the lives of most consumers of mental health and substance abuse services and to use that understanding to design service systems that accommodate the vulnerabilities of trauma survivors and allow services to be delivered in a way that will facilitate consumer participation. (p. 4)

For a number of authors writing about *trauma-informed* care, services, and practice, the need to work in trauma-informed ways emerged out of health and human services contexts, specifically in relation to women's complex intersectional experiences of gender-based violence, trauma, marginalization, mental health, and substance use (Fallot & Harris, 2009; Harris & Fallot, 2001; Elliot, Bjelajac, Fallot, Markoff, & Glover Reed, 2005; Quiros & Berger, 2013).

Whereas *trauma-specific* services are designed to directly address and treat trauma, *trauma-informed* services do not treat trauma-related issues, but rather “provide services in a manner that is welcoming and appropriate to the special needs of trauma survivors” (Harris & Fallot, 2001, p. 5). Trauma-informed practice is not about therapeutic intervention relating to trauma, but about access to services that are:

thoroughly incorporating, in all aspects of service delivery, an understanding of the prevalence and impact of trauma and the complex paths to healing and recovery. Trauma-informed services are designed specifically to avoid retraumatizing those who come seeking assistance as well as staff working in service settings. These services seek ‘safety first’ and commit themselves to ‘do no harm.’ (Fallot & Harris, 2009, p. 2)

Key principles of trauma informed practice include: trauma awareness, safety and trustworthiness, choice and control, connection and collaboration, and a strengths-based empowerment approach (Ammann & Matuska, 2014; Elliot et al., 2005; Fallot & Harris, 2009; Quiros & Berger, 2013). Of note, a number of the foundational values in the practice of APA align with the core principles of trauma-informed practice: choice, empowerment, collaboration, safety, trustworthiness are all arguably highly desired within the context of APA practice (Goodwin & Rossow-Kimball, 2012; Grenier, 2011; Hutzler, 2008; Kelly, 2006). The major key principle of trauma informed practice that is missing in APA is the practice of incorporating trauma awareness, and then, by extension, the application of this trauma awareness to the other overlapping principles and values shared by trauma-informed service and APA. To my knowledge, we have yet to significantly and adequately incorporate trauma awareness into APA education and professional practice. We thus have a starting point—developing trauma awareness—from which we can build trauma-informed adapted physical activity practice. I will begin by introducing the available literature on trauma-informed physical activity more broadly. I will then share information to develop trauma-awareness from a variety of perspectives, followed by some practical suggestions for building trauma-informed environments and practices in adapted physical activity.

### **Trauma-Informed Physical Activity**

The majority of research on trauma-informed physical activity centers on yoga, and specifically the protocol for “Trauma-Sensitive Yoga (TSY)” developed by David Emerson and colleagues out of the Trauma Center at Justice Resource Institute in Brookline, Massachusetts (Nolan, 2016; Smoyer, 2016). Smoyer (2016) notes that ‘trauma-informed yoga’ is a more general term, and TSY is a specific training program and protocol: one that is designed to

acknowledge trauma and avoid retraumatization through specific instructional strategies (Nolan, 2016). Trauma-sensitive yoga has been done with: “low-income women with substance use disorders” (Smoyer, 2016, p. 65); women with posttraumatic stress disorder (PTSD) where the primary form of trauma experienced was interpersonal or related to intimate partner violence (Nolan, 2016); and “war veterans, rape survivors, at-risk youth, and survivors of chronic childhood abuse and neglect” (Emerson et al., 2009, p. 123). Classes are held most often in the Trauma Center, but also in a variety of locations, such as “veterans centres, residential schools for teens, domestic violence shelters, rape crisis centres, and other community and residential facilities” (p. 124).

Emerson et al. (2009) detail principles and practices for TSY: practices that are run by certified Yoga instructors with specific TSY training. They point to the prevalence of PTSD, and note that “an essential aspect of recovering from trauma is learning ways to calm down, or self-regulate.” (p. 124). They continue:

meditation, relaxation, and physical postures, can reduce autonomic sympathetic activation, muscle tension, and blood pressure, improve neuroendocrine and hormonal activity, decrease physical symptoms and emotional distress, and increase quality of life. For these reasons, Yoga is a promising treatment or adjunctive therapy for addressing the cognitive, emotional, and physiological symptoms associated with trauma, and PTSD specifically. (p. 124)

These authors note that traditional treatments for trauma tend to “neglect the physical, visceral, and body-based dimensions of trauma” (p. 124). As such, an embodied practice, such as yoga offers embodied engagements that other forms of therapy typically ignore.

Clark et al.’s (2014) feasibility study on TSY for survivors of domestic abuse, finds that

the yoga intervention was personally meaningful to participants, and that “the participants in this study were not harmed, were grateful for the opportunity to contribute, and felt that the study would benefit others” (p. 156). Further, in terms of feasibility, the yoga group did require slightly more resources than typical group psychotherapy for trauma. However, the authors note that:

yoga is a natural extension of existing breathing exercises and meditation in many of [the research site’s] group therapy programs. Likewise, the practice of yoga entails very few adverse side effects, requires little to no equipment, and can be conducted in the same space as traditional group therapy, reducing logistical concerns. (p. 156)

From these results, the authors urge more research in the area of providing low-cost, safe, effective and meaningful interventions such as yoga for survivors of partner violence.

Smoyer (2016) investigated responses to trauma-sensitive yoga from low-income women with substance use disorders, studying whether lay instructors (without yoga certification) were able “to provide basic trauma-informed practice,”: an important study because many community-based services and organizations may not have the resources available to hire certified, or even specialized, instructors. Participants articulated benefits of relaxation, mindfulness, and body movement. Participants expressed valuing the simplicity of the activities: activities that could be led by a lay instructor who has undergone a short training session. The author noted that certified teachers should not be supplanted, but that “creating opportunities for social service providers and agency volunteers to lead elementary yoga classes focused on gentle poses and stretches... is more sustainable... [and could] bring more diverse and vulnerable populations to the mat” (p. 79).

Nolan (2016) conducted a narrative review of five studies on TSY that explored the

therapeutic benefits of this form. The author suggested that TSY can: reduce PTSD symptoms and co-occurring symptoms related to depression and anxiety; impact participant satisfaction, and physical and emotional safety; offer a sense of control; increase the likelihood that participants continue with a yoga practice; be used as an adjunct therapy alongside psychotherapy; and offer symptom relief for participants who had previously been unresponsive to traditional therapeutic modalities. Applying lessons learned within TSY classes to other therapies and life in general was suggested to enhance the effects of this intervention. All of the studies in this review, however, originated from the Trauma Center, thus the author suggested further research needs to be conducted by independent researchers.

There is a dearth of literature on trauma-informed sport and physical activity outside of the yoga context. The one existing research project that explores trauma-informed sport and physical activity uses team sport (basketball) as a pilot therapeutic intervention with traumatized assigned-female youth in residential treatment (D'Andrea, Bergholz, Fortunato, & Spinazzola, 2013; D'Andrea & Spinazzola, 2009). In this study, trauma-informed practice and positive youth development theory are mobilized within a therapeutic behavioural intervention strategy. The curriculum was termed “Do the Good,” and it:

trains coaches to facilitate skills through four sports-themed therapeutic goal modules: ‘play to the whistle’ (e.g., perseverance, putting aside frustration while pursuing a goal), ‘show up’ (e.g., commit to one’s best possible performance, awareness of emotional reactions to distress), ‘build your team’ (e.g., leadership skills and responsibility-taking), and ‘fill the tank’ (e.g., provide support for one another, framing one’s games in terms of successes). (D'Andrea, Bergholz, Fortunato, & Spinazzola, 2013, p. 742)

The therapeutic goals are said to align with “gold-standard therapeutic practices for traumatized

children, which include building secure attachment relationships with adults and peers, developing competency at developmentally-appropriate tasks, and self-regulating in the service of achieving goals” (D’Andrea & Spinazzola, 2009, p. 2). This intervention was found to have “a significant positive impact on behavior and mental health” for the youth involved (D’Andrea et al., 2013, p. 747).

Interestingly, one of the major interventions was at the level of the coaches: “the more frequently coaches used DTG [Do The Good] coaching behaviors,” they argue, “the more frequently players resolved conflicts, helped others, encouraged peers, communicated on the court, and participated in circle-ups...[and] the less frequently conflicts occurred” (D’Andrea & Spinazzola, 2009, p. 12). We can learn from these practices to build our own trauma-informed work.

Another very useful publication on trauma-informed sport and physical activity is “Women on the move: Trauma-informed interventions based on sport and play, a toolkit for practitioners” (Ammann & Matuska, 2014). This toolkit includes two parts: a principles and practical guide; and a toolbox with a variety of physical activity exercises. The principles and practical guide is an excellent introductory resource for framing trauma-informed practice in the context of sport and physical activity, outlining trauma, a trauma-informed sport approach, program design, and practice recommendations. The toolkit includes ice breakers, relaxations techniques, warm ups, stretching, cool downs, skills and drills, basic rules, and play-based games. A significant number of the practical suggestions I will discuss later are drawn from these authors’ principles and practical guide.

Ultimately, the trauma-sensitive yoga and sport literature approaches trauma from an overarchingly psychiatric perspective (with a significant reliance on the American Psychiatric

Association's Diagnostic and Statistical Manual of Mental Disorders 'Post-Traumatic Stress Disorder' diagnosis as the marker of trauma). At the same time, it does also acknowledge experiences rooted in interpersonal trauma, intimate partner violence, and poverty. It also offers some grounded and fruitful suggestions for how we might move towards more trauma-informed physical activity practices and environments (which will be discussed more later).

Although these (largely therapeutically-oriented) studies on trauma informed physical activity offer important insights, our engagement with trauma in APA, I argue, must draw from not only psychiatric, but also social, political, and embodied knowledges about trauma. We must include psychiatric knowledge, because it is a predominant way that trauma is discussed popularly and within trauma-informed practice, both in health care (Fallot & Harris, 2009; Harris & Fallot, 2001; Klinik Community Health Centre, 2013; Manitoba Trauma Information and Education Centre, 2013a) and physical activity contexts (Ammann & Matuska, 2014; Beltran et al., 2016; Carless, 2014; D'Andrea et al., 2013; Emerson et al., 2009; Jindani & Khalsa, 2015; Nolan, 2016; Spinazzola, Rhodes, Emerson, Earle, & Monroe, 2011; van der Kolk et al., 2014). To do trauma-informed work, it can be useful to have a sense of the (often medically-coded) signs of trauma, and how experiences of trauma might manifest in the thoughts, feelings and behaviours of ourselves and others (Harris & Fallot, 2001; Klinik Community Health Centre, 2013). But this conversation must also address the social and political aspects of trauma that are often only insinuated, talked around, or left out of predominantly psychiatric discussions. We need to recognize that trauma experiences and responses can be damaging, and at the same time we need to be critical of the tendency to individualize and pathologize these experiences and responses (Burstow, 2003; Gilfus, 1999). Social and political understandings of trauma can help us to relate to people who have experienced trauma without assuming they are damaged victims

(Burstow, 2003; Gilfus, 1999; Tseris, 2013). They can help us understand and intervene into the structural inequalities and violences that lead to many experiences of trauma. These non-medicalizing understandings can also help us to determine how to make interventions into how we act as instructors or leaders, how we run programming, and how we foster environments that are accountable to trauma and its impacts.

So, we need to talk about trauma, and we need to talk about it in multiple ways. Because, for the most part, we are not learning about trauma in our adapted physical activity classes. We do not talk about how disability, mental illness, and trauma are deeply intertwined, both medically/psychiatrically and socio-politically (Fallot & Harris, 2009; Kafer, 2016). We are not practicing in trauma-informed ways in our adapted physical activity contexts. We are not recognizing, at least in academic discourse and practice-based contexts, how we might be causing trauma by virtue of the very ways we understand and engage with disability and bodies doing physical activity. And we are not prepared as professionals to encounter trauma, and experience vicarious trauma, through our own professional practice, even though we do. And so, I invite you to delve with me further into this necessary and dangerous conversation. I will begin with the aim of increasing our trauma awareness by exploring a series of ways to conceptualize trauma.

### **What is Trauma? A Series of Conceptualizations**

“Trauma is a not a disorder but a reaction to a kind of wound. It is a reaction to profoundly injurious events and situations in the real world and, indeed, to a world in which people are routinely wounded” (Burstow, 2003, p. 1302). Trauma is magnificent and ordinary. Fallot and Harris (2009) argue that trauma is pervasive (see also Danieli, 1998a), with the vast majority of people having experienced a traumatic event at least once, but five traumatic events

on average. These events have expansive and life-shaping impacts that reach across generations (Danieli, 1998a). Fallot and Harris (2001) also argue that trauma is: magnified by intersections with poverty, homelessness, disability, addiction, and mental illness; perpetuated and perpetrated by institutions and service providers; and that trauma impacts service providers as well. Given the prevalence of trauma, its intersections with disability, the roles that institutions and service providers can play in perpetuating and perpetrating trauma, and given that service providers can experience trauma in their lines of work, it is vitally important to address trauma—and center trauma-informed practice— within the profession of adapted physical activity.

### **Psychiatric Engagements with Trauma**

In discussing trauma and physical activity, many scholars turn to the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM), and specifically to the definition of PTSD (Beltran et al., 2016; Carless, 2014; D’Andrea et al., 2013; Emerson et al., 2009; Jindani & Khalsa, 2015; Nolan, 2016; Spinazzola et al., 2011; van der Kolk et al., 2014). Indeed, scholars writing on trauma-informed practice (which will be outlined in detail later) forefront the vital importance of knowledge and awareness of trauma, often citing or alluding to the need for practitioners to conceptualize trauma in relation to PTSD, and to recognize signs of PTSD as a core component of practicing in trauma-informed ways (Ammann & Matuska, 2014; Emerson et al., 2009; Fallot & Harris, 2009; Klinik Community Health Centre, 2013).

The fifth (and latest) edition of the DSM has created a new diagnostic category specifically for “Trauma- and Stressor-Related Disorders” (American Psychiatric Association, 2013), when previously the diagnosis of PTSD was accounted for under “Anxiety Disorders” (American Psychiatric Association, 2000). The creation of this new category includes attempts to

account for trauma-related disorders that present through a myriad of experiences and responses such as anhedonia (lack of pleasure), dysphoria (unease or dissatisfaction), dissociation (feelings that the world is unreal or out-of-body experiences), and/or anger/aggression, as opposed to solely anxiety-related presentations. Trauma experiences and responses are complex and widely varied.

The category of trauma- and stressor-related disorders includes diagnostic criteria for a host of defined disorders, each of which have a criterion related to “exposure to [at least one] traumatic or stressful event” (American Psychiatric Association, 2013, p. 265). These disorders include: reactive attachment disorder and disinhibited social engagement disorder; PTSD (which includes a pre-school subtype and dissociative subtypes); acute stress disorder (similar to PTSD but with shorter duration and more immediate presentation); adjustment disorders; and other specified trauma/stressor-related disorders including persistent complex bereavement disorder as well as cultural syndromes (American Psychiatric Association, 2013). There is also an appended “glossary of cultural concepts of distress,” some of which are related to experiences and expressions of trauma and stress. The systems by which trauma- and stressor-related disorders are classified are both changing and growing.

This new diagnostic category accounts for disorders that arise from both trauma and/or stressor-related circumstances. Traumatic events that are described within the diagnostic criteria for these disorders include, but are not limited to: neglect; unstable primary care relationships; isolation; “exposure to actual or threatened death, serious injury, or sexual violence” either directly, as a witness, via a loved one, or via “repeated or extreme exposure to aversive details” (e.g., for first responders, sexual assault center professionals) (American Psychiatric Association, 2013, p. 271); war; “threatened or actual violent personal assault” including physical or sexual

abuse or assault, kidnapping, or torture (p. 281-282); serious accidents including motor vehicle accidents; and disasters (natural and human-made). Identifiable stressors can: be single or multi-event stressors (e.g., a break-up vs. ongoing relationship difficulties); be recurrent or continuous (e.g., seasonal job loss vs. progressive illness); relate to “developmental events” (e.g., moving out, graduation, retirement) (p. 287); and can affect a person, a small group, or a community (e.g., death of family member vs. natural disaster). What qualifies as traumatic event(s) or stressor-related event(s) is also widely varied, and is dependent on how one conceptualizes trauma.

The DSM-V (American Psychiatric Association, 2013) details ‘pathological’ reactions to trauma and stressors as criteria for mental illness diagnoses. Most reactions are deemed pathological if they negatively impact ‘socially appropriate’ functional performance in the contexts of school, work, social, or everyday life. Some of the (deemed pathological) reactions that are accounted for within these disorders include: attachment difficulties; emotional withdrawal; “culturally inappropriate, overly familiar behaviour with relative strangers” (American Psychiatric Association, 2013, p. 269); extended periods of grief and mourning; “marked distress that is out of proportion” to a stressor (p. 286); a sense of being out of control; dizziness; intrusive memories, dreams, flashbacks of the traumatic event(s); avoidance of memories/thoughts and/or avoidance of people/places/things/situations/discussions relating to the traumatic event(s); negative changes in mood or thoughts, such as amnesia, negative beliefs, distorted thoughts, negative emotions, decreased interest in participation in meaningful activities, detachment, inability to feel of positive emotions; changes in arousal and reactivity including angry and irritable behaviours, recklessness, hypervigilance, difficulty concentrating, increased startle response, sleep problems; dissociative symptoms including depersonalization (out-of-

body feelings) and derealization (surroundings seem unreal or distorted); depressed mood; anxiety; panic attacks; and a variety of other physical, cognitive, emotion or behavioural symptoms. Responses to trauma and stressors are also complex, widely varied, changing and growing within DSM classification, and ultimately dependent on how one conceptualizes trauma.

Of particular relevance to APA practitioners, trauma and disability are sometimes interconnected within medical and psychiatric literature. Researching within the context of the military, Carless (2014) states that “bodily injury is a major risk factor for posttraumatic stress disorder” (Carless, 2014, p. 1440; see also Koren, Norman, Cohen, Berman, & Klein, 2005). While this researcher’s statement is context-specific to military events and experiences, it is certainly possible that non-military bodily injury, which may result in impairment and disability, may also have traumatic events and experiences associated with it (Day, 2013; Erevelles, 2014). The DSM-V states:

Life-threatening illness or debilitating medical condition is not necessarily considered a traumatic event. Medical incidents that qualify as traumatic events involve sudden, catastrophic events (e.g., waking during surgery, anaphylactic shock). Stressful events that do not possess the severe and traumatic components of events... may lead to adjustment disorder but not to acute stress disorder. (American Psychiatric Association, 2013, p. 282)

Experiences of disability and chronic illness therefore are only sometimes understood as contributing to a trauma-related mental disorder within the DSM-V. The structures of the DSM delimit diagnosis to circumstances when diagnosing clinicians consider such experiences as either severe and abrupt enough to cause acute stress disorder or PTSD, or when these

experiences result in the presence of “marked distress that is out of proportion to the severity of the stressor” such that they would be considered an ‘adjustment disorder’ (American Psychiatric Association, 2013, p. 286). Thus, in the DSM-V, disability and trauma are certainly not always related, and it is inappropriate to assume that everyone who experiences disability also experiences, or has experienced, trauma. At the same time, it is unclear what is considered “out of proportion to the severity of the stressor.” How do we account for trauma that is not necessarily related to a single “stressor” incident, but to insidious violences experienced by disabled people daily that may be either directly imposed or sanctioned within healthcare, government, and social systems? As I will detail below, the DSM-V definitions of illness and disability-related trauma diagnosis, as well as other trauma-related diagnoses, are limited in their scope and sensitivity, rarely dealing with social and political dimensions of trauma that also impact how disability and trauma converge.

*This manuscript is a poor record  
Poorly records  
The stops and starts  
The gaps  
The disappearances  
The fallings (and yes, the apt autocorrection: the failings)  
The flailings  
The belly aches and tongue ties  
the stuffing my face with all of the things  
The (minor even if it felt major) car accident and the micro(macro)aggressive sanism  
The diagnoses  
And lesions  
And exploratory surgery  
Which discovered no answers  
To name a few of the  
countless upon countless  
things I cannot list  
as items on a list*

*And as I write this I am upping my meds  
Word soup swirls the screen in front of my face  
Corrections/deletions/blinking cursors/slow fingers*

*this trauma-body senses  
not much too much*

*And I (don't) know  
how to  
weave  
feelings and ideas and systems and synapses  
This medicopsychosociopoliticoembodied  
being  
becoming  
none without the other*

*So I patchwork shitty poetry  
And let time leak by  
until the drugs kick in  
And I can tell you stories  
About the social and the political  
That squeeze this body into the medicopsycho  
Alone.  
Because I can't be it alone.*

### **Complicating Trauma: Introducing the Social and Political**

Clare (2017) offers a conflicted and nuanced perspective on how to engage with diagnostic logics within a world widely governed through medical and psychiatric knowledges:

*it is impossible to name all the ways in which diagnosis is useful.* It propels eradication and affirms what we know about our own body-minds. It extends the reach of genocide and makes meaning of the pain that keeps us up night after night. It allows for violence in the name of care and creates access to medical technology, human services, and essential care. It sets in motion social control and guides treatment that provides comfort. It takes away self-determination and saves lives. It disregards what we know about our own body-minds and leads to cure. *Diagnosis is useful, but for whom and to what ends?* (p. 48, emphasis in text).

In other words, medicine and psychiatry can sometimes alleviate the harms of trauma, but it cannot account for the harms of medicine or psychiatry, nor all of the sources of harm that

medicine and psychiatry cannot account for. We must thus work through and between multiple forms of knowledge about trauma. Social and political aspects of trauma that must be considered, but are inadequately addressed by the DSM and dominant psychiatric understandings of trauma, include oppression-induced trauma; insidious trauma and microaggressions; anti-pathologizing orientations to trauma; and the embodied nature of both personal and sociopolitical trauma.

**Oppression, trauma and microaggressions through the lens of ableism.** Numerous authors argue that predominant psychiatric understandings of trauma, including the DSM-V fail to adequately account for systemic social and political aspects of trauma (Burstow, 2003, 2005; Danieli, 1998; Gilfus, 1999). Burstow, (2003) argues:

specific traumatic events happen to specific people in specific locations and within specific contexts, and they inevitably involve other human beings. As such, trauma is inherently political... trauma inherently involves others and societal structures... Insofar as people are not helped or helped inadequately, the trauma takes on whole new dimensions. The reaction of others, in other words, figures significantly in trauma. (p. 1306)

For example, even in the most seemingly apolitical of traumatic events (e.g., barely surviving a hurricane), sociopolitical forces such as poverty, racism, and ableism will impact who lives in under-protected neighbourhoods, who can be evacuated safely, and who is likely to easily access respectful and helpful medical care, social programs, and housing reparations in the aftermath (Titchkosky, 2007). Gilfus (1999), similarly argues that psychiatric models of trauma only attend to the symptoms in the aftermath, rather than the source or cause of trauma, ultimately disregarding the social and cultural context within which the violence and trauma take place. The connections between social and cultural contexts, oppression, and trauma are obscured if we

approach trauma from psychiatric perspectives alone.

Numerous scholars and activists have pushed for a recognition of experiences of oppression (including racism and poverty, as well as interpersonal trauma including violence against women, rape and child abuse) as potential sites of trauma (Burstow, 2003; 2005; Danieli, 1999; Gilfus, 1998). For example, disability-related oppression takes multiple forms: including state-enforced poverty, lack of access to economic stability, employment, and housing, iatrogenic trauma, assault, relations of domination, forced sterilization, institutionalization, extermination, and ableism (Hollomotz, 2013; Snyder & Mitchell, 2006; Withers, 2012). These forms of disability-related oppression, and their role in trauma, are unreadable unless we take a sociopolitical orientation to trauma.

When we examine disability, oppression, and trauma together, a useful set of interrelated lenses to employ are that of ableism and disablism. Ableism is a:

network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.

(Campbell, 2001, p. 44)

By extension, disablism a “set of assumptions and practices promoting the differential or unequal treatment of people because of actual or presumed disabilities” (Campbell, 2008, p. 152).

Considering that adapted physical activity has a primary focus on disability-related research and practice of physical activity, we cannot consider our work outside of the functions of disability-related oppression, ableism, and disablism. This includes experiences and impacts of ableism and disablism for people who experience disability (Wickman, 2007), as well as from their peers (Zitomer & Reid, 2011) and from practitioners of adapted physical activity (Goodwin, 2017;

Spencer-Cavaliere, Thai & Kingsley, 2017). I argue that practicing and researching in adapted physical activity without considering disability-related oppression, ableism, and disablism as a site of potential trauma is fundamentally unethical.

Oppression, such as that resulting from ableism and disablism, manifests in both overt and covert ways (McGibbon, 2012). Undoubtedly, in relation to disability, there is much direct and overt violence. At the same time, specific attention needs to be paid to insidious trauma.

Burstow (2003) writes:

oppressed people are routinely worn down by the insidious trauma involved in living day after day in a sexist, racist, classist, homophobic, and ableist society: being ogled by men on the street, slaving long hours and for minimum wages in a fish processing plant, hearing racist innuendoes even from one's White allies. (p. 1296)

This daily barrage takes its toll, but is not always easy to point to.

One example of oppression-related insidious trauma is the 'microaggression,' an enactment of violence that involves often covert discrimination, harassment or prejudice which can instigate or perpetuate trauma (Michaels, 2010; Nadal, 2018). For example, Dávila (2015) writes specifically on disability and microaggressions, including "low expectations, disregard, and bullying" (p. 454). In relation to 'mental illness' (MI), Peters, Schwenk, Ahlstrom and McIalwain (2017) argue that microaggressions include "conveying stereotypes about individuals with MI; invalidating the experiences of having a MI; defining a person by their disorder; and misuse of terminology" (p.93). Further, these authors argue that people experiencing 'mental illness' encounter some different microaggressions than those who are exposed to microaggressions due to race, gender, or sexual orientation: these include microaggressions around "seeking attention or being dramatic, bringing MI upon themselves, and using MI as an

excuse” (p. 103). The difficulty with microaggressions is in part due to their insidious nature. As APA practitioners, we may be unwittingly causing or perpetuating insidious trauma, even when we can rightly say we have not caused overt harm (for more on professionals perpetrating microaggressions in practice, see Peters et al., 2017). On microaggressions and mental illness labels, Cassani (2017) writes:

the language of mental illness ‘others’ people and is a human rights violation committed mindlessly by our entire culture. Forced treatment is the most obvious violence against us but microaggressions happen daily everywhere. When separation and microaggressions are legitimized and put into public policy and discourse the way it’s been done, we become second class citizens and subhuman - and it’s all very acceptable as far as most are concerned... This is oppression and bigotry systematically supported and then denied by almost everyone, including those most seriously affected. We internalize it and come to believe these lies. (para. 3-5)

Our everyday practices, such as the way we defer to psychiatric mental illness labels, can do insidious damage.

In relation to racial microaggressions, Wing Sue et al. (2007) outline three forms: microassaults, microinsults, and microinvalidations. While we must be cautious when drawing direct parallels between experiences and histories of racism and ableism, they are not mutually exclusive, and the research of Wing Sue et al. (2007) can help illuminate some of the functions and effects of microaggressions in relation to disability. In their research, these authors note that they:

have purposely chosen to concentrate on racial microaggressions, but it is important to acknowledge other types of microaggressions as well. Gender, sexual orientation, and

disability microaggressions may have equally powerful and potentially detrimental effects on women, gay, lesbian, bisexual, and transgender individuals, and disability groups. (p. 284)

If we are to address oppression, ableism, and disablism in our professional practice, we must learn about, and reflect on, microaggressions perpetrated by ourselves and by others.

In detailing the concepts of microassault, microinsult, and microinvalidation, Wing Sue et al. (2007) state that “a microassault is an explicit racial derogation characterized primarily by a verbal or nonverbal attack meant to hurt the intended victim through name-calling, avoidant behaviour, or purposeful discriminatory actions” (p. 274). Microassaults are most often overt in nature. In relation to mental distress and disability, microassaults include verbal attacks such as the ever-present ‘crazy bitch,’ staring and then avoiding eye contact with a disabled person, or refusal to allow someone entry into a venue because of mobility tool use.

Wing Sue et al. (2007) argue that “a microinsult is characterized by communications that convey rudeness and insensitivity and demean a person’s racial heritage or identity. Microinsults represent subtle snubs, frequently unknown to the perpetrator, but clearly convey a hidden insulting message to the recipient” (p. 274). Microinsults are often covert in nature. In relation to disability, calling something ‘lame,’ or saying, ‘just kill me if I end up like that’ are microinsults.

“Microinvalidations are characterized by communications that exclude, negate, or nullify the psychological thoughts, feelings, or experiential realities of a person of color” (p. 274). Microinvalidations are also often covert in nature. In relation to disability, telling someone they are ‘so high functioning,’ or that ‘it’s so good to see you get out of your house,’ or alternatively, saying ‘everyone is disabled in some way’ are microinvalidations. These authors also unpack a

series of dilemmas that face people when experiencing microaggressions, including the dilemma of clashing divergent realities, the “invisibility of unintentional expressions of bias” (p. 277), the “perceived minimal harm” of microaggressive acts (p. 278), and “the Catch-22 of responding to microaggressions” (p. 279), wherein the victim must not only determine ‘did this really just happen?’ ‘was it on purpose?’ and ‘should I do something?’ but also ‘how will this differentially and negatively impact me if I try to address it?’ Microaggressions not only do damage and reinforce precarity for those who encounter them, but they also demand significant labour in order to be addressed.

Michaels (2010) argues that microaggressions can include not only verbal or non-verbal, and specific or non-specific acts, but also ‘can refer to environments that are either intentionally or unintentionally unsupportive to a person’ (p. 2). The above authors offer the example of a university where all of the buildings are named after heterosexual upper class white men, which can make it difficult to envision yourself as welcome in the space if you are racialized, queer, non-binary or a woman. Another example is holding an all-ablebody/minded panel on disability or mental illness (which I have experienced a lot), or holding adapted physical activity programming in venues without automatic door openers (which I am guilty of). It may seem like small details, but it speaks to whose bodyminds are prioritized in that space. This kind of attention to supportive and unsupportive environments is a central aspect of developing trauma-informed practice, as we will recognize below in discussions of practical suggestions for building trauma-informed physical activity.

**Anti-pathologization and trauma.** As Burstow (2003) argues “the diagnosis [of PTSD] individualizes social problems and pathologizes traumatized people” (p. 1296; see also Berger, 2004; Burstow, 2003, 2005; Gilfus, 1999; Tseris, 2013; Quiros & Berger, 2013). Thus,

psychiatric discourses of trauma serve to efface social injustices, problematize individuals who experience such injustices, and then target these pathologized individuals with interventions that often amount to traumatizing violence (e.g., forced institutionalization, chemical restraints), as well as rendering individuals targets of further social injustice (e.g. within health, legal, and welfare systems) (Diamond, 2014; Kirby, 2014). In fact, Burstow (2013) and other members of the anti-psychiatry movement conceptualize diagnostic and psychiatric systems as the greatest perpetrators of harm towards people experiencing mental distress, including trauma (see also Burstow, LeFrançois & Diamond, 2014).

One of Burstow's (2003; 2013) arguments is that by naming a set of experiences and reactions to trauma as a mental disorder we do a number of problematic things: we essentially create a mental disorder; we flatten the nuanced and complex ways that traumatic events and reactions are experienced in order to fit them into diagnostic categories; we give over agency to psychiatric systems; we remove agency from the person to name and engage with their experiences and reactions outside of pathologizing discourses; and we are implicated in the iatrogenic trauma that psychiatric systems perpetrate and perpetuate. As such, Burstow (2003) states "I am recommending that we substantially break with psychiatry, that is, that we not look to psychiatry for trauma frameworks and that we rigorously demedicalize" (p. 1301). For Burstow, this means not spending time or energy on redefining trauma-related diagnoses within the DSM, not focusing on diagnostic labels, and avoiding a deficit model that understands reactions to trauma as necessarily pathological. As Day (2013) points out, "a predominant portion of the literature on trauma is grounded in an illness ideology, focusing on the negative impacts of trauma" (p. 2064). Burstow (2003) argued that radical trauma work must not only attend to the political aspects of trauma, but also move away from this sole focus on negative

impacts. This involves a paradigm shift away from pathologizing trauma experiences or responses through psychiatric language and systems (see also Quiros & Berger, 2013).

For example, “many trauma theorists assert that traumatic events alter survivors’ assumptions about the world” (Gilfus, 1999, p. 1250). The assumptions that are altered relate to the world being benign, safe, meaningful, just, controllable and predictable - these are the presumed ‘healthy’ assumptions that become altered in ‘unhealthy’ ways after experiencing trauma. However, both Burstow (2005) and Gilfus (1999) argue that much of trauma theory is developed from a privileged position that assumes the ‘default world’ is neutral and safe, which is an untenable assumption for many who experience trauma (especially if this trauma is ongoing and related to oppression and/or marginalization). Gilfus (1999) stated:

notions of a just world and a safe home are not automatic, readily available, or equally distributed. Poor and working-class people often do not have the experience of living in a just or predictable world... Sheer physical survival often depends on being smart about the very real dangers and injustices in the world. (p. 1251)

It is only by assuming the neutrality of the world that diagnostic criteria can be developed which consider fear, avoidance, or hypervigilance, for example, to be pathological. Both Burstow (2005) and Gilfus (1999) challenge pathologization, arguing that responses to trauma such as fear, avoidance, and hypervigilance are valid and appropriate coping strategies. Further, these authors suggest that the context in which trauma occurs often still persists: as such, fear and avoidance reactions are especially appropriate in light of this ever-present danger. As Burstow (2003) puts it:

what is implicit in all of this is that the trauma reactions known as symptoms are not just proclivities that somehow beset traumatized people and populations. Some are

heightened awarenesses that arise by virtue of the experience. Some are dynamics that flow from the logic of the situation. Most are constructive ways of conducting oneself in fraught and often impossible situations. (p. 1305)

Is it so dangerous for us to consider that our reactions to trauma are in fact the best ones available? For example, dissociation, in my experience, can be intensely useful, protective, and sometimes generative (see also Levine, 1997). “So-called symptoms are best theorized as survival skills. Correspondingly, traumatized people are most adequately conceptualized as competent practitioners of their lives, none of which means that they do not get stuck or that help is inappropriate” (Burstow, 2003, p. 1305-1306). While thought and behaviour distortions may be involved, which can be addressed therapeutically if so desired, fundamentally the person who experienced trauma knows the dangers in the world. What would radically shift if we took to heart the notion that people who experience trauma are competent practitioners of our bodies and lives?

*Even as I read the word*

*Or write it*

*As now*

— — — —

*I*

*Thankfully... Float... Away*

*Why write it, then?*

*Because.*

*I can(?)*

## **The Embodied Nature of Personal and Sociopolitical Trauma**

Despite some of the complicated histories and violences surrounding the word ‘trauma,’ Burstow (2003) argues for us to keep using the term for a number of reasons. It is a word used by those who have experienced it. It also is a word that spans both physical and psychological, as well as personal and social, experience. And, it is embodied. I argue that it is because of the embodied nature of trauma that we should be especially aware of it within adapted physical activity. For Burstow (2003), “whatever its application, there is a physicality to trauma. Trauma befalls *embodied* individuals, and even when there is no explicit assault on the body, people become alienated from their bodies in some respect” (p. 1302, emphasis added). Further, Burstow (2003) argues that embodied trauma is “characterized by opposing pulls and directions” (p. 1303).

Trauma is disconnection from bodies, disorientation in space and time, dissociation from self and others, both fleeing and haunted by the past. It is also deep dark feelings, an embodied reaction to a wound, so numb that we self-harm to both feel and numb out further at the same time. Trauma cannot be adequately witnessed by either self (the almost invariable associated spotty amnesia) or others (no-one can really know about that event as you do - you are deeply intensely alone in it). Burstow (2003) argues that it is necessary to understand “that trauma is not a free-floating feeling or set of feelings or orientation. Trauma is a concrete physical, cognitive, affective, and spiritual response by individuals and communities to events and situations that are objectively traumatizing” (p. 1304). Trauma happens to, and is felt through, bodies.

*I am a tent  
having come untethered  
the one you (or I?) stumble chase down the beach  
Stakes whipping around wildly  
wind gusts suck and bellow  
Telescoping poles bent and protruding at odd angles  
nylon rips on branches and the sharp edges of rock  
Winter is coming  
Do you feel it?*

**Fight, Flight, and Freeze Responses.** The following lists, drawn together from the Manitoba Trauma Information and Education Centre (2013b), detail numerous ways our bodies sense and communicate about trauma.

Fight

Crying  
Hands in fists, desire to punch, rip  
Flexed/tight jaw, grinding teeth, snarl  
Fight in eyes, glaring, fight in voice  
Desire to stomp, kick, smash with legs, feet  
Feelings of anger/rage  
Homicidal/suicidal feelings  
Knotted stomach/nausea  
burning stomach  
Metaphors like bombs, volcanoes erupting

Flight

Restless legs, feet /numbness in legs  
Anxiety/shallow breathing  
Big/darting eyes  
Leg/foot movement  
Reported or observed fidgety-ness, restlessness, feeling trapped, tense  
Sense of running in life- one activity-next  
Excessive exercise

Freeze

Feeling stuck in some part of body  
Feeling cold/frozen, numb, pale skin  
Sense of stiffness, heaviness  
Holding breath/restricted breathing  
Sense of dread  
heart pounding  
Decreased heart rate (can sometimes increase)  
Orientation to threat

For me, these lists are a reminder that we encounter a vast array of embodied signals that relate to trauma, any of which may be experienced during everyday activities, and may be more presently felt when we are asked (by others or by ourselves) to tune into our body within physical activities practices. The last items in the ‘flight’ column point directly to the ways that the sense of ‘running in life’ (perhaps metaphorical, perhaps literal), or the practice of ‘excessive exercise,’ draw together the embodied nature of trauma with physical activity specifically: both a ‘symptom’ of, and a coping strategy for, these embodied sensations of trauma. Our bodies sense, and may need to move in, with, and through, trauma.

Torrell (2016) goes so far as to state that the body is a pivot point for both disability and trauma. In discussing a memoir by disabled writer Kenny Fries, Torrell (2016) notes that:

the scars on his legs are an access point to his past in that he experiences very real emotional connections to them... His legs thus provide him access to a fuller account—or a more complete emotional memory—of his experiences. (p. 97)

Our bodies, in parts and in relations, tell our trauma stories in pasts, presents and futures (even if we can’t so easily read them). Morrison and Casper (2012) argue similarly that:

the body itself provides a link between disability studies and critical trauma studies, arguing both for the significance of representations as well as a materialist understanding of breach, for a notion of the organic, fleshy body as it is damaged, sometimes profoundly, in its operations of life. (Conclusions section, para. 2)

The body is one locus of convergence for disability and trauma (as well as for trauma and other forms of marginalization or oppression) and it is precisely this locus that adapted physical activity intervenes in most often.

In order to move—to navigate a sometimes-treacherous world—the trauma-body also

senses and feels. Within the context of trauma treatment, Levine (1997) and van der Kolk (2014) both advocate for body-based therapeutic intervention, specifically because of the sensorial embodied nature of trauma. For example, van der Kolk (2014) weaves scholarship from neuroscience, developmental psychopathology, and interpersonal neurobiology to discuss how responses to trauma involve deeply embodied, visceral, sensorial reactions to our memories and to our social and cultural worlds. Fundamentally, van der Kolk (2014) argues that:

the body keeps the score: If the memory of trauma is encoded in the viscera, in heartbreaking and gut-wrenching emotions, in autoimmune disorders and skeletal/muscular problems, and if mind/brain/visceral communication is the royal road to emotional regulation, this demands a radical shift in our therapeutic assumptions. (p. 86)

The shift van der Kolk is seeking is one that honours, and mobilizes, the embodied nature of trauma. It is one that includes approaches to treatment that center “breath, movement and touch” as much as (or more than) intellectual or talk-based interventions (p. 64). It is one that mobilizes yoga, theatre, and other social/relational embodied experiences to move through trauma. While, in general, this chapter is not about how to treat trauma, it is valuable to be aware of how embodied practices impact trauma reactions, if we hope to create movement and physical activity spaces that are trauma-informed.

Carter (2015) also discusses trauma as an embodied affective structure: one that is delineated by social valuation of certain sensory and emotional/affective ways of being. In other words, trauma-as-embodied is also always trauma-as-social-and-political. For Carter, the issue is not that embodied affective or sensory responses to trauma are maladaptive, but rather that they are (pre)determined by social valuations of ‘appropriate’ ‘in proportion’ or ‘in control’

sensory/affective ways of being. This, in turn, enables discrimination of ‘inappropriate’ sensory/affective ways of being. Carter elaborates further, noting that “traumatized individuals are disabled by a society that cannot comprehend, or make room for such affective or psychosomatic responses that do not adhere to the assumed stability of able-bodymindedness” (Trauma Culture, Trauma Confusion section, para. 9). Our messy, leaky, inappropriate, out of proportion, out of control, trauma-sensing-feeling-bodies get us in trouble. Carter (2015) writes:

while recognizing the numerous social barriers for traumatized individuals is certainly important, the experiences and embodiments of trauma must also be reconceptualized culturally as both relational and political. Just as all disability is constituted through the (false and oversimplified) binary of disabled or abled, embodiments of trauma are also constituted through the unmarked binary of traumatized or un-traumatized. We know whose affects and responses are ‘inappropriate’ or ‘dysregulated’ because we have socially determined what a proper and regulated affective response looks like. Thus, individuals who live with the affect of trauma are socially constructed as an Other, and like other disabilities, trauma is ‘experienced in and through relationships’ with the un-traumatized norm. (Trauma Culture, Trauma Confusion section, para. 9)

We need to critically consider how we are relationally upholding embodied sensory and affective norms within our movement and physical activity practices, and how judging behaviour, sensations or affects as “inappropriate’ or ‘dysregulated’ functions to relegate those experiencing embodied trauma (or other disabled embodiments) to the status of ‘Other’. Put simply, in judging or pathologizing certain embodiments of trauma, we are marginalizing, Othering, and often, in turn, enacting or enabling violence against those we seek to support.

In order to avoid this ‘Othering,’ we must attend to embodiment, make space for non-

normative embodiments, and honour the knowledge that arises from these embodiments. Gilfus (1999) argues specifically for attending to trauma embodiments, which are invariably tied to local, specific, experience-based ‘survivor’ knowledge:

As a survivor-researcher... I often experience the rules (spoken and unspoken) of the academy and the professions. One of those unspoken rules is that it is not particularly safe to be ‘out’ as a survivor - not that I want to disclose my personal history all of the time or even very much of the time - but the fact that it is not safe requires that the skills, knowledge, and vision I bring as a survivor must usually be silenced and split off from my public academic voice in order to be taken seriously. Survivor knowledge is still usually considered an illegitimate source of knowledge (unless filtered and interpreted by an ‘expert’). (p. 1247-1248)

We must consider that we, as APA professionals, are surrounded by others (with and without disability) who have experienced trauma, and we may also have experienced it ourselves. In our work, what our moving bodies know is important, and if our bodies move with trauma, this trauma-body knowledge is important too. By not addressing trauma we are missing a vital opportunity to value body knowledges (yes, the ‘difficult’, ‘out of control,’ and ‘resilient’) in ourselves and those we work with: knowledges that can contribute to more ethical, relational, accessible, and socially just research and practice.

### **Trauma and Differentially Distributed Harm: Disability Justice, Access, Intersectionality, and Intergenerational Legacies**

Trauma, including community trauma, can be a barrier to accessing physical activity opportunities (Pinderhughes, 2017; Ponic, Nanjjuma, Peterson, Poole, & Scott, 2011). However, Ponic et al. (2011) argues that whether or not we acknowledge trauma as a barrier to physical

activity depends on how we conceptualize marginalization. Marginalization can be conceptualized as a single mechanism (e.g., poverty) or as multiple additive mechanisms (e.g., “gender and poverty as additive mechanism for a single mother” (p. 9)). These conceptualizations lead us to understand barriers to participation in relation to cost of programming or to lack of childcare, for example. However, neither of these framings account for barriers related to trauma, safety and disempowerment. Alternatively, when marginalization is conceptualized in relation to “multiple mechanisms...as a result of intersecting systems of power” (p. 9) including “systems of race, class, and gender” (p. 10), trauma can be understood as a barrier to physical activity. The authors argue that when marginalization is conceptualized in this manner we can expand our understanding of barriers, wherein “disempowerment and trauma are viewed as significant barriers to participation in physical activity and these need to be addressed alongside other barriers such as low income and lack of childcare” (p. 10). For physical activity contexts and practices to be responsive to trauma-related barriers, our understandings of trauma and marginalization should incorporate analyses of how embodied and psychosociopolitical experience is always already shaped by overlapping and intersecting systems of power. We need to start thinking about the people we are working with not as an individual *with* a specific identity (e.g., person with a disability, person with mental illness) who have been traumatized, but rather as humans existing within complex overlapping systems of power and oppression that differentially distribute exposure to violence and potentially resulting trauma.

### **Thinking Trauma Together with Disability Justice and Access**

One way of thinking through disability and trauma, which I argue is important for ethical APA research and praxis, is to consider how (critical) disability studies and trauma studies

converge or diverge. Some authors have suggested that there is a disconnect between trauma studies and disability studies (see for example Berger, 2004; Torrell, 2016). Berger (2004) argues that trauma studies and disability studies do not connect, despite dealing with injury and their effects, situating their inquiries within social contexts, and exploring concerns with representation. This author suggests that both fields are related to metaphor, however while trauma studies is a field of making (at times negative) metaphors for un-wordable/unspeakable experiences; critical disability studies work often actively avoids negative metaphors associated with disability. Torrell (2016) unpacks this further, stating that trauma studies tends not to address trauma as socially constructed (but rather ‘real’ bodily injury), and disability studies disavows pain and suffering as contributing to tragedy narratives,<sup>34</sup> making the two fields somewhat difficult to reconcile. However, Torrell also argues that perhaps bringing these fields together serves to complicate both fields in theoretically important ways:

the ultimate challenge to combining disability and trauma studies is how to fuse the two approaches in a method that addresses the personal experience of trauma, pain, and loss at the same time that it defends against negative cultural beliefs and asserts the value of lives that have those experiences. (p. 93)

So how might we do this?

Berger (2004) offers that both trauma studies and disability studies are committed to “a radical remaking of social structures, institutions, and norms” (p. 577). Beyond acknowledging the body as a pivot point between disability and trauma (as both Morrison & Casper (2012) and Torrell (2016) suggest), we must consider that trauma is a disability justice issue (Carter, 2015). In an article addressing how to engage with trauma in educational environments, Carter (2015) conceptualizes “trauma as a disabling affective structure,” stating that “while it would be

problematic to completely collapse the traumatized bodymind and the disabled bodymind, there are undeniable overlaps in both subjective embodiments” (Trauma Culture, Trauma Confusion section, para. 2). As such, trauma needs to be attended to through pedagogical choices that “consider experiences of, and responses to trauma as issues of disability (in)justice” (Introduction section, para. 1). Kafer (2016) suggests that the growth of Mad studies within and alongside critical disability studies compels us to attend to trauma, suffering and mental distress. By accounting for trauma, Kafer suggests we may expand critical disability studies theories and practices to include wider conceptualizations and experiences of disability and distress. I suggest that by drawing together trauma and disability, the same expansive and nuanced conceptualizations could be said to benefit APA research and practice.

As one grounded example of how this plays out in practice, both Carter (2015) and Kafer (2016) argue for the use of ‘trigger warnings’ and other trauma-informed practices as matters of accessibility.<sup>35</sup> Carter (2015) suggests that “when social responses to the affects of trauma are appropriately understood as disabling, the contours of the debate extend beyond the specifics of trigger warnings toward broader considerations of accessibility in the classroom” (Trauma Culture, Trauma Confusion section, para. 2). Kafer (2016), building on Price (2011) also argues for considering ‘trigger warnings’ as a practice of accessibility, urging us to consider trigger warnings as impacting access rather than ensuring ‘safety’. Kafer writes:

what—as teachers, as scholars, as activists—can we do to make the spaces we inhabit more accessible? ... Can we, as disability justice activists insist, make it possible for us ‘to stay in our bodies as much as possible, take care of our disabled selves, and be part of the community that [is] coming together’ (Mingus)? Recognizing that histories of trauma are always potentially present is one way of creating such spaces; when we conceptualize

trigger warnings as forms of access—both to difficult material and for people with histories of trauma and/or mental disability—we make room for explorations of how we discuss and respond to those histories... What is powerful about the framework of access—as opposed, for example, to ‘accommodation plans’—is that it requires neither diagnosis nor documentation. We can move away from ‘violently contradictory’ ‘medico-administrative’ definitions of disability (Samuels 125), ones that presume disability as a problem to be solved bureaucratically (Titchkosky), to framings that center access as radically democratic possibility. (p. 17)

Trigger warnings, as an access practice, make possible an engagement with trauma that resists individualization and pathologization of trauma reactions, and that acknowledges the labour involved in navigating trauma for students and instructors alike.

In addition to considering trigger warnings as access practices for educational, research and activist contexts, as Carter and Kafer discuss, Clare (2017) adds another layer to what trigger warnings can do: “trigger warnings are in essence tools for self-care and collective space care” (p. xx). This resonates deeply for me, and I am moved to draw together accessibility and care in my own work (such as this dissertation) by offering trigger warnings that undoubtedly will never be able to attend to all of the unique and specific ways people are triggered and traumatized, but will hopefully soften the entry point and allow a moment for a form of consent to difficult discussions for those who are diving in.

### **Thinking Trauma Intersectionally**

The fields of trauma studies and disability studies both ask us to actively interrogate and shift how we structure environments, practices, beliefs and values. Torrell (2016) suggests that thinking these two fields alongside each other brings new possibilities for intersectional analysis

to both fields. For example, Torrell links sexual assault-related trauma and disability experience, stating that “an important outcome of the merger of disability and trauma in literary studies might also be to make the problem of sexual abuse toward disabled people and the social frameworks associated with it more visible across disciplinary divides” (p. 95). Torrell suggests that experiences of disability and medical trauma are related, that experiences of disability and sexual abuse are related, and that experiences of disability and stigma-related trauma are related, noting “that even when there is no overt connection between the experience of disability and trauma, the experience of a trauma such as sexual abuse can be impacted by disability” (p. 96). Discussing trauma in the context of critical disability studies, as well as disability and crip community, is an issue of intersectionality (Carter, 2015; Kafer, 2016; Torrell, 2016).

Here, I draw on a poststructuralist conceptualization of intersectionality. As Spade (2015) details, exposure to “intersecting vectors of harm” (p. 44), such as racism, sexism, ableism and sanism, come to unequally “distribute wealth and life chances” for some people over others (p. 5). Drawing on Kimberlé Crenshaw’s theory of intersectionality, Spade notes that “people who experience multiple vectors of subjection, for example racism and sexism, face unique harms not captured by racial justice movements that use male experience as the norm or feminist movements that use white women’s experience as the norm” (p. 10-11). Exposure to harm is exactly what is at stake here. Harm and trauma are (re)produced differentially, depending on the systems of subjection one is targeted by. Experiences of trauma are directly related to, and influenced by, racism (e.g., police brutality), sexism, homophobia, and transphobia (e.g., bullying and gender policing), intimate domestic or partner violence (e.g., sexual abuse), relationships of power and domination (e.g., child abuse), as well as ableism and sanism (Burstow, 2003; Wineman, 2003). Oppression is compounded and multiplied when we consider

that many disabled folks are subject to ableism, *and* are also subject to racialization, sexism, misogyny, homophobia and transphobia, classism and poverty (Clare, 1999, 2017; Erevelles, 2011; McGibbon, 2012). As Gilfus (1999) articulates, racism, sexism and classism:

come together to create differential levels of vulnerability or exposure to particular types of victimization... Traumatic injury is not like a virus that randomly infects people. It happens to specific groups of people more than others and is perpetrated by some groups of people more than others. (p. 1243)

This is not to say that certain individuals or populations are inherently more vulnerable to violence and trauma, but rather, as McGibbon argues (2012), they are considerably more *under threat*, and we must ask the question ‘what, and whom, are they under threat from?’ In addition to disability, each individual’s set of experiences, and the ways that health, government and social systems are structured, are always already layered with numerous other dimensions of oppression and trauma.

We cannot think nor do our work outside of how multiple axes of oppression intersect within the people and systems with whom we work. For Kafer (2016), discussions of trauma within critical disability studies, and beyond, can: spark attention to racism, classism, and settler colonialism; broaden our intersectional analyses around disability; and add complexity to claims of the desirability of disability. Carter (2015) goes further to liken the trauma bodymind to a form of neurodivergence, wherein triggers—be they sensory, psychosomatic, affective or structural—may be a point of intersectional resonance. Carter writes that:

while I am focusing here on triggers within context of trauma, many neurodivergent people experience triggers in ways that often similarly impacts their embodied subjectivities. I am using the experience of a trigger then to call for solidarity between

individuals typically understood as mentally disabled and communities who have experienced racial and post-colonial traumas. In doing so, I am purposely expanding the category of neurodivergence to include people who may never receive a medical diagnosis, or clinical recognition as such. This is an overtly political move toward an intersectional approach to trauma and disability. (Trauma Culture, Trauma Confusion section, para. 3)

The author here is pointing to legacies and present enactments of racial and post-colonial violence that both incite and trigger historical, intergenerational, and insidious trauma. Quiros and Berger (2013) also argue for deep engagement with the sociopolitical aspects of trauma, specifically addressing intersectionality, stigma and oppression as critical concepts to understanding trauma and practicing in trauma-informed ways. The authors suggest that despite discussions of intersectional and sociopolitical aspects of trauma within theoretical literature, there is a gap in the practice-based literature relating to these concerns (and specifically in relation to “the impact of racial and cultural trauma on women” (p. 152)). This gap is certainly evident within the existing trauma-informed physical activity literature, and one that needs attention. I am working to address this need for intersectional and sociopolitical trauma practice, both here and within the upcoming chapter on practical suggestions for trauma-informed physical activity.

### **Intergenerational and Historical Trauma**

Trauma impacts not only individuals, but also families, communities, service providers, organizations, cultures and generations (Manitoba Trauma Information and Education Centre, 2013a). Burstow (2003) argues that “in making this claim, community theorists are not simply meaning that all people within the community are traumatized but that the community as an

integral whole is traumatized” (p. 1297). The fabric and systems of communities and cultures are susceptible to trauma as well. For example, “cultures can be traumatized when repeated denigration, attempts at assimilation and genocide occur. First Nations communities in North America continue to live with the impact of the intergenerational trauma of colonization and the residential school system” (Klinic Community Health Centre, 2013, p. 12). Histories and present enactments of colonialism, assimilation and genocide have immediate, transgenerational, and intergenerational traumatic effects.

In the first edited volume on multigenerational legacies of trauma, Danieli (1998a) highlights and holds space for discussions on intergenerational trauma in the context of the holocaust, wars, genocide, repressive regimes, crime, and domestic (gender-based) violence, Indigeneity, as well as within the context of life-threatening conditions including cancer and AIDS. Acknowledging intergenerational trauma means acknowledging that the impacts of both personal and mass violence and trauma echo and reverberate through generations in a complex interconnected historical, political, social, relational, and neurobiological manner (Danieli, 1998a). It also means acknowledging that historical and intergenerational trauma is not only related to incidents of trauma that happened in the past, but is also an ongoing, ever-present process of new and repeated traumatic events and experiences (Duran et al., 1998).

Danieli (1998a) discusses the “conspiracy of silence” (p. 4), including the predominant avoidance, dismissal or denial of the existence and effects of intergenerational trauma by society and by mental health and other professionals (and sometimes within families). This silence compounds trauma and proves “detrimental to the survivors’ familiar and sociocultural reintegration by intensifying their already profound sense of isolation, loneliness, and mistrust of society. This further impede[s] the possibility of... healing, and made their task of mourning

their massive losses impossible” (p. 4). Drawing on all contributors in their edited volume, Danieli (1998b) argues that “the conspiracy of silence is the most prevalent and effective mechanism for the transmission of trauma on all dimensions” (p. 678). First, we must acknowledge intergenerational trauma and its functions in the present lived realities of many. Danieli argues for a “multidisciplinary, multidimensional integrative framework” (p. 671) for engaging with trauma and its effects, with the intention of helping to “decipher, disentangle and clarify complex issues and guard against unidimensional reductionistic impulses” (1998b, p. 671-672). In other words, trauma must be considered as a complex, multidimensional issue that can only be adequately addressed by drawing on multiple, situated knowledges, experiences and perspectives. Rousseau, Yang and Eubanks (2010) argue that:

specifically, [addressing historical and intergenerational trauma] needs to be a part of graduate education and professional development as part of sensitization training...historical trauma and microaggressions need to be personally understood in order to apply them professionally. This study cannot be simply an intellectual exercise. It is critical to incorporate the concepts of historical trauma and microaggressions – as well as the personal stories of those who have experienced them – into our everyday communications and work. (p. 5)

In order to disrupt the ‘conspiracy of silence’, as Danieli (1998b) puts it, we need to communicate about the concepts and center lived stories in ways that not only teach us about intergenerational trauma and microaggressions in theory, but equip us to act in support of those most affected by oppressions and the resulting trauma-related concerns. This includes taking a critical look at how ‘helping professions,’ such as adapted physical activity, are complicit in past and contemporary forms of colonial violence and iatrogenic trauma caused by settler health-and-

wellbeing researchers and practitioners wanting to ‘help’.

**Help and harm.** Gagné (1998) takes a sociological approach to trauma in exploring the role of “colonialism in generating trauma in First Nations citizens” (p. 358). For Gagné (1998), trauma is reinforced by systems and social structures that not only wound, but create a cycle by which people who have experienced trauma are positioned in a forced state of economic, social and political dependency on the systems that perpetrated the harm in the first place (by, for example, being forcibly removed from lands that also provided primary food source, or by having systems of internal government rendered illegal). Parallels can be drawn here to the forced state of cyclical dependence that many disabled people experience in relation to government, health and social service systems, although often not with the added violence of this cycle being perpetuated over generations. In line with centering systemic change that reduces enforced dependency, Gagné suggests that centering “Native researchers in trauma studies within their communities may prevent some of the negative effects of health studies” (p. 367). This position is reflected in other authors’ calls for trauma ‘survivor’-centered perspectives and practices (which I will discuss more below).

In arguing for centering Indigenous researchers, Gagné (1998) suggests that settler researchers may inadvertently perpetuate colonial violence while attempting to ‘help’. Gagné warns that we must become “aware of the motives and the potential negative effects of public health surveillance systems...The knowledge generated about certain populations may reinforce the image of disorganized and sick communities, hence forging unequal power relationships and justifying paternalistic and dependent roles” (p. 367). Duran et al. (1998) express similarly that “the mental health field [is] merely another tool of social control” (p. 349), one that has delegitimized traditional indigenous healing practices, has enacted colonial violence, and has

contributed to further perpetuating and perpetrating trauma experiences and responses. Burstow (2003) animates this concern further, articulating that:

magnification of trauma by others and by society at large occurs in manifold ways, including denying the injury, minimizing the injury, failing to accommodate, and failing to help... What is particularly significant to questions of radical praxis, trauma is magnified exponentially in the name of help, especially by those helping institutions that occupy central locations in the relations of ruling. Moreover, trauma is systematically produced by them. As such, officially mandated institutions of help, especially arms of the state, must be understood as central players in the traumatizing of people and communities. (p. 1307)

To do radical trauma work we must be attentive to the ways that our practices, and the systems we practice within, may not only perpetuate trauma but may in fact be perpetrating it.

Within ‘helping’ professions, the social location of practitioners means that some experiences of trauma and/or marginalization (especially complex intersectional ones, and intergenerational ones) are not accounted for due to the practitioners’ privilege-based positionality (Quiros & Berger, 2013; Rousseau, Yang & Eubanks, 2010; Wing Sue et al., 2007). Highlighting the often-divergent sociocultural context of helping professionals and their ‘clients’, Quiros and Berger (2013) state that:

For women from marginalized communities...traumatic experiences shaped by oppressive social structures are every-day occurrences. Yet, these experiences are likely to be ignored by white (as well as some non-white middle-class) therapists because of the inequalities that are ingrained in society and lack of awareness of the privileges and advantages afforded to them. (p. 152)

To deeply account for the divergences of world-views between ‘helping’ professionals and those of us experienced with trauma, we must reflect upon and question our own positions of privilege and the (paradigmatic) assumptions that influence how we construct ‘problems’ and how we understand ethical action.

To support this questioning and reflection, I offer my next chapter, which draws together embodied, psychiatric, socio-political, and intersectional understandings of trauma within a series of practical suggestions for fostering trauma-informed physical activity programs and environments. These practical suggestions specifically target pathologization, structural inequality, privilege, embodied discomfort, our responsibilities to do our own research, drawing intentionally on marginalized perspectives, as well as changing our language and our physical, social, cultural and institutional environments. Undoubtedly, there is much more that can be said about practical engagements with trauma from a variety of perspectives, especially given the processual, complex, and dynamic nature of trauma-informed practice (Emerson et al., 2009). I hope that this next chapter offers some sparking questions, critical reflections, and start points for enacting trauma-informed physical activity practice that takes seriously not only medical or psychiatric engagements with trauma, but sociopolitical and embodied aspects of trauma as well.

## **Chapter Six - Trauma-Informed Practice in Adapted Physical Activity: Practical Suggestions Moving Forward**

Elliot et al. (2015) argue that since we have “no way of distinguishing survivors from nonsurvivors, best practices are those that treat all [people] as if they might be trauma survivors, relying on procedures that are most likely to be growth-promoting and least likely to be retraumatizing” (p. 463). We can’t necessarily know or see evidence of the ways that trauma is impacting those we work with, but we can make program and environmental design decisions that assume as a starting point that some people (if not everyone) may benefit from trauma-informed services. Key principles of trauma informed practice include trauma awareness, safety and trustworthiness, choice and control, connection and collaboration, and a strengths-based empowerment approach (Ammann & Matuska, 2014; Elliot et al., 2005; Falloot & Harris, 2009; Quiros & Berger, 2013). Further, as I have argued above, we need to also address the gaps in the trauma-informed physical activity literature by engaging deeply with social, political, and oppression-related trauma.

In this section, I work to draw together practical suggestions from the trauma-informed literature with anti-oppressive trauma-related practices from anti-racist, LGBTQ2I and trans-affirming, anti-sanist, anti-ableist, and fat positive action. I do so in order to build a resource that deeply acknowledges dimensions of trauma that are oppression-related, and that works to decrease the potential for oppression-related retraumatization. How I draw from these different forms of anti-oppressive action will be unequal, partial, and non-exhaustive. I will jump between, and work to weave, ideas and practices that are unique to a specific form of anti-oppressive action, or that may have overlaps and parallels to other forms. To be sure, there is not enough room in this chapter to cover all possible aspects of anti-oppressive action (for example, I

have not engaged explicitly or deeply with anti-ageist or anti-audist practices). I have chosen to focus on areas of my practice that I want to build or strengthen; the areas that I am noticing are of the most pressing need for my community as it is right now. I offer the following eight domains of action for building trauma-informed physical activity: challenging pathologization, normalization, and sanism; acknowledging structural inequality exists and does damage; recognizing privilege; dealing with embodied discomfort; doing our homework; valuing marginalized histories, struggles, perspectives, and choices; shifting language; and shifting environments.

### **Action Domain One: Challenging Pathologization, Normalization, and Sanism**

As discussed in earlier chapters, one of the reasons we need to challenge pathologization is because there are larger political issues at stake. Pathologization individualizes problems that can also be understood as issues of structural inequality and oppression (Burstow, 2003).

Diamond (2013) suggests that:

a starting point [for anti-sanist community praxis] is to emphasize a clear understanding that being psychiatrized, or being perceived as mental ill, has consequences in the world we inhabit that are often unjust and vary depending on one's economic and social marginality and privilege. However, it is equally important to emphasize that sexism, racism, ableism, audism, classism, ageism, adultism, misogyny, transphobia, and heterosexism are entrenched in social and political institutions that rule, including psychiatry, which inevitably shape the everyday experiences of differently situated people, putting some people at greater risk of violence and marginality. These oppressive processes are each infused with one another, are inseparable, and are completely integrated into the social and material world. (p. 73-74)

Pathologization, within psychiatric and other systems, has material, embodied and social consequences. Practices of pathologization inform, and are informed by, other oppressive processes that work in concert to differentially distribute violence, marginality, and trauma. As such, if we are to do anti-sanist work, we must also consider how these other oppressive processes function in overlapping and divergent ways to make spaces less safe for a myriad of people. Thus, anti-sanist work must be attentive to, and inclusive of, other anti-oppressive practices.

For Diamond (2013), building anti-sanist praxis—drawing together theory and practice to challenge psychiatrization—involves:

resistance efforts [that] are based in the recognition that all people are implicated in, and affected by, psychiatric dominance...It is highly critical of dominant constructions of *madness*, *normality*, or *sanity*, recognizing the flawed nature of simplistic dichotomous and oppositional constructions of difference. (p. 74, emphasis in text)

In other words, we must question our categorical and binary thinking of sanity and insanity in order to do anti-sanist work. This questioning of binary thinking, as well as challenging how practices of pathologization are justified and reinforced by mobilizing binary thinking, is also critical to trans affirming and anti-racist work. We must acknowledge that binaries such as straight/gay, male/female, man/woman, white/not-white, abled/disabled, healthy/fat all serve as a foundation for normalizing (making natural or neutral) one way of being and pathologizing another. This pathologization then serves to individualize and justify trauma and injustice.

Withers (2014) notes: “the pathologization of oppressed groups helps legitimize their oppression, on the grounds that because they are inferior they are in need of special limitations or protections” (p. 121). For example, both homophobia and transphobia have been enacted and

sanctioned by psychiatric systems through DSM categories that pathologize homosexuality and gender variance as mental illness. Homosexuality as a mental illness diagnostic category was partially removed from the DSM in 1980, and “fully removed” by 1986 (Canadian Mental Health Association, 2017). However, ‘Gender Identity Disorder’—which targeted trans people specifically— was added in 1980 to replace previous diagnoses (Canadian Mental Health Association, 2017). In the most recent edition of the DSM, ‘Gender Dysphoria’ has replaced these previous terms. This diagnosis continues to be used to pathologize trans people (in particular, those who do not fit the binary of man/woman, or who actively reject it).

### **Depathologizing Responses to Oppression**

Kirby (2014) notes that while being trans is beginning to be considered less ‘pathological’ in wider society, trans people’s resistance to transphobia is becoming more and more pathologized:

Instead of being trans people who creatively survive transphobia, we are trans people with anxiety disorders, anger disorders, bipolar [disorder], schizophrenia. Our basic identities are less and less considered a ‘mental illness,’ but our strategies for surviving are being taken out of context and individualized as ‘mental illness.’ (p. 163)

Further, many trans people are forced into (often violent) engagements with mental health service systems, and required by psychiatric systems to obtain a ‘gender dysphoria’ mental illness label from gatekeeping professionals, in order to access hormones or surgery that make life livable (Kirby, 2014). These services take years to access, with wait times extended by a lack of practitioners working in this area, by administrative policies that require multiple practitioners to confirm ‘diagnosis,’ and by widespread transphobia within medical systems, posing an ever-present threat to survival. Further, Kirby remarks that trans youth are exposed to frequent

isolation, discrimination, and violence from a young age, with many experiencing ongoing trauma as a result. The mental illness diagnoses that trans (and racialized) people receive, for Kirby, might as well be called “people who have been oppressed disorders” (p. 170). Kirby further notes that, based on the DSM’s history, they foresee continual shifts in the DSM’s diagnostic categories that will target and pathologize marginalized people’s reactions to oppression, even as their previously-pathologized identities are removed.

Explicating the importance of depathologization in the context of racial injustice, Kirby (2014) states that:

it’s not enough to get our identities out of the DSM, because someone else’s identity is in there. It doesn’t say in the DSM anywhere ‘young, black men’s anger syndrome,’ but it might as well. There are a disproportionate number of young black men diagnosed with schizophrenia. Soon it may not say ‘gender identity disorder’ but it will say ‘anger disorders,’ ‘oppositional defiance disorder,’ ‘anxiety disorder.’ (p. 170; for more on how black men are targeted by psychiatric diagnosis, see also Clare, 2017, p. 121-122).

Similarly, feminist scholars have noted the disproportionate number of ‘difficult’ or ‘provocative’ women diagnosed with Borderline Personality Disorder, a diagnostic vestige of the historical diagnosis of hysteria, and one which is weaponized in no small part towards women with experiences of complex gender-based trauma (Diamond, 2014; Simon Gunn & Potter, 2014; Warne, 2013).

The mental distress of constantly experiencing racism, sexism, misogyny, transphobia—the anger, trauma, ‘depression’, ‘anxiety’—is not a symptom of individual pathology, it is a reaction to experiencing ongoing threat, violence, trauma, and discrimination. The danger is that pathologization, through psychiatric diagnostic categories in this case, will continue to be

mobilized differentially to target some people more than others, while covertly individualizing and depoliticizing how this distress is a reaction to social and political injustice. As such, Kirby (2014) suggests that, beyond depathologizing identities, we need to work to depathologize reactions to oppression as well.

Wing Sue et al. (2007) highlight another aspect of practicing depathologization that is worth noting, specifically in relation to racism and cultural difference. These authors argue that to do professional work attentive to the dynamics and dilemmas of microaggressions, and their potential trauma-triggering or trauma-inducing effects, we need to be: learning about racism; actively interrogating power relations; fostering an environment where ‘clients’ or participants can offer critical feedback; being willing to discuss issues of oppression and its impacts; and conscientiously not devaluing or pathologizing personal and cultural actions or beliefs that are different from our own. As will be discussed further in a later section, thinking race through the binary of white/not-white can lead to assumptions (mostly by white folks) that Eurocentric cultural practices are the value-neutral standard by which we judge the cultural practices of ‘others’ as less progressive and pathological. By drawing on pathologizing and binary thinking, we construct both subjects and entire cultures as ‘other.’ Gilfus (1999) notes that:

the construction of the pathologized trauma survivor, known primarily by a checklist of symptoms, tells us little about the worlds of violence through which survivors have traveled and about which they can teach us. It also raises questions about what we can know of the survivor if we see her only as not us, if we see her only as not whole, and not a subject in her own right. (p. 1253)

An anti-pathologization stance to professional practice offers alternatives to this flattening erasure.

## **Challenging Pathologization, Normalization and Sanism within the Trauma-Informed Practice Literature**

Pathologization runs through the literature on trauma-informed practice in both covert and overt ways. For example, within their practical resource guide, Ammann and Matuska (2014) offer an extensive set of tools and considerations for developing trauma-informed physical activity, many of which I will draw on in later sections. They also include a section on inclusion, specifically focusing on women with disabilities. This section is of particular interest to me as an adapted physical activity practitioner, and one that indicates more work needs to be done in this area. Some important issues are addressed within this section. For example, the authors note transportation as a barrier that needs to be mitigated. The authors advocate for active recruitment of people with a variety of physical, sensory and other impairments, and argue for peer support, role models, and recruitment of disabled leaders. They also suggest learning sign language and including sign language interpreters in programming. These are all important considerations to developing inclusive trauma-informed physical activity contexts and practices. Unfortunately, the overall tone of this single page dedicated to disability is paternalistic, pathologizing, racist, and ableist. The authors' first point includes implicit racism, noting "be aware that, due to religious and cultural biases, many families still hide their disabled family members and specifically women with disabilities. They are often regarded as second class, and a burden to their family" (p. 23). While this may hold true in some contexts, this dangerous framing from the outset denies the ways that colonialism, racism and ableism work in concert, and suggests that western or Eurocentric views of disability are more 'progressive' and less pathological than those of other cultures. Further, the authors suggest that working with disabled women demands program leaders be "flexible, creative, patient and enthusiastic" (p. 23), as though these are

special criteria for working with disabled people rather than general traits that would facilitate the inclusion of a wide variety of people. The authors ask us to “look for the abilities of the women, *not their disabilities*”, and suggest we find Paralympic athletes to speak to our participants “to have women with and without disabilities experience what can be achieved *in spite of disabilities*” (p. 23, emphasis added). These suggestions all reproduce damaging ableist notions of disability as undesirable, tragic, pathological, and something to be ignored, normalized, or overcome: notions disability scholars have argued against at length (Clare, 1999; Withers 2012). The practice guide and tool kit by Ammann and Matuska (2014) tend to frame trauma firmly from within a pathologizing medical framework, and do little to attend to sociopolitical, oppression-based, or intersectional analyses of trauma.

We must be critical of how pathologization, sanism, normalization and ableism are at work within trauma-informed practice literature and resources. This means understanding that the key principles for trauma-informed practice, such as safety, trustworthiness, connection and collaboration, while valuable, are also influenced by pathologizing, ableist and sanist discourses.

*Don't worry  
They say  
You're not crazy  
It's trauma; It's real*

*But I am compelled  
To ask  
Is it so terrible  
If I am  
real; crazy*

Various authors writing on trauma (see Herman, 1992; Levine, 1997; van der Kolk, 2014) insist that if you are experiencing trauma you are not ‘going crazy’ even if you feel that you are. For example, in discussing trauma-informed yoga, Smoyer (2016) uses a quote from a participant who states they feel like they are “going crazy half the time” (p. 75), and discusses

how trauma-informed yoga and mindfulness can bring a welcomed distancing from those experiences of ‘going crazy’. Similarly, Ammann and Matuska (2014) articulate that:

it can be useful for survivors to know that what they are experiencing are normal responses to a life-threatening event and that they are not ‘going crazy’. This knowledge can put their experiences in context and make their reactions less disturbing or frightening. (p. 15)

This approach may be soothing to some people. However, when these authors work to separate ‘crazy’ from ‘traumatized,’ their attempts at de-pathologizing responses to trauma are based on deeply sanist logics and practices of othering and pathologizing ‘real crazy’ people. How might we push back against this distancing, so as not to perpetuate violences enacted upon Mad experiences and subjectivities?

Further, the trauma-informed key principles of connection and collaboration can be problematic when considered in light of some experiences of trauma such as intimate partner violence. Nicki (2001) argues that we:

should not underestimate or undervalue the ideals of autonomy and independence.... accounts that emphasize connectedness must be careful not to ignore the lives of severely abused women for whom a strong sense of disconnectedness, of being separate and apart, is necessary in their struggles to manage, overcome, or survive. (p. 98)

While working with the tenets of trauma-informed practice, we must also remain critical of their implications, including the contexts or experiences in which they may not only no longer valuable, but may in fact undermine necessary strategies of survival and thriving.

Likewise, Burstow (2003) critiques two underlying assumptions of the therapeutic goal of fostering ‘trustworthiness,’ which assumes that the ‘normal, healthy’ response is to return to

trusting the good in people. First, we need to question the assumption that trust is appropriate because the world is inherently safe. For those who experience ongoing daily microaggressions and violences, this is not an accurate assumption to make. What is the danger in striving for, and especially in claiming, spaces as ‘safe’? Do our attempts to foster trustworthiness actually serve to undermine the lived realities, and developed coping strategies, of people who experience trauma? Second, we need to question the assumption that “people who have been traumatized have a less realistic picture of the world than others” (p. 1298). Believing the world is safe takes a particular kind of subject position, one that is imbued with privilege. Burstow argues that one could consider that people who have experienced trauma do in fact have a more realistic view of the world, in all its precarity and potential threat. So, what is the impact of asking us to trust in a world that has proven both unsafe and untrustworthy? Challenging the key principles of safety and trustworthiness, Burstow (2003) argues that “practitioners should be joining with clients in acknowledging and lamenting the utter inadequacy of conventional views” of the assumed safety and benign neutrality of the world (p. 1311). As practitioners, we must not only understand the social injustice that surrounds us, but we can also validate this approach to living, and get mad about it. Radical trauma work demands we both intervene and advocate (both individually and systemically). Burstow continues:

More generally, insofar as regaining power is central to what so much traumatized coping is about, an absolutely critical direction for radical trauma praxis is redirecting some of the focus off controlling self and onto acquiring real power in the larger world. (p. 1311)

Much of the trauma literature centers individual change, choice, control, growth and healing, but misses this crucial point, that we must also support and facilitate people who have experienced trauma to gain systemic choice and control. So, is there something better to strive for than safety

and trustworthiness? Arao and Clemens (2013) argue for ‘brave space’<sup>36</sup> rather than ‘safe’ space: space where we are supported to feel brave and make brave choices, not experience paternalistic protectionist ‘safety’ measures intended to ensure comfort, which may in fact limit our capacity for choice and control. I’m not totally sold on giving up safety as an important considering in building trauma-informed spaces, given how my own felt sense of safety impacts my capacity to participate in most spaces. Therefore, I will be discussing ways that we can facilitate felt-senses of safety throughout this chapter. At the same time, I do hope to hold the generative possibilities of both safety and bravery together.

There is much work to be done on trauma-informed sport and physical activity: work that engages trauma-informed practice beyond a therapeutic intervention targeted to normalize pathologized individuals. For me, anti-sanist praxis involves not shaming people for using medication, seeking diagnostic labels, or engaging with medical or psychiatric systems, as there are very real reasons why we might choose (or be forced) to do so (Clare, 2017; Kirby, 2014). At the same time, it involves understanding why these choices may not be safe for a variety of reasons. It involves understanding that psychiatry is *not* a safe space for some people, and it means refusing to only offer resources and supports that are reliant on pathologizing systems and practices (e.g., by offering a resource list that solely highlights psychiatric-based resources). It involves a move away from pathologization of trauma (and other oppression-related) experiences, reactions, and coping behaviours, and towards collaborative strengths-based and growth-based approaches (Ammann & Matuska, 2014; Gilfus, 1999; Quiros & Berger, 2013; Tseris, 2013). Danieli (1998) advocates for an approach to trauma that not only recognizes the increased vulnerability of individuals, families, groups and communities that have been exposed to trauma, but that also recognizes the resilience that these experiences can often generate.

Likewise Gilfus (1999) notes:

if we decontextualize trauma from culture and oppression, we miss potential sources of injury and strength...there are features of traumatic experiences themselves that create existential predicaments that give rise to new cognitive and epistemological strategies that become survivors' strengths. (p. 1244)

A survivor-centered anti-pathologizing approach enables us to learn and build from these survivor strengths, which can include (but are not limited to):

the development of profound survival skills, an enhanced ability to understand other traumatized and oppressed individuals and groups, a passion for justice, a desire for a different kind of society, a certain critical realism, and what is particularly significant, a less distorted view of the world. (Burstow, 2003, p. 1310)

Burstow (2003) advocates for avoiding a deficit model of understanding trauma experiences and reactions, in favour of one that is non-pathologizing, validating of coping strategies as survival strategies, and supportive of collective determination regarding which new skills might be valuable to acquire.

### **Action Domain Two: Acknowledging Structural Inequality Exists and Does Damage**

Another, deeply related, aspect of doing anti-oppressive trauma-informed work involves acknowledging that structural inequality exists and does damage. In addressing trauma and the use of 'trigger-warnings' in the classroom, Carter (2015) advocates for pedagogy that includes a Feminist Disability Studies Praxis (FDSP) framework, wherein we understand:

that like other neurodivergent people, those affected by trauma or other triggering experiences are disabled by social barriers and ideologies that marginalize them. These experiences and subjectivities are not individual issues in need of cure, but rather the

consequences of systemic forces of inequality and oppression. Ableism intersects here with race, class, gender, sexuality and citizenship in ways that leave the most marginal even more vulnerable to policing measures that dismiss them as ‘excessive,’ ‘improper’ and ‘inappropriate’ for the classroom and, though unspoken, society at-large...A FDSP would understand psychosomatic and affective responses, like the experience of being triggered, as appropriate responses to the horrors of structural inequality. (A Feminist Disability Studies Praxis section, para. 6)

Within this section, I will highlight a series of systemic forces that are operating in physical education, physical activity and sporting contexts with respect to race, sexual orientation and gender identity, and fatness. These are complex issues that cannot be fully covered within the scope of this project, but addressing some elements of these systemic forces will offer opportunities for beginning to shift our practice towards trauma-informed service that is responsive to oppression-related trauma.

### **Race and Structural Inequality**

In discussing stages to becoming a white anti-racist ally, Sejal Patel (Teaching Tolerance, n.d.) suggests the following:

- 1) Realize the meanings behind privilege, racism and whiteness.
  - 2) Look within before you look outward. How do you relate to the definitions? Pinpoint the ways in which you experience privilege as a white person.
  - 3) Look outward, find out the historical, global and social patterns of the effects of racism and other forms of oppression.
  - 4) Act. Realize that you want to do something about this system, and come at it with a sensitivity and understanding that you come from a privileged background whether you like it or not.
- (unpaginated)

I argue the Patel's first stage is in part about acknowledging structural inequality around whiteness and race (I will return to the other 3 stages suggested in later sections). To do anti-oppressive trauma-informed work, we need to learn and to teach about racism, whiteness, and white supremacy. Given how racism and trauma are intimately interconnected, I argue that any act perpetuating racist ideologies or practices is inherently not trauma-informed: on the contrary, racist acts and microaggressions can be trauma-inducing or triggering (Wing Sue et al., 2007). As such, a deeper understanding of racism—and how we approach it in physical education, sport and physical activity contexts—is needed if we are to build intersectional trauma-informed practice.

Writing on physical education (PE), Flintoff and Dowling (2017) argue that “due to its close links with sport, a practice centrally implicated in the creation and maintenance of racialised bodies and hierarchies (Hylton, 2008), we argue PE offers an important context for a study of whiteness and racism in education” (p. 1). However, when race is addressed in PE teachers’ education and their own pedagogy, it is typically in a single class, with little attention to structural issues of racism or assumptions about whiteness as an unmarked norm (Douglas & Halas, 2013; Flintoff & Dowling, 2017). Flintoff and Dowling (2017) note that “although accepting of their professional obligation to address race, this was discharged within superficial, ‘one-off’ sessions focused on the racialised other, rather than whiteness and racism” (p. 5). Instead, we must be learning and teaching about racism and whiteness throughout our schooling, and we need to be interrogating how these structural issues frame our assumptions, pedagogy and practices in physical activity contexts (Douglas & Halas, 2013; Flintoff & Dowling, 2017). If we hope to employ anti-racist tactics within trauma-informed practice, we must gain an awareness of how racism is deeply woven into physical education teacher education and practice.

## **Histories and presents of racism and whiteness in physical education and**

**kinesiology.** Smith and Jamieson (2017) offer a history of American kinesiology and physical education, highlighting historical enactments of racism, racial ideologies, and racial management techniques, many of which are tied to eugenic logics and practices (see also Peers, 2015b). Some racist practices and ideologies highlighted include: scientific racism; segregation within physical activity and sporting contexts; the erasure of African American female leadership; narratives of racial ‘inclusion’ as progressive developments towards racial harmony which are undermined by practices of segregation that followed ‘inclusion’; white exceptionalism and white supremacy; delayed desegregation of American Alliance for Health, Physical Education, Recreation and Dance; and the induction of many “practitioners who engaged in racial practices that contributed to a racial hierarchy in physical education and sport that valued White bodies as the standard of measure” into the National Academy of Kinesiology (with significantly delayed induction of scholars and practitioners of color) (p. 173). Parallel and overlapping racist eugenic logics and practices are also evident in APA histories and present enactments: logics and practices that mobilize physical education and sport as “support nets” to promote the success of white physically disabled Canadians (Peers, 2015b, p. 96), while at the same time “sieving out” (p. 129) and “ensnaring” (p. 90) racialized, developmentally disabled or mentally ill people through institutionalization and other pathologizing systems of domination. All of these practices and ideologies influence the ways we teach and coach sport and physical activity today.

Flintoff and Dowling (2017) argue that “the fact that PE practitioners and scholars in western countries are an overwhelmingly white group (Douglas & Halas, 2013) not renowned for their critical reflection on equity issues, lends further weight to [this] contention” (p. 1). Although histories of physical education, kinesiology, sport and physical activity are deeply

intertwined with racist and white supremacist practices and ideologies, Douglas and Halas (2013) point out that racism, whiteness, and white supremacy are infrequently mentioned in our training or professional practice (see also Flintoff & Dowling, 2017).<sup>37</sup> Given this, it is imperative that we consider how whiteness functions to uphold racist ideologies and practices in physical education and physical activity contexts. Dowling and Flintoff (2016) offer some advice in this regard:

whiteness is a theoretical lens that acknowledges the shortcomings of previous race inequality perspectives that have tended to focus on ‘the Other’ (e.g. Muslim girls, black and minority ethnic students), ignoring the part that white teachers play in the racialisation of pedagogical spaces in PE. Hegemonic beliefs and practices about race tend to position whites as ‘normal’ and racially ‘unmarked’, and Others as ‘deficit’ and ‘named’. Whiteness perspectives highlight that we are all positioned within race relations that exist in a given social and historical moment, distributing unequal access to power. Importantly, these relations are open to change which is a central aim of antiracist education. (p. 4)

Even if we banish explicitly racist practices from PE, we still have to deal with all of the invisibilized ways that whiteness is privileged and naturalized as the ‘neutral’ category by which everything else is judged. Exploring whiteness, racism, and white supremacy as structural systems of domination and oppression demands we question and challenge the things we may take for granted as neutral or apolitical (especially if we are white). So, I ask myself, and you as a reader, to be attuned to the importance of interrogating whiteness,<sup>38</sup> while at the same time being critical of how this project may function to reify already unequal power relations and uphold white supremacy even as we work to disrupt it (Applebaum, 2016).

Flintoff and Dowling's (2017) exploration of how white PE teachers address race in their pedagogy highlight some concerns we need to be aware of if we hope to build anti-racist physical activity spaces and practices. These concerns include how white teachers tend to overlook the fact that most of the activities in PE are Western and Eurocentric (e.g., baseball, basketball, hockey), and yet they are "presented as universal and normative, with their cultural and social historical roots (including the legacies of colonialism and Eurocentric ways of reasoning) overlooked" (p. 5). The forms of physical activity we teach have historical roots, and are not value neutral. They may be exclusive, and celebratory of only some cultures and histories, even if our intention is otherwise. For example, I used to say that I teach 'contemporary dance,' and yet I did not teach, or even recognize that there are, forms of contemporary dance from a myriad of cultures. What I actually meant is that I teach Western Eurocentric contemporary dance (meaning largely white, and informed by Eurocentric and colonial traditions) (Decottignies, 2017). Saying that I teach contemporary dance upholds whiteness as universal and value neutral. Teaching only Western Eurocentric contemporary dance is likely one of the reasons why our dancers have mostly been white. As Flintoff and Dowling (2017) write, "a fundamental challenge of working to dismantle or disrupt whiteness, either through research or teaching is to recognise that we are always enmeshed with it, always attempting to work through whiteness" (p. 8). My own whiteness (and histories and presents of white supremacy) is showing again, if we know to look.

**The discursive gymnastics of whiteness in physical education.** Flintoff and Dowling (2017) found that there were a number of ways that PE teachers reacted when confronted with discussions of race and racism, practices I call 'discursive gymnastics'. One practice was "a key strategy of white silence, where we switched to talking about gender or class rather than race" (p.

8). That is, teachers skirted around the issue at hand, devaluing or actively ignoring race by decentering it. At times, they flipped between disclosing racist stereotypes at the same time as touting equality and tolerance: “Although many of our educators talked about fighting for inclusive practice and equal rights, nevertheless, negative stereotypes about racialised others are woven into the texts – such as the fear of others being violent, criminal, and dangerous” (p. 8). Further, they leapt from denouncing overt racism directly to perpetuating covert racism through discourses of ‘colour blindness’:

Our participants were keen to distance themselves from what they saw as the more ‘overt’ racist practices reminiscent of their parents’ generation, through deploying a more ‘progressive’, ‘colour blind’ discourse of race. Race is ‘not seen’; racial differences ‘not acknowledged’, and racism is regarded as belonging to past generations, when parents ‘didn’t know better.’ (p. 8)

The above discursive gymnastics highlight the lengths we white folks will go to justify, intellectualize, distance, silence, or deny the ways that racism and white supremacy impact our practice. It also, perhaps, highlights the work we must do to acknowledge and address this structural inequality.

**The myth of a ‘colour blind’ meritocracy.** If we are to create anti-racist physical activity spaces, we need to interrogate the assumption that physical education contexts are a space of ‘colour blind’ meritocracy. Flintoff and Dowling (2017) write:

PE and sport have long been seen as meritocratic spaces, ‘level playing fields’ where everyone has equal access and opportunity to do well and be rewarded on merit... As such, PE constitutes the ideal space for the deployment of colour blind discourses in the narratives – for ‘not seeing’ racialised bodies, only able bodies... Colour blind

pedagogy... draws on liberal notions of meritocracy and equal treatment but with little appreciation of the impact of structural racism on educational experiences. (p. 6-7)

White universalism, meritocracy, and ‘colour blind’ discourses serve to erase the role of physical activity leaders in the perpetuation of racist and white supremacist physical activity contexts and practices. As Diane Flint (Teaching Tolerance, n.d.) states:

To be ‘colorblind’ implies the invisibility of race, something we all know to not be invisible...colorblindness feels like an erasure. To be colorblind is to not see my family, where we come from, our history, and our ways of being. ‘Colorblind’ avoids difference rather than recognizing and valuing it. I do not see how a white activist can be an ally from a position of colorblindness. I understand that many people use this term to challenge racial stereotyping, to not see people ‘as’ their color and the associated racial stereotypes, but it functions as assimilation. If we become ‘colorblind,’ than to which worlds and ways of being are we being blinded [sic]? What are we not ‘seeing?’ And in which ‘hue’ will we be operating? (Unpaginated)

To advocate for a ‘colour blind’ approach is to advocate for active ignorance of the systemic barriers and violences that racism and white supremacy (re)produce, as well as the brilliant generativities that diverse cultures and experiences bring to life and living. Kanter and Rosen (2016a) argue that the claim of colorblindness:

has the unintended effects of both invalidating fundamental aspects of someone's identity (for example, “I don’t even see you as...”) and sweeping under the carpet the differences that exist between people that have created unequal pain and suffering, or privilege. Colorblindness is associated with passivity about racial justice and increased racial prejudice. (Educate Yourself section, para. 3)

Color-blindness does not serve anything except to perpetuate white supremacy. We need to realize how discourses of meritocracy, white experience as universal, biological racism, and colour blindness in sport, physical activity, and physical education, serve to uphold racist beliefs and practices (Flintoff & Dowling, 2017; Smith & Jamieson, 2017; Teaching Tolerance, n.d.). We need to acknowledge that these discourses perpetuate structural inequality and do damage—traumatizing damage—and we need to work to undermine them in our education and practice.

### **Sexual Orientation, Gender, and Structural Inequality**

Another aspect of acknowledging structural inequality in sport and physical activity contexts relates to sexual orientation and gender. Addressing homophobia and transphobia, and fostering trans affirming spaces, is an important aspect of building anti-oppressive trauma-informed practice. LGBTQ2I people, including trans youth and adults, experience higher rates of mental distress and trauma-related diagnoses, and are at a higher risk for substance use and suicide (Canadian Mental Health Association, 2017). The Canadian Mental Health Association (2017) highlights three social determinants of health and wellness that are differentially distributed for LGBTQ2I people: “social inclusion; freedom from discrimination and violence; and access to economic resources” (What Factors Impact Health? section, para. 1). Vastly higher rates of poverty, discrimination and stigma in accessing employment, housing, healthcare and social services, hate crimes including sexual and physical assault, absence of social support from family and friends, and daily microaggressions including mis-gendering, can all contribute to mental distress for LGBTQ2I people (Canadian Mental Health Association, 2017).

Homophobia and transphobia are rampant in sporting contexts (Birch-Jones, 2017; Denison & Kitchen, 2015; The 519 Church Street Community Centre, n.d.). For example, consider that “gender identity remain[s] explicitly excluded from the International Olympic

Committee (IOC) Charter when defining the prohibitions against discrimination, and [there are] continued efforts to re-introduce gender testing by the IOC for ‘suspicious’ looking female athletes” (Birch-Jones, 2017, p. 1). Here, transphobia is being systemically supported, and advocated for, by international sporting committees.

Transphobia and homophobia are different things. Homophobia relates to sexual orientation, whereas transphobia relates to gender. Transphobia exists within both the heterosexual and the LGBTQ2I community (as does internalized homophobia). A major study, titled “Out on the fields: The first international study on homophobia in sport” (Denison & Kitchen, 2015), highlights ongoing concerns with homophobia and transphobia in sport in Australia, Canada, Ireland, New Zealand, United Kingdom, and the United States. Birch-Jones (2017) offers some highlights of Canadian findings. First, homophobia is frequently experienced by both straight and LGBTQ people in sport: “81% of Canadian participants witnessed or experienced homophobia in sport; more than half (57%) of gay men, nearly half (45%) of lesbians and 41% of straight men said they had personally experienced homophobia” (p. 3). Further, over 80% of gays and lesbians have experienced homophobic verbal slurs in sporting contexts. “86% of gay Canadian youth and 89% of lesbian Canadian youth said they were at least partially in the closet, keeping their sexuality secret from all or some of their teammates,” due to fears of bullying, rejection and discrimination from coaches, officials, and teammates (p. 3).

Further, being a fan at a sporting event does not feel safe either: “66% of Canadian participants believe an openly gay, lesbian or bisexual person would not be very safe as a spectator at a sporting event” (Birch-Jones, 2017, p. 3). In fact, school PE classes and spectator stands were considered the most homophobic spaces in Canadian sport. Even if we are not

athletes, we are exposed to homophobia, and made to feel unsafe, in both educational and social sporting contexts. These safety concerns are not just free-floating fears, but are born out of grounded experiences of being the target of bullying and assault. Given that one of the key principles of trauma-informed practice is the felt sense of safety, we need to acknowledge that (lack of) safety is of paramount concern for LGBTQ2I people in sport and physical activity. This signals a need to consider how we might create spaces that are LGBTQ2I affirming, in terms of shaping team dynamics, and supporting students, participants or athletes as well as spectators or audience members. We can make an impact here, first by acknowledging this structural inequality, and second, by taking some of the actions I will discuss later to build more inclusive spaces.

### **Action Domain Three: Recognizing Privilege**

I return again to Patel's (Teaching Tolerance, n.d.) first stage to becoming a white anti-racist ally: "realize the meanings behind privilege, racism and whiteness" (unpaginated). We have learned a bit about acknowledging racism and whiteness above, but what about privilege? Applebaum (2016) writes: "whiteness often goes unnoticed for those who benefit from it, but, for those who don't, whiteness is often blatantly and painfully ubiquitous" (p. 3). In other words, if you haven't thought much about how whiteness functions to unequally distribute both privilege and oppression, then you are probably white. Spade (2015) notes that:

access to certain privileges that serve in determining the distribution of life chances (e.g. Whiteness, perceived ablebodiedness, employment, immigration status) often offer some individuals degrees of buffering from the violences faced by people of color, people with disabilities, immigrants, indigenous people, prisoners, foster youth, and homeless people. (p. xiv)

Now is the time to start interrogating our own privilege, along a number of axes, in order to better understand how we may be wielding it in dangerous, and potentially trauma-triggering ways.

In their “Welcome to the anti-racist movement, here’s what you’ve missed,” blog post, Oluo (2017) first notes that while the Trump era has ushered in a host of white folks who have become more attentive to race and racism, this movement began long before we well-intentioned white folks got involved. We have some catching up to do, and if we want to contribute to this movement rather than taxing it further, a critical starting point is to examine our own white privilege. Oluo points to a great paradox in doing anti-racist work, one that we ought to reflect upon before mobilizing any anti-oppressive practice, stating;

**Your privilege is the biggest risk to this movement.** That’s right: the biggest risk. The compromises you are willing to make with our lives, the offenses you are willing to brush off, the everyday actions you refuse to investigate, the comfort you take for granted—they all help legitimize and strengthen White Supremacy. Even worse, when you bring that into our movement and refuse to investigate and challenge it, you slow down our fight against White Supremacy and turn many of our efforts against us. (Your Privilege is the Biggest Risk to the Movement section, para. 1, emphasis in text)

At the same time, the author argues:

**Your privilege is the biggest benefit you can bring to the movement...** You have access to people and places we don’t. Your actions against racism carry less risk... You can ask your office why there are no managers of color and while you might get a dirty look and a little resentment, you probably won’t get fired... You can talk to fellow white people about why the water in Flint and Standing Rock matters, without being dismissed

as someone obsessed with playing ‘the race card.’ You can ask cops why they stopped that black man without getting shot. You can ask a school principal why they only teach black history one month a year and why they pretty much never teach the history of any other minority group... You can explain to your white friends and neighbors why their focus on ‘black on black crime’ is inherently racist. You can share articles and books written by people of color with your friends who normally only accept education from people who look like them. You can help ensure that the comfortable all-white enclaves that white people can retreat to when they need a break from ‘identity politics’ are not so comfortable. You can actually persuade, guilt, and annoy your friends into caring about what happens to us. You can make a measurable impact in the fight against racism if you are willing to take on the uncomfortable truths of your privilege. (Your Privilege is the Biggest Risk to the Movement section, para. 1-2, emphasis in text)

Oluo (2017) offers some concrete anti-racist actions we can take, each relying on our willingness to recognize our privilege and mobilize it. We are complicit in oppressive systems when we remain inactive or ignorant (willfully or otherwise), even if we do not overtly take oppressive actions. We can begin mobilizing our privilege by doing the work ‘in our own backyard’: that is, by focusing on our place of employment, education, housing or other immediate spheres of influence, and by beginning to build meaningful reciprocal relationships with people of diverse cultures and ethnicities (Kanter & Rosen, 2016b, c).

So, to take up Oluo’s (2017) and Patel’s (Teaching tolerance, n.d.) call to examine and mobilize our privilege, here are some useful resources I have found. A webpage entitled “29 stupid things white people do and what we can do instead”<sup>39</sup> (Baltimore Racial Justice Action, n.d.) offers an important list of (sometimes well-intentioned, but ultimately problematic) beliefs,

statements, and practices that most white folks (myself included) uphold and enact frequently in everyday life. These often unacknowledged or unconscious statements and beliefs are steeped in racist assumptions, and ultimately function to perpetuate racism. They also signal our attempts to assuage white guilt and protect white fragility. For example, #23 argues that while there may be some overlaps, we cannot draw direct parallels across experiences of different forms of oppression, as they have emerged out of different (although not necessarily unrelated) histories, potentially target different bodies, function in different ways within different contexts, and enact different violences. Further to this point, because you have experiences of oppression does not excuse you from the very real fact that you are undoubtedly implicated in the oppression of others. We all are. And we need to be both responsive and responsible for the damage we cause, knowingly and unknowingly. We need to reflect inward on our assumptions, especially the most uncomfortable ones.

Dowling and Flintoff (2016) offer another resource, a short professional development guide that uses narrative exploration to examine whiteness and racism in physical education contexts. This resource is intended to help professionals to “reflect upon their own racialised identities and offer some recommended literature that can assist in analyzing them with the view to develop antiracist pedagogies” (p. 4), as well as to “disrupt taken-for-granted social practices and evoke social change” (p. 5). This resource is another good first step towards reflecting inwards on our privilege so that we can responsibly act to make change.

From here, I will focus on some differing aspects of privilege relating to race, gender, ability, and body size. I am highlighting everyday experiences that we may take for granted because of privilege related to our subject positions. I will then detail some echoing and overlapping considerations that demonstrate how privilege and oppression intersect within

specific contexts and practices, making life more livable—or more precarious—for some people more than others.

### **White Privilege**

Regarding whiteness, Holladay (2000) offers some examples of white privilege at work in our everyday lives:

When I cut my finger and go to my school or office's first aid kit, the flesh-colored band-aid generally matches my skin tone. When I run to the store to buy pantyhose at the last minute, the 'nude' color generally appears nude on my legs. When I buy hair care products in a grocery store or drug store, my shampoos and conditioners are in the aisle and section labeled 'hair care' and not in a separate section for 'ethnic products.'...When I am told about our national heritage or 'civilization,' I am shown that people of my color made it what it is...schools that I attend or have attended use standard textbooks, which widely reflect people of my color and their contributions to the world. When I look at the national currency or see photographs of monuments...I see people of my race widely represented and celebrated. (unpaginated)

White privilege is insidious if you have access to it, and glaringly obvious if you do not benefit from it. This is true of other forms of privilege as well.

### **Cis Privilege**

The 519's "Being an effective trans ally" tip sheet (n.d.a) also asks us to understand cis-gender privilege. Cis-gender is a term for "someone who exclusively identifies with the sex they were assigned at birth" (Trans Student Educational Resources, 2017, unpaginated). Some examples of cisgender privilege (Killermann, 2014) include: Using public facilities such as restrooms, gym locker rooms, store changing rooms, without "fear of verbal abuse, physical

intimidation, or arrest” (unpaginated). Further, this author notes:

your validity as a man/woman/human is not based on how much surgery you’ve had or how well you “pass” as non-transgender...Strangers call you by the name you provide, and don’t ask what your “real name” [birth name] is and then assume that they have a right to call you by that name... Your identity is not considered a mental pathology (‘gender identity disorder’ in the DSM-IV) by the psychological and medical establishments... You are not required to undergo an extensive psychological evaluation in order to receive basic medical care...your gender [is] an option on a form... You don’t have to convince your parents of your true gender and/or have to earn your parents’ and siblings’ love and respect all over again. (unpaginated)

It is precisely the things that we take for granted that are often indicators of our privilege.

### **Able-bodied/Able-minded Privilege**

We can also consider able-bodied privilege. Ridgeway (2013) offers some important examples of able-bodied privilege:

You can go about your day without planning every task, like [bathing, eating, and] getting dressed...Others don’t get frustrated with you in public for needing special accommodations or holding up lines... You don’t frequently encounter communication barriers...Leisure activities like gardening, knitting or woodworking are easy for you... You can expect to be included in-group activities... Typically you don’t have to rely on others to accomplish tasks...Others don’t assume you need to rely on them to accomplish tasks...you don’t have to think about your daily pain level when planning events and activities...Public access to buildings, parks, restaurants etc. is easy for you. (unpaginated)

Further, Moreno (2017) notes that able-bodied privilege means that you are not pitied, nor are you considered inferior, or broken because of a disability or mental illness. You don't need expensive mobility equipment, or low-stimulation environments, in order to navigate the world. Ultimately, unlike how many disabled people's lives are understood, **“your life is seen as worth living”** (unpaginated, emphasis in text).

### **Thin Privilege**

Ridgeway (2012) highlights some aspects of thin privilege:

You're not assumed to be unhealthy just because of your size...When you're at the grocery store, people don't comment on the food selection in your cart in the name of 'trying to be helpful'...Your health insurance rates are not higher than everyone else's...You don't receive suggestions from your friends and family to join Weight Watchers or any other weight-loss program...You don't get told, 'You have such a pretty/handsome face' (implying: if only you'd lose weight you could be even more attractive)...People do not assume that you are lazy, based solely on your size...You are not perceived as looking sloppy or unprofessional based on your size...You can eat what you want, when you want in public and not have others judge you for it or make assumptions about your eating habits...You can walk out of a gas station with a box of doughnuts and not have people yell at you to 'Lay off them doughnuts, fatty!' (This actually happened to one of my friends.)...Friends don't describe you to others using a qualifier (e.g. 'He's kind of heavy, but REALLY nice, though')...You can choose to not be preoccupied with your size and shape because you have other priorities, and you won't be judged. (unpaginated)

Especially in the context of sport and physical activity, we must work to undermine the

assumptions and biases we have about fatness if we hope to build spaces that are less fatphobic and more body positive.

### **Overlapping and Echoing Points of Privilege and Oppression**

In addition to specific ways that we encounter privilege around race, gender, disability, and size, there are a number of overlaps and echoes across various forms of privilege. First, ultimately, due to privilege (whether because you are white, able-bodied, sane, thin, heterosexual or cis-gender), **“you don’t make other people uncomfortable by *just existing*”** (Moreno, 2017, unpaginated, emphasis in text). Further, access to sport is unequally distributed based on both privilege and oppression (Donnelly, 2008; Ridgeway, 2013). I will highlight some other overlapping and echoing considerations of privilege and oppression here, including housing, employment, clothing, healthcare, issues of objectification, sexualization, and representation, violence, as well as travel, identification and documentation.

Our access to housing and employment are influenced by privilege.<sup>40</sup> For example, Killermann (2014) notes that, with cis privilege, “you can reasonably assume that your ability to acquire a job, rent an apartment, or secure a loan will not be denied on the basis of your gender identity/expression” (Killermann, 2014, unpaginated). Our capacity to access sport is often dependent on our capacity to earn expendable income, and “poverty is the single greatest barrier to participation” in sport (Donnelly, 2008, p. 389). Poverty, unstable employment, over-employment, and a lack of stable housing options negatively impacts our free time and our available sporting opportunities. Additionally, economic privilege means you are not frequently required to share personal financial information in order to access subsidies and services. Further, accessing basic necessities like clothing are also a matter of privilege.<sup>41</sup> Clothing is also designed with normative body shapes and gendered assumptions in mind, meaning that you will

likely have much more success finding clothes if you experience able-bodied, cis, and thin privilege as well (Killermann, 2014; Ridgeway, 2012, 2013).

With respect to health care, Killermann (2014) notes that cis-privilege means that if you go to “the emergency room, you do not have to worry that your gender will keep you from receiving appropriate treatment, or that all of your medical issues will be seen as a result of your gender”<sup>42</sup> (unpaginated). Additionally, Ridgeway (2012) notes that, if you are thin, “when you go to the doctor, they don’t suspect diabetes (or high blood pressure, high cholesterol, or other “weight-related” diagnoses) as the first/most likely diagnosis”<sup>43</sup> (unpaginated). Privilege impacts our capacity to access to supportive and effective healthcare. Additionally, similar privilege-related assumptions that limit access to supportive and effective health care also function to limit sport and physical activity opportunities. For example, someone with thin, or able-bodied, privilege will be able to access a vast array of sport and physical opportunities, whereas disabled and fat folks have drastically limited opportunities that tend to focus solely on ‘weight loss’ or therapeutic benefits of physical activity.

Similarly, privilege means that your ‘difference’ does not define you, and you are less likely to be objectified based on difference.<sup>44</sup> For example, Ridgeway (2012) notes “your size is probably not the first thing people notice about you (unless you’re being thin-shamed – the opposite of fat-shamed)” (unpaginated). Our experiences of objectification, and (de)sexualization,<sup>45</sup> are different depending on our experiences of privilege. Further, if you move through with world with particular forms of privilege, it is easy to find positive representations of yourself in media and popular culture.<sup>46</sup> Issues of representation, sexualization and objectification are numerous and ongoing in sporting contexts (Darvin & Sagas, 2017), and are complicated by intersecting vectors of both privilege and oppression. Additionally, privilege also

impacts our exposure to violence,<sup>47</sup> as evidenced by the above discussed statistics of homophobic violence in sport (Birch-Jones, 2017).

Privilege also impacts our capacity to travel freely and easily,<sup>48</sup> which is relevant in sporting contexts where team travel is often an aspect of participation. With able-bodied privilege, for example, air travel is vastly easier (as is driving and public transportation) (Ridgeway, 2013). You are not required to: book flights through a medical desk; arrive earlier than others; spend hours trying to determine what documentation is needed; provide this extensive documentation that need yearly renewal at a cost; or be subject to getting kicked off a flight if you do not have certain forms of documentation, which they may or may not tell you that you need in the first place. Further, if you live with thin privilege, airlines won't charge you extra to fly (Ridgeway, 2012).

The differential distribution of privilege is also at work every time we are asked for identification. Identification documents (ID), and contexts wherein these documents are checked, can be sites of violence for trans people,<sup>49</sup> as well as for immigrants, poor people, disabled and Mad people. Checking ID is in essence a procedure that positions us to make judgements about people based on their appearance. The kinds of situations in which ID is requested are often high stakes (e.g., banking, getting a mortgage, accessing health care, air travel), and if one's current physical appearance (e.g., gender presentation) does not match their identification, we are exposing trans people to potential sites of violence (Milloy, 2014). In part, this becomes an issue of non-consensually 'outing people,' or requiring people to out themselves (Birch-Jones, 2016). Identification is also an issue around disability and citizenship. Able-bodied privilege means you don't have difficulty obtaining a driver's license, you are not constantly asked for official medical documentation to 'prove' disability and mental illness (such as to access educational

accommodations), nor are you expected to pay for this documentation over and over. Obtaining documentation such as medical confirmation of disability or mental illness is frequently required to access basic support services and accommodations, and it is often time consuming, labour intensive, expensive, and requires people to submit themselves to medical systems that might be experienced as traumatizing. Further, we are not subject to fears and trauma around deportation if we are asked for ID as citizens of the country we live in; for non-documented immigrants, requests for ID often carry with them the threat of deportation or denial of service. If we experience white privilege, we are subject much less (if at all) to ‘carding’ by police, a racial profiling tactic where police ask for identification vastly more often from racialized folks, subjecting them to increased surveillance, police brutality, and criminalization (Wakefield, 2017). If you have a home address to put on your identification, you likely have economic privilege that many poor and homeless folks do not.

So, we are beginning to acknowledge our privilege. Now, how can we mobilize it in ways that are generative and responsive? Drawing on Andrea Smith, Fortier (2017) argues we must: move beyond the ‘confessions of privilege’ that are commonplace in both activists and academic circles. Confessions of privilege, Smith explains, ‘rarely [lead] to political projects to actually dismantle the structures of domination that enable this white/settler privilege. Rather, the confessions become the political project themselves’ (Smith 2014:215). These confessions are often used to absolve white people/settlers from their responsibility to engage in and support anti-colonial resistance in tangible and material ways, including the relinquishing of stolen land and the loss of material benefits gained from living in a settler colonial state...On the other hand, the responsibility of non-Indigenous peoples to engage in self-reflexive and critical actions and research around

their own relationships to colonialism and the processes of decolonization is important in the development of self-determining relationships of solidarity. (p. 22-23)

Given this tension, how do we take tangible action while we continue to critically reflect on privilege? A first place to start is the acknowledge and address the feelings of discomfort that inevitably accompany the recognition of such privilege, inequity and injustice.

#### **Action Domain Four: Dealing with Embodied Discomfort**

If privileged folks need to tolerate anything, it's our own discomfort. Drawing our attention to, and learning to mobilize, our privilege is hard and uncomfortable work. We are asked to question what we fundamentally take for granted, and to disrupt systems that we have previously been comfortable within. This work is important precisely because it is uncomfortable. So how do we move with and through this discomfort? Here, I will draw lessons from anti-racist practice. Flintoff and Dowling (2017) note that for the PE teachers they interviewed:

Intellectually...racist beliefs are rejected, but across a range of contexts (at home and abroad) embodied reactions are practically impossible to avoid, illustrating how the normativity of whiteness against which racialized others and lives are defined as being inferior, and is internalised early on in childhood. (p. 8)

To do anti-racist work, therefore, we need to attend to the internalized, embodied reactions of deep discomfort that accompany our self-reflections on racism and white supremacy. This embodied reaction is also a site for anti-racist intervention.

Anti-racist and anti-white supremacist action is deeply uncomfortable (Kanter & Rosen, 2016d; Oluo, 2017; Rust-D'Eye, 2017). We are unsettling fundamental beliefs, comforts, and privileges (Regan, 2010). It is unsettling. And that, in part, is the point. This discomfort is a

symptom of white supremacy, and becoming unsettled is an entry point for doing anti-racist and anti-colonial work.<sup>50</sup> Rust-D'Eye (2017) argues that racism and white supremacy are embodied through implicit sensorial memory and implicit associations, and it is white people's job to interrogate these sensorial memories and associations by deeply feeling into discomfort.<sup>51</sup> The author notes:

When the world around us (the media, movies, advertisements, YouTube videos, etc.) repeatedly associates certain qualities with certain people, we can form Implicit Associations without having had any interaction with the people or qualities in question. In the West, this phenomenon has been widely used to sustain existing systems of privilege and oppression. For example, when the media, etc. persistently associates negative traits with People of Colour, Women, and a host of others, the implicit memory systems of the populace are conditioned to evoke fearful or derogatory felt-sense responses towards those groups. (Implicit Memory, Implicit Associations section, para. 2)

Rust-D'Eye (2017) argues that we must work to attend to how implicit sensorial memories and implicit associations shape our embodied experiences if we hope to do anti-racism work: "it is a trait of being privileged that one has the social and economic means to continuously distract oneself from things that are uncomfortable, including – or perhaps especially – inner sense experience" (Implicit Memory, Implicit Associations section, para. 7). Attending in this way involves some uncomfortable work. When we assume we should feel comfortable at all costs, at whose expense is this made possible?

One feeling that is common when working for anti-racist praxis is guilt. As Diane Flint (Teaching Tolerance, n.d.) notes, white guilt often makes people so uncomfortable that they would rather ignore the injustice than act to change it. Further, we often express our feelings of

guilt in such a way as to hold people of color responsible for making us feel better and taking care of our feelings. The ways we feel and respond to embodied experiences of guilt can be damaging, and perpetuate inequity and racist practices. Rust-D'Eye states that:

if there is one skill that I believe is crucial for White People to practice in order to participate in truly inclusive group cultures, it is exactly this: to tolerate a host of body sensations, and their attendant discomfort. The phenomenon of White Fragility attests to just how challenging this can be for some White People. It is uncomfortable to be called out (or even to be called in) for a behaviour or remark that was unintentionally hurtful; it is uncomfortable to have one's viewpoint de-centralized where it has previously been 'the norm'; it is uncomfortable to tolerate the grief that arises when one truly opens one's heart to the reality of pain and suffering in oneself, or in another. If White People are going to contribute to truly inclusive group cultures, we must actively practice tolerating discomfort in our bodies, so that we can open ourselves to the personal and cultural transformation that discomfort will bring. (Implicit memory, Implicit Associations section, para. 9-10)<sup>52</sup>

Once we have worked to tolerate our own discomfort, what further actions can we take to foster this anti-racist personal and cultural transformation? Oluo (2017) offers the following reflection on beginning anti-racist practice:

You will get better at this, but at first you will fuck up a lot, and you will always fuck up a little. You are a human being and human beings are inherently flawed. You [may also be] a human being who has lived with an entire life of unexamined privilege and racist social programming. You are going to fuck up hardcore... You will need to get used to the pang of guilt from realizing you have fucked up and it has hurt people. Because it will hit

you again and again. (Oluo, 2017, You Will Fuck Up section, para. 1)

So, let's fuck up. And try again. And fuck up again. And repeat. That is the nature of the work.

Also, let's be ready to "apologize when you make a mistake" (The 519, n.d.a, p. 1). It's not our job to judge whether we've made a mistake, if someone takes the time and effort to let us know they experienced our actions as difficult or problematic, we should apologize. And then do our homework to figure out how to make change. Also, if someone addresses us with a concern, we will likely have an emotional reaction. We need to cultivate communities of supportive people to work this through with, so we do not expect emotional care from the person who has brought up a difficult experience with us. It should not be their job to make us feel better about our mistake.

### **Action Domain Five: Doing Our Homework**

Sejal Patel (Teaching Tolerance, n.d.) suggests the third and fourth stages to becoming a white antiracist ally are to:

Look outward, find out the historical, global and social patterns of the effects of racism and other forms of oppression. [Only then can you] Act. Realize that you want to do something about this system, and come at it with a sensitivity and understanding that you come from a privileged background whether you like it or not. (unpaginated)

To me, this practice of looking outward to find patterns involves doing our homework. Certainly, doing our homework is one of the key principles of trauma-informed practice. Specifically, becoming more trauma aware involves learning about trauma and its impacts. To provide trauma-informed service, Elliot et al. (2005) state that "all staff of an organization, from the receptionist to the direct care workers to the board of directors, must understand how violence impacts the lives of the people being served, so that every interaction...reduces the possibility of

retraumatization” (p. 462). Trauma-informed care is a commitment to both personal and systemic change in how we approach people and the services we provide, and this change demands that we educate ourselves and support the education of our colleagues. I have tried to support this learning throughout this chapter, in part by introducing a series of ways to conceptualize trauma. This includes understanding the complexity of trauma from multiple perspectives, and for Burstow (2003) it means considering trauma on a continuum: not a continuum that assumes ‘everyone has it’, but one that holds important that some experience complex, layered, unequally distributed vulnerabilities to trauma. Further, awareness training must not only address interpersonal dimensions of trauma but sociopolitical dimensions as well: for example, assessment practices ought to include questions related to trauma—and specifically to sociopolitical and oppression-related trauma (Quiros & Berger, 2013, p. 154). Trauma awareness work that takes account of oppression must therefore, I would argue, include anti-oppressive awareness work.

Oluo (2017) argues for what I think is one of the simplest, and most important, practices of any anti-oppressive work: Google it. Trans, racialized, queer, disabled, and Mad folks are constantly asked to do free labour about their needs and desires, but this information is available if we do the work. It is not the job of marginalized folks to constantly be educating those with privilege. Oluo states “if we have to live it, the least you can do it Google it” (Free Individualized Education is Not a Thing We Do Anymore section, para. 1). Clearly the work of anti-oppressive trauma-informed practice is vast and complex, but one thing we can do easily is take responsibility for our own education (Kareem Nittle, 2017; the 519, n.d.a).

To further support us doing our homework, I will point to a couple of initial resources I have found useful in facilitating my learning about trauma and trauma-informed practice. First, I

want to highlight Elliot et al. (2005), who have composed a list of trauma-informed resources, including approaches to: training curricula; group interventions; peer-run work; program development; service design; self-assessment; and consumer input (p. 474). Though not speaking directly to trauma-informed *physical activity* practices, these authors direct us to a vast array of resources for developing and strengthening our trauma-informed practice.

For initial discussions of racial trauma, see Danieli (1998), Meadows-Fernandez (2017), Turner and Richardson (2016), and Wing Sue et al. (2007). Additionally, Hardy (2013) is worth a read, as this author highlights a series of ways that racial trauma impacts racialized people, and follows with 8 steps to healing after racial trauma, including: naming racial trauma; affirmation and acknowledgement; validation; creating spaces to dialogue about race; supporting racial storytelling; both shifting and counteracting the process of internalized devaluation; and channeling the rage that racial oppression produces.

In terms of building trans-affirming spaces, one resource I have been drawing on extensively is The 519's tool kit for trans-inclusive practice. The 519 is a Toronto-based organization that advocates for LGBTQ2I community and inclusion, and this organization offers a series of general practices that contribute to ensuring safer and more meaningful environments for queer, non-binary and trans folks. The full set of resources from The 519 (n.d.b) is available here: <http://www.the519.org/education-training/training-resources/trans-inclusion-matters/creating-authentic-spaces>. Their tip sheets focus on “being an effective trans ally” (The 519, n.d.a), “creating a welcoming environment” (n.d.c), “gender-specific and gender-neutral pronouns” (The 519, n.d.d), “starting conversations” (The 519, n.d.e), “washrooms and change rooms” (The 519, n.d.f), “being a supportive peer or co-worker” (The 519, n.d.g), as well as “your rights as a trans person” (The 519, n.d.h), “if you are transitioning on the job” (The 519,

n.d.i), and “supporting an employee in transition” ((The 519, n.d.j).

Specifically in relation to sport, there are major initiatives pushing for the development of more LGBTQ2I inclusive sporting practices in Canada. For example, the Canadian Association for the Advancement of Women and Sport and Physical Activity (CAAWS) hosts a website full of resources (Canadian Association for the Advancement of Women and Sport and Physical Activity, n.d.). This site also highlights *Leading the Way: Working with LGBTQ Athletes and Coaches*, a practice resource created in collaboration with Sport Canada, AthletesCAN, and the Coaching Association of Canada (Birch-Jones, 2017). This resource covers issues relating to LGBTQ inclusion in sport, including: definitions; statistics; myths; questions we can ask ourselves in order to assess our environments and practices; content on creating inclusive environments; an extensive resource list; and best practices regarding language, athletes coming out to coaches or leaders, locker rooms, dating, travel to unsafe places, and supporting trans athletes. Specifically in relation to trans acknowledging and affirming sport practices, I draw on the *Trans+Sport: Changing Spaces into Safer Places* resource (The 519 Church Street Community Centre, n.d.), and a webinar with a specific focus on trans inclusion hosted on the CAAWS website (Birch-Jones, 2016).

### **Action Domain Six: Valuing Marginalized Histories, Struggles, Perspectives, and Choices**

Radical trauma practice, for Burstow (2003), attends to “the centrality of oppression in the traumatizing of human beings, communities, and the earth itself. It is also based on compassion and respect for traumatized individuals and communities: their history, their strengths, their naming, their conundrums, their choices” (p. 1310). Similarly, Gilfus (1999) actively argues for a ‘survivor-centered’ approach to trauma-related research and practice,<sup>53</sup> noting that “a survivor-centered stance involves first and foremost the acknowledgement of the

survivor as a complete human being, with a cultural and historical context, capable of expert knowledge, who is a subject in [their] own right” (p. 1253). Honoring the expert knowledges and perspectives of people who have experienced trauma involves supporting self-definition, self-determination and self-direction within practice-based interventions.

Likewise, Quiros and Berger (2013) argue for ‘empowerment’ as one of the key features of trauma-informed practice, which for these authors means “a maximizing of consumer skill building and allowing for clients to be involved in the planning, operating, and evaluation of services” (p. 156). We need to value the histories, struggles, perspectives, and choices of those we are serving in all stages of program design and delivery. The 519 (n.d.a) argues that, to do this, we can start by simply listening. For example, notice and pay attention to the experiences, needs, and barriers encountered by trans and non-binary folks. When someone says they have experienced a barrier, it’s not our job to judge whether or not this is true. We can believe them, even if at first we don’t understand why it matters. This seems obvious, but so many of my friends have tried to address barriers (for example a lack of trans-inclusive washroom and locker room access) and have been told that because no-one else has brought forward this concern, it can’t be a problem. By not listening, we are in danger of making traumatized people the ‘problem,’ rather than making structural inequity and oppression the problem.

We can resist the pull to conceptualize trauma as an individual pathology in part by incorporating histories derived from the communities we serve, including disability histories, Mad histories, queer histories, and histories of people of color (Poole et al., 2012; Smith & Jamieson, 2017). Smith and Jamieson (2017) suggest, for example, acknowledging that the histories we tell are partial and biased, and as such, we must actively teach and share marginalized perspectives. These authors argue that:

intervening in one's own teaching is perhaps the most direct, impactful action one can take...Providing students with readings by and about coaches, athletes, and faculty of color as core content, not specialized "race lesson" content, will expand [learning] in meaningful ways for future kinesiologists of color, as well as for their White counterparts who also benefit from learning about the competing narratives regarding their field's histories. (p. 174)

If we are missing out on perspectives from scholars and practitioners of color, we are functionally limiting the scope, relevance, and possible impacts of our field at the same time as upholding white supremacy. One simple action in this area includes critically considering our citational practices, or who's perspectives we draw on when doing research or designing and delivering programs (Ahmed, 2017).

We must also interrogate whom we name awards after, celebrate as 'pioneers' of our fields,<sup>54</sup> and hold in the highest esteem (Smith & Jamieson, 2017). If all of our 'esteemed' influencers in our field are white (or cisgender, straight, male, able-bodied and (or) sane), we need to be interrogating how our practices of celebration and representation serve to both symbolically and functionally exclude others. Further, we must invest actively in the leadership of, for example, people of color within our fields of scholarship and practice (Kanter & Rosen, 2016b; Smith and Jamieson, 2017). Our "choices should honor the self-determination of people of color, that people of color are not looking to be rescued, and that it may be a good thing to seek feedback from people of color about your choices" (Kanter and Rosen, 2016b, What Should I Do? section, para. 1). We can hold this together with the understanding that seeking feedback should be done without expectation that marginalized people owe you anything of the sort.

We can also acknowledge that not all perspectives are equal. For Diamond (2013), anti-

sanist praxis “recognizes and values the many different forms of resistance against psychiatric dominance, but avoids liberal tendencies that exalt all perspectives and actions as equal” (p. 74). As discussed above, privilege and oppression come together to create diverse constellations of experience as well as exposure to violence and trauma. Each perspective we hope to honour is situated within a different constellation, and as such, can bring to light some issues while obscuring or excluding others. For example, we can consider Ammann and Matuska’s (2014) trauma-informed tool kit, which offers a vast array of practices that can build more trauma-informed physical activity spaces and opportunities. These authors engage with trauma in many important ways, while at the same time addressing disability in some problematic ways that make evident the subject position of the authors (which reads as though the authors are non-disabled experts talking about how to include people experiencing disability). They position the locus of control and expertise regarding disability and inclusion within the realm of non-disabled program leaders. For example, one suggestion is to “*make women with disabilities aware that participation in sport and physical activities is their right and that it can enhance their health, their lives and their abilities*” (p. 23, emphasis added). This statement implies disabled individuals are not aware or in control of their rights, health, lives and abilities. Further, the authors explicitly state that we must “teach the women without disabilities to be the strongest advocates for the participation of those with physical, sensorial or mental challenges,” as though disabled people are not equipped to take up this charge for themselves (p. 23). While the intention of this section is undoubtedly good, the effects of these statements are extremely problematic: these statements are indicative of a lack of engagement with disability communities, as well as with sociopolitical dimensions of trauma including ableism. We must critically analyze the information we are drawing upon, and the perspectives and struggles that

we may be overlooking due to our experiences of privilege, in order to do anti-sanest and anti-oppressive practice.

### **Enacting Valuation of Marginalized Histories, Struggles, Perspectives, and Choices Through Collaboration and Connection.**

Collaboration and connection are also key principles of trauma-informed practice (Ammann & Matuska, 2014; Fallot & Harris, 2009), and I would argue that these principles are especially relevant to trauma-informed practices that target sociopolitical change. They are entry points for considering how community, culture, and collective action can deepen our trauma-informed practice. Burstow (2003) suggests we ought to: make moves toward critical adult education that involves collaboratively “coexploring the traumatizing and oppressive situations and structures together and [supporting participants in] taking up real tasks” (p. 1313); as well as encouraging and supporting “actions that counter alienation” (p. 1313). We can foster practices that challenge the individualization and pathologization of trauma experiences and reactions, such as actions emphasizing “community, group work, and witnessing” (p. 1311). Danieli (1998b) argues similarly for “the importance of culture as transmitter, buffer and healer” (p. 680) of trauma, where connection to community and culture,<sup>55</sup> as well as culturally relevant healing practices, are of critical importance to surviving and thriving with experiences of trauma (see also Walters & Simoni, 2002). Herman (1992) discusses the critical role of community:

the response of the community has a powerful influence on the ultimate resolution of the trauma. Restoration of the breach between the traumatized person and the community depends, first, upon public acknowledgement of the traumatic event and, second, upon some form of community action. (p. 70)

Duran et al. (1998) highlight that approaches are being practiced that target the healing of groups

and communities, taking a systemic approach to intervention, rather than an individual approach. We need to collaboratively develop strategies of self-protection and resistance, including strategies that honour culture and community as sites of resilience and strength.

Some specific ways we can collaborate in trauma-informed physical activity program design, drawing from Ammann and Matuska (2014), include supporting participants to: choose and decorate the space where activities are held; decide how they would like to be grouped for activities; pick uniform or costume colors; consult on program timing and duration; collaborate on rules for conduct; form groups to interview and evaluate potential coaches/trainers/instructors; pick which sports, skills, or exercises they would like to practice; teach each other skills and support each other's practices; choose life skills to develop together through sport and physical activity; as well as structure and lead different parts of the program, such as starting rituals, warm-ups, or closing rituals. Collaboration of this nature within trauma-informed practice can also "emphasize the removal of power imbalances by involving participants in all phases and aspects of the process, seeking their interpretation of the information, recognizing their ownership of the knowledge, and changing language" (Quiros & Berger, 2013, p. 157). I will turn now to this last action: changing language in our practice.

### **Action Domain Seven: Shifting Language**

#### **Invitatory Language**

Language is a major consideration in the practice of trauma-sensitive yoga, as outlined by Emerson et al. (2009). These authors provide a list of instructions that you may have heard before in yoga (or other physical activity contexts):

'Push just a little further,' 'Hold just a little longer,' 'Shine your nipples to the front of the room,' and 'Imagine I am going to come up and punch you in the stomach—I really want

to feel that strong belly.’ (p. 126)

After making the connection to the ways that these statements (and others) may evoke or trigger body knowledge of trauma, I am taken aback by how some of these kinds of instructions slip out of my mouth when I am teaching. These authors note how they came to realize that much of yoga instruction is about pushing people to do better, harder, stronger, longer. In contrast, those designing trauma-sensitive yoga decided to make it “not so much about *getting students to do something* but more about *inviting them to try something*” (emphasis in text, p. 126). The concept and practice of “invitatory language” evolved out of this noticing. Invitatory phrases that these authors highlight include “‘when you are ready,’ ‘if you like,’ and ‘as you like’” (p. 127). The authors work to actively undermine coercive or demanding practices in the yoga context by forefronting invitatory language. The authors note that:

our instructions are clear and simple, but we make an effort to invite students rather than command them. Consider the following two sets of instructions: ‘Stand up tall,’ and ‘If you like, try standing up tall.’ Try giving yourself each of these instructions out loud. Get a feeling for the differences between these two simple instructions, and you will have a clearer understanding of a key principle of trauma-sensitive Yoga. Invitatory Language supports the primary clinical goal of helping trauma survivors develop a friendly, non demanding, gentle relationship with their bodies. (p. 127)

As a physical activity facilitator and practitioner, this conceptual shift in using language is both illuminating and sometimes difficult, but something I have come to value deeply.

Invitatory Language is referred to as one way in which choice is deeply integrated into the structure of classes. It is noted that choice includes not only what to do, but also when to choose not to do something. Emerson et al. (2009) note:

identifying how the body feels is very difficult for trauma survivors who have, in many cases, been avoiding noticing their bodies...for a prolonged period of time. Making choices to lessen pain, strain, or discomfort may be more challenging still. (p. 127)

These authors argue that practicing choice, to both do or not do, within supportive community can decrease some feelings of social alienation that many trauma survivors experience. We can give multiple reminders throughout classes/sessions that people can choose to alter or opt out of exercises, or do them at their own timing. We can use “if this is uncomfortable for any reason” prompts to offer more reminders for our participants to make choices about stopping or changing an activity, without assuming why they may be making a choice to stop (p. 126).

### **Non-Discriminatory and Affirming Language**

Considering our language use is also critically important to any anti-oppressive work, because words we use every day can have triggering effects. Racial slurs, homophobic or transphobic language, words like ‘crazy,’ ‘lame,’ and ‘that’s so gay,’ and metaphors such as ‘crippling,’ ‘paralyzing,’ or ‘pioneer’ all carry histories and value judgements that make spaces feel less safe for the people who are targeted by this language,<sup>56</sup> even if it is unintentional. The 519’s “Creating a welcoming environment” tip sheet argues that to build safer spaces, people need to know “that inclusive and affirming language is the standard” (The 519, n.d.c, p. 1).

One way we can be sure that inclusive language is standard is by referring to people with the language that they use to refer to themselves (Peers, Spencer-Cavaliere, & Eales, 2014). In part this may mean using the language used by pathologized communities, rather than prioritizing language developed from within pathologizing knowledge systems (Poole et al., 2012). People refer to themselves in a host of ways, including Deaf, hard of hearing, disabled, person with a disability, cripp, Mad, anti-psychiatry, mentally ill, chronically ill, spoonie, Black,

brown, Indigenous, mixed-race, bi-racial, two-spirited, lesbian, gay, transgender, trans, non-binary, queer, genderqueer, male, female, etc. Further, the meanings of some words are different depending on your connections to specific cultures or communities. Queer, for example, is a word that means different things to different people: some find it to be a derogatory word, and may identify with gay or lesbian, while others disidentify with gay and lesbian, and prefer queer as a reclaimed term with personal, theoretical and political meaning (Mitchell, 2017). Ultimately, to respect how our participants identify, we need to attend to how they refer to themselves, as well as asking how they would like to be referred to.

Further, it is important to note that Eurocentric definitions regarding gender and sexual orientation do not account for the breadth of identifications, expressions and experiences of people from diverse cultures, who may have culturally specific relationships to sexual orientation, gender, and queerness. For example, “two-spirited [is a] term chosen to express distinctly Indigenous / Native American gender identity and gender variance. ‘Two-spirited’ or ‘two-spirit’ usually indicates a person whose body simultaneously manifests both a masculine and a feminine spirit” (Birch-Jones, 2017, p. 5). We cannot equate these identifications, expressions or experiences across cultures, and we need to be attentive to the nuances and specificities of different cultural relationships to sexuality and gender.

**Trans-affirming language.** Some specific guidelines for queer and trans affirming language include how we use gender-specific versus gender-neutral pronouns. The 519’s tip sheet on pronouns states that gender specific pronouns are “ways we refer to each other in the third person” that assume a specific gender (e.g., he, she) (n.d.d, p. 1). Gender-neutral pronouns include “they, them, their” and “ze, sie, zie” (ibid). We must ask after someone’s pronouns: we can’t assume by looking at someone which pronoun they use. Another way to learn about

someone's pronoun is to "be attentive to how others refer to this person. If you are still unclear or concerned that people might be using the incorrect pronoun, politely and privately ask that person what pronoun they use" (ibid). This is a matter of respect - we must use the pronoun that a person wants you to use, as "it's not up to you to decide someone else's identity" (ibid). One suggestion this resource offers is to start meetings by asking everyone to share their names and pronouns, and use nametags that include a place for someone to share their pronouns. Practice if you are having difficulty, in your head and in conversation, and "ask co-workers, peers, and friends to point out when you've made a mistake" (ibid). The 519 (n.d.e) also has a "starting conversations" tip sheet, which teaches us to "avoid assumed use of gendered titles" (e.g. Mrs. Ms. Miss, Sir, Lady, Gentleman) in emails and other forms of communication (p. 1). Instead, we can use first and last names, or refer to people as 'folks,' 'friends,' 'everyone,' 'honoured guests,' and the like.

Unless a person has specifically told you to refer to them otherwise, here are some other basic considerations for language use, represented in the following "PSA" shared by a trans activist on Facebook:

Never call trans men FTMs [Female-to-Male] or trans women MTFs [Male-to-Female] without their permission...

Never use "born in the wrong body" or "used to be a boy and became a girl" or "biologically/genetically male/female" [or "transsexual"]- all are just fancy ways to misgender someone (Self-identification with these phrases is different)

Being trans is not a sexuality nor is it a "sexual disorder" or any kind of disorder at all... don't refer to their pronouns as "preferred pronouns" - they're not preferred, they're mandatory. ("PSA", n.d., unpaginated)

The last point in this “PSA” struck me, as I have made this mistake regularly. I find this list to be an important series of considerations that highlight the nuances of how we talk and think about trans people and trans affirming practices.

**Multi-lingual environments.** We must also recognize that the language we offer programming in matters: working in English alone will necessarily exclude some people from our programming. As part of an anti-sanist praxis, Diamond (2013) argues for fostering multilingual environments, including making print materials available in different languages, and hiring American Sign Language interpreters for events and classes (Diamond, 2013). We can work to hire facilitators who are proficient in multiple languages, or collaborate with different organizations to offer programming in different languages, developing teaching teams with a translator or community member who is willing to offer translation services. We can acknowledge that language matters, especially as it connects to culture and community, which are both critical elements to building trauma-informed practice.

### **Action Domain Eight: Shifting Environments**

To do trauma-informed work, Emerson et al. (2009) argue that an environment in which participants “feel safe and less vulnerable” is paramount (p. 125). While I do want to take Arao and Clemens’ (2013) and Burstow’s (2003) concerns with safety seriously—acknowledging that safety cannot be guaranteed, that the world is inherently unsafe for some people more than others, and that seeking comfort at all costs most often protects the most privileged from feeling uncomfortable—I want to discover ways to foster both *safer* and *braver* spaces. So, here, I will discuss some ways our environments might be made safer as a starting point for engaging with trauma bravely. Quiros and Berger (2013) argue that, to build trauma-informed spaces, our physical and emotional environments need not only *be* safe, but *feel* safe:

This means creating a physical environment that generates a sense of safety, including the minutest details such as type of furniture, the pictures on the walls, and predictability of daily schedules. Achieving safety on all levels requires an understanding of the wide range of trauma reactions that clients may experience and of the extent to which practices and settings ensure and reinforce the physical and emotional safety of consumers...[for] example, symptoms among women with histories of trauma in a residential substance abuse center were triggered by the unpredictability of daily schedules, such as constant changes in group times, interruption of meetings by other staff, and high rates of staff turnover. Because consistency and predictability are hallmarks of emotional safety, these occurrences contributed to an environment where women felt powerless and unsafe. (p .155)

In a similar vein, The 519 (n.d.c) offer a “perceive and feel framework” for approaching LGBTQ2I access and inclusion. This is a framework that forefronts fostering physical and social environments (including language) that are both *perceived* and *felt* as safe and inclusive. Trauma-informed practice is in the details, and often these details may not be obvious until we learn more about trauma, as well as the specific needs and triggers of the people we work with. There are, however, some basic considerations that contribute to supportive physical environments, as well as social, cultural, and institutional environments.

### **Physical Environment**

Drawing from Ammann and Matuska (2014), as well as Emerson et al. (2009) and Smoyer (2016), physical environment considerations for trauma-informed practice include: removing harmful objects from the ground (glass, rocks, sharps, holes); covering publicly exposed windows; providing soft lighting, but not too dark; covering mirrors, or facing away

from mirrors; reducing noise both from within and outside the space when possible; considering flooring (uneven, cobble stone or small tile flooring can be uncomfortable to move across if you are using a wheelchair); designing space so there are at least a few locations where participants do not have to have anyone behind them (circles work great for this, but can also add a feeling of surveillance because everyone can see each other); ensuring safe, accessible washrooms are available for people of all abilities and genders; ensuring safe transportation options are available; ensuring appropriate clothing and equipment is provided if needed; ensuring there are multiple seating options, including chairs without arms, that are suitable for people of a variety of body sizes; and ensuring first aid materials are available, and practitioners are trained in first aid.

Specifically for developing trans-inclusive physical environments, The 519 Church Street Community Centre (n.d.) reminds us that we need to be sure to consider:

accommodation in terms of team rooms, washrooms, change rooms and showers (this means both providing all gender spaces as well as private change and shower facilities in segregated spaces); accessible lockers (these are often located in gender segregated areas); consideration when choosing team and travel uniforms; and cost (due to systemic discrimination trans youth are more likely to be unemployed or underemployed, street-involved or homeless). (p .6)

For washrooms specifically, The 519 (n.d.f) suggests having “at least one single-stall, gender-neutral washroom at your organization” (p. 1). At the same time, we cannot “assume that a person who identifies as trans wants to use gender-neutral washrooms” (The 519, n.d.f, p. 1). Instead, our job is to “provide options: Point out all washroom location options. Let the person decide where they want to go” (The 519, n.d.f, p. 1). Additionally, “if someone has an issue with

a person who identifies as trans using a particular washroom or change room, it is their responsibility to remove themselves from that situation” (The 519, n.d.f, p. 1). Likewise, from Birch-Jones (2017), best practices regarding trans inclusion in sport includes “allow[ing] everyone to change in the locker room of their choice and make a privacy area for changing clothes and showering for any athletes (or coach) to use” (p. 19). Given that choice is a key principle of trauma-informed practice, we must ask after and honour the washrooms and locker room choices made by our participants. Further, The 519 (n.d.b) suggests putting up “positive and inclusive symbols, images, and artwork” in the physical space, as well as attending to who is represented in the reading materials, publications and brochures that are available through your organization (p. 1).

### **Social, Cultural and Institutional Environments**

In addition to attending to the safety of physical environments, we also need to attend to social, cultural and institutional environments (Ammann & Matuska, 2014; Birch Jones, 2017; Townsend & Polatajko, 2013) to do trauma-informed work. Drawing from Ammann and Matuska (2014), Emerson et al. (2009), Smoyer (2016), and D’Andrea and Spinazzola (2009), I will highlight some practices that can shift social, cultural and institutional environments: practices that intervene at the level of organizational procedures and programming design, instructor qualities and behaviours, activity or exercise elements, emotional climate, and group dynamics.

**Organizational procedures and programming design.** If we wish to create trauma-informed programs, we need to develop clear and consistent policies, procedures and practices for accessing our programming. We should provide clear information about our programming, in multiple formats (e.g., print, online, by telephone). This information can include who is teaching,

details about location and how to accessibly enter or exit the building, as well as parking and transportation routes. We can offer consistent schedules, holding activities in the same location and at the same time. We can be sure to schedule and finish programming early enough that individuals aren't leaving alone in the dark, or establish buddy systems for travelling to and from programs. We can be sure not to end programming late. We can set up clear communication procedures, such as procedures for participants to notify us if they are sick or will be missing sessions. We can ensure accident/injury procedures are in place, and communicate these procedures as needed. Further, Diamond (2013) argues that doing anti-sanist work also involves shifting organizational priorities to focus on:

dismantl[ing] other barriers to participation, including making event fees optional or sliding scale, providing free child care and transportation, using wheelchair accessible spaces, providing ASL interpretation, creating spaces for specific marginalized groups to strategize at larger events, and, if possible given the resources available, creating multilingual environments. (p. 75)

To build Mad affirming and anti-oppressive spaces we must work to remove barriers in an intersectional fashion.

We must also question the necessity of the information we are gathering from participants. For example, to build trans affirming spaces, we must “make sure forms have a space for legal name and another name (some people don't go by their legal name). Make sure forms reflect only what you need to know” (The 519, n.d.c, p. 1). For example, does identifying the sex someone was assigned at birth matter for safe and inclusive participation? (e.g., often forms ask someone to select F or M, with no option for non-binary or trans folks). If not, why would we ask for it?

As discussed above, we must also be attentive to the fact that requirements to provide documentation and identification (such as drivers' licenses, passports, school ID, birth certificates, or official documentation such as medical records) is a fraught issue when you are trans, disabled, Mad, a new immigrant or refugee, or a racialized person (Cray & Harrison, 2012; Milloy, 2014; Spade, 2015). We can ask ourselves: does our gym, or programming, or registration procedures really need to ask for ID in order to provide services? We can reduce the amount of time, money, effort, and threat people experience by critically questioning the need for, and by changing procedures for, requesting documentation and identification within our programs.

Inclusive policies and practices, around gender and sexual orientation, for example, should be in place before a trans or genderqueer person arrives to participate, such that they do not have to become the 'test-case' for rolling out new procedures. Further, established lines of communication regarding feedback, complaints, and processes of accountability should be made clear such that a participant's experiences can be acknowledged and acted upon should they encounter personal or institutional violence in our practice contexts (Birch-Jones, 2017). Other social, cultural and institutional environment considerations around supporting trans athletes, from Birch-Jones (2017), includes:

develop[ing] and enforc[ing] a sexual harassment policy that applies to everyone...Educat[ing] athletes, coaches, and other team staff about their rights and responsibilities covered in the sexual harassment policy...[and] Mak[ing] parents who are concerned about LGBTQ people in the locker room aware of the respectful and nondiscriminatory environment that includes sexual orientation and gender identity. (p. 19)

To do trauma-informed work, we must be proactive in shaping the social, cultural and institutional environments of our organizations and programs.

Organizational culture matters when considering how to do trauma-informed work. Falloot and Harris (2009) put forth a “Creating Cultures of Trauma-Informed Care approach to organizational change” which:

is built on five core values of **safety, trustworthiness, choice, collaboration, and empowerment**. If a program can say that its culture reflects each of these values in each *contact, physical setting, relationship, and activity* and that this culture is evident in the experiences of staff as well as consumers, then the program’s culture is trauma-informed.

(p. 3, emphasis in text)

These authors outline key elements and steps for the planning and implementation of trauma-informed organizational culture changes. The steps include initial planning, a kickoff training event, short-term follow up, and longer-term follow up. Initial planning involves making an administrative commitment, developing of a working group with all stakeholders represented, and trauma ‘champions’ that push the initiative forward. The training event involves an introduction to what it means to build a trauma-informed culture, emphasis on trauma-informed care for service providers as well as those who are seeking service, specific information based on the organizational context (for example, specific information on providing trauma-informed sport and physical activity), and discussions on how to practically implement change within the organization. Short-term follow-up involves the working group developing an implementation plan, to be reviewed by all stakeholders as well as outside consultants. It also involves two education sessions: an introduction to trauma; and a workshop on ‘staff support and care’ which emphasizes the vital importance of the trauma-informed core principles being practiced and

respected within the work environment in order for them to be practiced in service provision contexts. Longer-term follow-up involves collaboration between the working group and outside consultants to support the review and relevant revisions of the organization's implementation plan for trauma-informed service provision. The authors also provide a detailed self-assessment and planning protocol to support the implementation of trauma-informed organizational practices. Included in this planning protocol is a useful list of questions relating to each of the core principles of trauma-informed practice; questions about the organization's service provision in the areas of safety, trustworthiness, choice, collaboration and empowerment, and questions that highlight potential areas for change.

Pushing this further, Falloot and Harris (2009) state that not only do staff need to understand the impacts of violence and trauma, but they must also experience their workplace as a space that enacts the key principles of trauma-informed practice within their own work practices and environments. I pose a hard question here, informed by my experiences in the fields of occupational therapy and adapted physical activity (wherein the assumptions we have about what our 'clients' or 'participants' need frequently diverges from what makes us 'good professionals'). Are our educational and work environments offering the same things to us as we hope to offer to those with whom we work? Do we experience these contexts as safe, trustworthy, choiceful, collaborative and empowering as we want to be for those we serve? In my experience, the answer is often no. 'Us' (professionals) and 'them' (participants/clients/patients/survivors) are not two separate categories, and we need trauma-informed practices and environments as much as those seeking our services might—especially if we are committed to supporting the leadership of members of the communities we serve.

Organizations must make plans to actively support their employees and volunteers to

conduct trauma-informed services. D'Andrea and Spinazzola (2009) found that coaches required ongoing support to successfully implement a trauma-informed sport intervention, with better outcomes resulting from ongoing phone-based consultation sessions with coaches to facilitate their practice throughout the season. It is noted that “coaches appeared to improve significantly...from beginning to end of the season. This suggests that time is required to fully integrate the program’s goals. Therefore, employing coaches from season to season seems important” (p. 14-15). Continuity in terms of coaching and programming were deemed critical to increase the efficacy of this trauma-informed approach.

**Instructor qualities and behaviours.**<sup>57</sup> van der Kolk (2014) discusses why social and emotional qualities of an instructor matter when doing trauma informed work. This author points to polyvagal theory,<sup>58</sup> noting that this theory:

provided us with a more sophisticated understanding of the biology of safety and danger, one based on the subtle interplay between the visceral experiences of our own bodies and the voices and faces of the people around us. It explained why a kind face or a soothing tone of voice can dramatically alter the way we feel. It clarified why knowing that we are seen and heard by the important people in our lives can make us feel calm and safe, and why being ignored or dismissed can precipitate rage reactions or mental collapse. It helped us understand why focused attunement with another person can shift us out of disorganized and fearful states. In short, Porges’s theory made us look beyond the effects of fight or flight and put social relationships front and centre in our understanding of trauma. (p. 78)

In other words, there is physiological evidence to support the impact of the instructor qualities and behaviours of those who lead our physical activity programs.

Ammann and Matuska (2014) also argue that trauma-informed physical activity practices and environments depend significantly upon building the coach-participant relationship. To build this relationship, they argue, a coach should develop: cultural knowledge; a sense of self that acknowledges strengths and limitations; skillful reactions to stressful situations; a focus on sport or physical activity; honesty and transparency; a sensitivity to participants' needs; presence and positivity; approachability; competence; empathy; and "respect, openness, kindness, curiosity and genuine interest" (Ammann & Matuska, 2014, p. 17). Emerson et al. (2009) note that "the goal of the teacher during the opening of the class is to set a tone of safety, gentleness, and non-judgmental self-study that can be maintained throughout the session and eventually beyond the mat" (Emerson et al., 2009, p. 125). These authors also highlight teacher qualities including: engagement; a welcoming, accepting and light attitude in class; and adaptability, or a willingness to make changes as the need arises.

There are also specific behaviours that instructors can develop to facilitate trauma-informed work. Emerson et al. (2009) note that doing trauma-sensitive yoga is first and foremost about process: it is "more about the 'how' than the 'what'" (p. 125). These, and other, authors offer some suggestions on the 'how' of instruction. We can use clear instructions to facilitate a sense of predictability. We can be in the room before everyone arrives and greet each participant. We can instruct from a predictable location in the class, and avoid moving around a lot so our position is predictable for participants. We can practice negotiating ongoing informed consent with every participant. We can demonstrate predictable and explicit expectations. We can make available specific roles and tasks for participants to take on, and we can keep them consistent. We can be sure to only promise things we can follow through on. We can avoid assuming that our participants need help. We can actively listen, paraphrase, and check-in. We can invite

feedback and work to implement changes based on this feedback. We can be directive if we are also willing to include invitations to students to have their own experiences with the class material (Emerson et al., 2009). We can avoid making value judgements during instruction, such as ‘this is hard for trauma-survivors’ or ‘this should feel good’. We can also pace our instruction so as to allow sufficient time to tune into embodied sensation, but not slow down so much as to have people “dissociate or drift off” (p. 126). We can give a variety of options for each portion of the class, so that “students [can] take some control over their experience” (p. 125). The authors note, further, that

We are teaching trauma survivors to identify what is happening right now in their bodies. If they detect pain on any level, we hope they become willing and able to say ‘No, I will not be in pain. My opinion about what is happening to me matters, and I can take control’. (p. 125)

Ammann and Matuska (2014) also provide an extensive table with “tips on how coaches can respond to common reactions of trauma survivors,” in relation to: depression or negative thoughts; anxiety and fear; nightmares and flashbacks; shock, disbelief and denial; sadness, loss and hurt; as well as anger and resentment (p. 18). In relation to depression and negative thoughts, these authors urge encouragement of ‘healthy’ behaviours such as eating and sleep,<sup>59</sup> waking at a regular time, staying active, and challenging negative thoughts. The authors also urge readers to “check if she has thoughts of committing suicide. Talking about suicide does not increase the risk of committing suicide. Not talking about it does” (p. 18). We need to be able to talk openly, and without shame, about suicide. Ask them if they have a plan, stay with them, and do your best to collectively determine a course of action that will keep them safe while honouring their agency (Ottawa Suicide Prevention Coalition, n.d.).

In relation to anxiety and fear, Ammann and Matuska (2014) suggest staying with the person, reassuring them that their reactions are common and will pass, encouraging emotional expression as well as deep breathing, and focusing on the present including attention to sensory input from the surroundings. In relation to nightmares and flashbacks, these authors similarly encourage reassuring participants that their reactions are common and will pass, encouraging emotional expression and deep breathing, avoiding any interpreting of dreams, and offering the suggestion that participants draw or write down their nightmares but alter the ending. In relation to shock, disbelief and denial, we can acknowledge what has happened and listen empathetically. In relation to sadness, hurt and loss, we can demonstrate acceptance, understanding, and reassurance of their value and worth. Further, we can encourage efforts to connect with others, encourage emotional expression, and be together in silence if that is what is needed at the time. In relation to anger and resentment, we can affirm that anger is often appropriate, make space for safe expressions of anger, reflect their feelings, and avoid arguing or responding with anger ourselves.

We also must consider how our instruction signals what we are going to do and/or how we are going to do it. In discussing the use of physical assists in yoga (such as touching someone's body or physically manipulating their positioning), Emerson et al. (2009) argue that ongoing explicit verbal consent to touch is vital. These authors suggest avoiding physical contact by instructors for the most part. Verbal assists are valuable and demonstrate our attention without physical contact. Physical assists can be done with longer term relationships with participants, but must be done with great care and consent. We can first focus our assists on ensuring safety, then on comfort/accessibility. Further, we need to describe each time exactly how we will touch to assist before doing so, and offer time before touching so the participant can give informed

consent. Emerson et al. (2009) point to the primacy of focusing on facilitating embodied knowledge and a friendly orientation to body and self within trauma-sensitive yoga practice as justification for prioritizing verbal assists over physical ones. They note that sometimes physical assists can achieve these goals, but are not fundamentally necessary. Given this, within Adapted Physical Activity we must ask ourselves about the unexplored dangers of physical practices such as ‘hand-over-hand,’ “physical assistance” or “coactive movement” (Sherrill, 2004, p. 197): where physical touch and guidance is commonly used on participants who are not demonstrating ‘proper’ technique or participation. While Sherrill (2004) argues that “physical assistance should always be accompanied by verbal cuing” (p. 197), in my professional experience, I have witnessed this practice frequently done without any explicit or ongoing negotiation of consent to touch. Further, verbal cueing is not the same as requesting consent. We can unknowingly be triggering or causing trauma through physical touch if it is not negotiated and consented to in an active, ongoing, and explicit fashion.

Doing trauma-informed work involves a refusal to demand or force anyone to do anything. As such, I would argue we need to critically question the notion of “play to the whistle,” which D’Andrea et al. (2013) claim develops perseverance. In the context of trauma-informed practice, and specifically in relation to safety, consent, choice, and control, I am wary about encouraging perseverance. The danger is that, by focusing on perseverance, we may in fact be fostering a coercive relationship toward sport participation. For example, in *What made Maddy run: The secret struggles and tragic death of an all-American teen*, Fagan (2017) highlights the life and death of Maddy Holleran, a young star athlete who committed suicide in no small part due to pressures to perform at an elite sporting level, and to not ‘quit’. The pressure to perform, to persevere, can in fact be damaging. As such, while there may be benefits to

learning perseverance, I question the merits of this goal within the context of trauma-informed practice, and would argue that a valuation of perseverance needs to be approached carefully within this context, and must be participant-driven. We must critically consider the explicit and implicit goals of our programming and exercises, such as perseverance, and how these goals may be alienating to some. For example, is the focus on weight loss, or on performing traditional gender roles (such as male lead and female follow in social dance), or on developing ‘proper’ (read: normative) form, or on emotional regulation? Have participants consented to these goals? We must make our goals explicit from the beginning so that participants can choose whether they are interested in working towards these goals. Alternatively, we can collaboratively develop goals that meet the needs and desires of participants, and design programming and instruction from there.

Emerson et al. (2009) also suggest that instructors “dress conservatively to minimize any distractions” (p. 126). I feel complicated in relation to this statement. For me, it is reminiscent of dangerous claims that women who dress provocatively are ‘asking for it,’ where we must police our bodies and our dress to avoid inappropriate (re)actions from others. At the same time, Kafer (2016) recounts a story where she attends a workshop run by a facilitator who was wearing a hat where “ARSON was spelled out in big orange letters across the front, hovering over an image of a burst of flame” (p. 8). Kafer writes:

once the facilitator put that hat on his head - about 10 minutes into the event- my mind began to buzz. I sat there for however long the workshop lasted, willing myself not to bolt, not to cry, not to betray in any way the increasing sense of panic taking over my mind, both numbing and electrifying my body. (p .8)

The impact of material items such as the clothing we wear can be a site that triggers trauma. As

facilitators of space, we ought to be reflecting on the impact that our physical presentation can have on those we work with, while holding together the notions that we can we never know and intercept every possible triggering thing.

**Social and cultural elements of the exercise/activity.** There are also some specific activities, or approaches to exercises, that can be included to build more trauma-informed practice. We can use opening and closing circles, which can help with transitions to and from activity. We can repeat some activities over the course of a programme to facilitate recognition and a sense of familiarity and stability. We can critically consider the necessity of ‘eyes-closed’ exercises, and make available the option to do these exercises with eyes-opened, which works to acknowledge and address hypervigilance. van der Kolk (2014) argues that we can use a range of activities from:

chanting to martial arts ... to drumming and group singing and dancing. All rely on interpersonal rhythms, visceral awareness, and vocal and facial communication, which help shift people out of fight/flight states, reorganize their perceptions of danger, and increase their capacity to manage relationships. (p. 86)

We can avoid exercises that demand holding breath, or breathing at a specific pace controlled by the instructor. Instead, we can have participants choose the pacing of their own breath, even if we ask them to explore different pacings. We can develop slow progressions into more difficult, trust-demanding or vulnerable exercises. Developing exercises that introduce more vulnerable or difficult poses or interactions progressively is critical. For example, hip opener exercises in yoga are identified by Emerson et al. (2009) as important but sometimes difficult, and are thus taught in a slowly progressing fashion. We can also implement closing rituals, even if these rituals are not in the form of a ‘check out.’

It is also important to consider that some sports or physical activities may be highly gendering, which may make some participants feel invalidated or unsafe. For example, ballet dance and ballroom dance both have very specific, codified roles based on binary understandings of gender (i.e., who leads and who follows, who lifts and who is lifted). Likewise, Smoyer (2016) notes that one “gender non-conforming” participant shared reservations about participating in a trauma-informed yoga intervention because they perceived yoga to be highly gendering, although they shared that their perspective changed after participation (p. 72). Understanding that traditional gender roles and expectations can be alienating, we can critically examine the gender roles and expectations that each physical activity or sport has typically adhered to, and work to disrupt these roles and expectations when appropriate.

When we run activities or exercises, we can choose not to play racist, sexist, misogynist, transphobic, homophobic, ableist or sanist music (trying to adhere to this suggestion will teach you something about how pervasive these sentiments are in popular culture). Further, just because the song uses a phrase (like the \*n\* word), does not mean you can repeat it. As Coates (quoted by Ruiz-Grossman, 2017) argues:

Words don't have a meaning without context...My wife with her girlfriends will use the word 'bitch'...I do not join in. I don't do that...This will give you just a little peek into the world of what it means to be black. Because to be black is to walk through the world and watch people doing things that you cannot do. (unpaginated)

Ruiz-Grossman (2017) unpacks this further, noting:

White privilege — or white people being raised in a society whose laws and culture communicate to them that ‘everything belongs to you,’ as Coates put it — makes some white people feel as though they have a right to do anything, including use a word they

have been repeatedly told is inappropriate for them to use... The moral of the story is: if you're white, just don't use the N-word, period. (para. 10)

Likewise, as mentioned before, we must also consider that all of the exercises, sports, or physical activities we are facilitating are situated within specific social and cultural traditions and histories. Yvette Robles argues that to make meaningful anti-racist change, we need to consider how we appropriate different cultures (Teaching Tolerance, n.d.). This is a matter of critically questioning our everyday clothing choices, Halloween costumes, make-up or accessory choices, musical choices, and the like. Arewa (2016) elaborates:

context, particularly as it relates to power relationships, is a key factor in distinguishing borrowing from exploitative cultural appropriation... When patterns of borrowing fail to acknowledge their sources and compensate them, they can be categorized as cultural appropriation. This is particularly the case when cultural flows reflect, reinforce or magnify inequalities" (When Borrowing Becomes Appropriation section, para. 2 & 6).

Questions of labour, power inequity, economic injustice, and white entitlement are wrapped into practices of appropriation, and need to be considered carefully.

A perfect example of appropriation, within sport contexts, is racist team names or mascots. Wenthe argues, for example, that "indigenous logos are racist, because they're a byproduct ultimately of colonialism. That they're ever even championed as honorific is a symbol of colonial violence" ((quoted in CBC News, 2016, para. 15). In a keynote lecture for the North American Society for the Sociology of Sport Conference in November 2017, Wenthe argued that one way we can reject this racist sporting practice is to refuse to repeat a racist team name (for example, say "Edmonton's football team" rather than repeating the racist and offensive term that this team uses as a name), as well as refusing to buy merchandise or attend games. We can also

ensure that we actively campaign to change team names, and refuse to work with or support organizations that will not do so. Further, we should not adopt racist team names or logos for our organizations or programs, and should develop explicit policies that restrict the wearing of racist paraphernalia in our programs. We must critically question the cultural aspects of the exercises or activities we do. We must consider how our choices uphold white supremacy, or function as cultural appropriation, or alternatively, how we might respectfully honour different cultures through a historically situated exploration of exercises and activities from cultures that are different from our own.

**Emotional climate.** Part of intervening into the social, cultural and institutional environment includes actively facilitating the emotional climate of a group. Some specific strategies that can foster a trauma-informed emotional climate include: ensuring confidentiality, and facilitating an agreement with participants to keep information shared in the group confidential; ensuring a ‘No Fight’ policy is in place, including bans on verbal and physical attacks; removing unwanted observers when possible to reduce feelings of surveillance, and ensuring that no one is entering or exiting inadvertently (e.g., random human walking through space); using ‘check-ins’ to facilitate dedicated safer space/time for sharing feelings; encouraging participants to talk freely, express opinions, and share emotions/experiences; allowing emotional expression, such as crying, without trying to stop or change it; and avoiding blame or judgement about how participants act, feel, speak, or live (Ammann & Matuska, 2014). At the same time, we must be careful not to force people to discuss their experiences, or dig deeper than what they are wanting to share. Learning from Carter (2015), Kafer (2016) and Price (2011), we can also use trigger warnings or content warnings, flagging any content we are planning to explore that

may be trigger of trauma or mental distress, and offering the opportunity for participants to consent to participation (or not).

As leaders and organizers of physical activity and sport, we must confront actions, however small, that threaten the emotional safety of our participants. This means that we have a responsibility to actively address microaggressions as they arise. For example, we must become attuned to, and then actively confront, racism in our daily life. To this end, the Southern Poverty Law Centre (2015) offers an extensive list of practical suggestions for responding to bigotry, including addressing racist comments, jokes, interactions, workplaces, policies, events, emails, familial exclusion, bullying, racial profiling, and our own mistakes and biases. While focusing on race, this resource importantly also touches on sanism, classism, homophobia, ethnocentrism, sexism, and other forms of oppression.

The questions we ask of participants also impact upon the emotional safety of our environment. Certain questions can be a form of microaggression. For example, from their “Being a supportive peer or co-worker” tip sheet, The 519 (n.d.g) argues that “if you have a question about someone’s body or identity, stop and think about why you might be asking that question. If it is a question about surgery or their body, chances are you don’t need to ask it” (p. 1). Asking after someone’s pronoun is a very different practice than assuming you have a right to know personal details about someone’s body or choice of medical interventions. Similarly, asking after someone’s medical or psychiatric diagnosis can have alienating effects, and must be done with care. We can ask ourselves whether this information is relevant to the safety and comfort of our participants, and if it is not, we don’t need to ask it.

Further, don’t ask a person of color if you can touch their hair (unless they are a close friend, at which point you probably know this is a fraught question). Black people (especially

women) are constantly asked this question, and it is a matter of white entitlement, exoticization, and ownership of Black bodies that we think we can and should be able to enter a stranger's personal space in this manner at our whim (Johnson, 2015; Opiah, 2013). More broadly, don't touch people's hair, skin, clothing, pregnant bellies, or mobility tools without explicit and enthusiastic consent. Ever. Also, don't ask people you don't know 'where are you from?' Another example of entitled white curiosity, this question implies that the person you are speaking to doesn't belong here: it is a question loaded with racist histories and implications, and can be experienced as a creepy exoticizing pick-up line (Khoo, 2016; Misra, 2015). Before asking these kinds of questions, interrogate your own assumptions about why you need to know, as your motivations may be informed by white supremacist and racist histories and presents.

**Group dynamics.** Ammann and Matuska (2014) advocate for establishing safe relationships with peers, coaches, and wider communities because social support is critical in moving with and through trauma. These authors suggest that relationships (including coach-participant as well as peer-to-peer) must be underpinned by "respect, trust, information, connection and hope," as well as being "consistent, predictable, non-violent, non-shaming and non-blaming" (p. 5). For these authors, connection includes peer support, group cohesion and inclusion. Peer support should be voluntary, respectful, non-judgmental and empathic. We can facilitate experienced group members to mentor less experienced members, fostering the development of a stable relationship. Group cohesion is supported by directly addressing bullying and gossip, making space for quiet or shy participants to contribute if they desire, being conscious of cliques forming, developing group bonding, facilitating conflict resolution early on when conflict arises, giving positive feedback, using democratic inclusive leadership styles, and avoiding favoritism. We can also support and encourage team work and team spirit. Inclusion

involves determining how each participant can be most meaningfully included in group activity, combining inclusive design with specific adaptations, and seeking out leadership from people with lived experience of trauma and disability.

We can also cultivate rituals of praise or team building mantras. At the same time, we must also consider how praise is used. What are we praising? For example, are we praising participants for pushing beyond their limits (thereby undermining the importance of choice and consent)? Or for achieving more ‘normal’ movement patterns, behaviours, or feelings (thereby reinforcing a pathologizing relationship towards non-normative ability or emotional states)? And how is praise impacting the person receiving it, as well as the others in the room? For example, D’Andrea and Spinazzola (2009) note that in the Doc Wayne Project with youth:

paradoxically, the use of specific praise was related to apparent worse outcomes. One explanation for these data may be that coaches used praise more frequently when they knew a player was otherwise struggling, in efforts to ‘cheer up’ the player. (p. 12)

We need to be reflecting on how praise is mobilized, and that it may draw unwanted attention to a participant and potentially be experienced as increased surveillance of their behaviour.

### **Closing Comments**

In this chapter, I weave the key principles of trauma-informed practice, “**safety, trustworthiness, choice, collaboration, and empowerment**” (Fallot & Harris, 2009, p. 3, emphasis in text), together with anti-oppressive, anti-racist, trans-affirming, and Mad-access practices. In doing so, I offer eight domains, each of which is a call to action (for myself and other movement and physical activity practitioners) for building Mad-accessible, anti-oppressive, trauma-informed physical activity. I invite us to challenge pathologization, normalization, and sanism. This also includes depathologizing responses to oppression, as well as challenging

pathologization, normalization and sanism within the trauma-informed practice literature itself. I ask myself and others to acknowledge that structural inequality in physical education, physical activity and sport exists and does damage. This includes unpacking structural inequality in relation to race, as well as sexual orientation and gender. I challenge us to recognize how privilege impacts our practices, including: white privilege, cis privilege, able-bodied/able-minded privilege, thin privilege; and how overlapping points of privilege and oppression intertwine. I argue that part of crafting Mad-accessible, anti-oppressive, trauma-informed practice involves actively dealing with embodied discomfort. I further argue that to do this work, we need to do our own homework, rather than relying on the unpaid labour of those in positions of marginality to do this work for us. I provide some resources as starting points for this homework. I also prioritize valuing marginalized histories, struggles, perspectives, and choices, and I suggest this valuation can be enacted in part through collaboration and connection. I outline ways we can shift our language-use in practice, including through invitational language, as well as through non-discriminatory and affirming language (such as trans-affirming language and supporting multi-lingual environments). I detail ways we can shifting our practice environments. We can shift physical environments. We can also shift social, cultural and institutional environments, in part by considering and intervening into: organizational procedures and programming design; instructor qualities and behaviors; social and cultural elements of the exercises/activities we offer; emotional climate; and group dynamics.

This chapter does not constitute a checklist. There is no way that I could possibly address all of the ways that trauma is experienced, nor all the ways that oppression (including both macro and microaggressions) can cause and perpetuate trauma, nor all of the ways that we might build practices that are trauma-informed. Further, there is no way to ‘get it right’. Trauma-informed

work is not a destination but a process. My goal in writing this chapter has been to learn how to perpetually recognize the ways that I may be unintentionally reproducing oppression and trauma, to strive to always acknowledge when I fuck up, and to put in the effort to ‘do it better.’ I find myself in need of several things at this moment: doing my homework more in relation to race and fatness in physical activity; continuing to check my privilege (including my academic privilege); growing specific qualities as an instructor including skillful reactions to stressful situations; further diving into the trauma literature from a variety of perspectives including neurobiological and oppression-related considerations of trauma; and developing more anti-oppressive organizational policies and procedures within the organizations that I co-lead. This work is lifetime work, and I am excited about how my practice will grow and change as approaches of trauma grow and change as well.

## Chapter 7 - Conclusions and Beginnings Again

These chapters may initially appear somewhat disparate. They are a set of seemingly different creatures, yet they intimately nest together. For me, these research-creation processes, linked together through episodic and cyclical Mad living, have brought me to a unique place. A place where I can weave together Mad politics, aesthetics and radical anti-oppressive trauma-informed Mad-accessible movement practices, into homes and love stories that support Mad art-making and community. Thus, in this conclusion (which is also another beginning), I will share what each of the three interrelated projects in this dissertation do to my Mad art-making and community building now.

As I mentioned in my introduction, Decottignies (2016) draws on a diverse group of disabled and Mad artists, scholars and activists in arguing that 'disability-identified art' (a banner under which Mad art can fall) makes three important interventions. First, it mobilizes resistance to dominant narratives, stereotypes and (mis)representations. Second, it explicitly affirms the creative potential of harnessing impairment, which for me includes Mad embodiments, experiences, and relations. Third, it inverts, reinvents, or reimagines both disability and artistic practice, specifically as a result of the generative “difference that disability makes” (Chandler, 2017a, unpaginated). Here, I want to draw on Decottignies’ articulations, as well as Price and Kerschbaum's (2016) argument that "disability cripps methodology" (p. 20), to consider what disability and madness *does* to our ways of being, making, and knowing. Fritsch (2013) argues that the term ‘crip’ can be considered a verb rather than a noun. It does not refer to someone who *is* disabled. Rather, it denotes *how* some people *do* disability. Crippling disability “both destabilize[s] it as a concept and open up desire for what it disrupts” (Fritsch, 2013, Introduction section, para. 2). Chandler (2017b) argues that crippling the arts involves a commitment to the

destabilizing and disruptive potential of disability as well. Crippling the arts, for Chandler (2017b):

refers both to the ways in which the inclusion of disability arts productively disrupts how we participate in arts and culture and the ways in which disability arts, particularly disability aesthetics, invite us to be individually and collectively satiated by a difference in a form that, according to Tobin Siebers, ‘prizes physical and mental difference as a significant value in itself.’ (p. 58)

Arguably, crip art and Mad art are not the same, but they are intimate bedfellows: at least, that is how I like to roll around with them. So, I borrow from these authors in speaking of maddened art, and what maddening can do.

Maddened art and living, for me, does as Decottignies (2016) suggests; it questions, challenges, and resists. It pushes, it pulls until strings break. It harnesses the tension between a rock and a hard place. It carefully avoids confessional tales.<sup>60</sup> It disrupts tragic portrayals. It disrupts illness-to-recovery progress narratives (see Morrow, 2013; Poole & Ward, 2013). It multiplies subjectivities (Kuppers, 2005; McCarren, 1998). It undermines the necessity to visibilize ‘mental illness’ symptomology on the body (Kuppers, 2003; Reid, 2017); it avoids realism and questions reality (Harpin, 2014). It is selves-conscious. I would argue that ‘making the personal political’ is vital to not only autoethnographic practice, but also to maddening art and living. I have found myself especially emboldened to tell Mad stories through art and performance when I have come to tie social, cultural and political elements to my personal experiences. In my own Mad art, I work to make artistic links between personal embodied experiences and the sociopolitical constructions of madness and sanity, normalcy and abnormalcy, and the (psy-based) systems of oppression that rely on these (and other) binaries. I

strive to employ specific, local, subjugated, embodied knowledges and stories to complicate imaginaries of madness, and also to revel in the pleasure-pain of Mad living.

From this dissertation project, I have come to know in my body, as Decottignies (2016) also suggests, that maddened art affirms. It affirms that episodes and cycles are important ways of being, thinking and knowing, and that they hold creative potential. It affirms that darkness does something to the light. It affirms that we don't need to be forced, coerced, or pushed to be harder, faster, better, or stronger in order to make, and do, and be of value. It affirms participation by invitation, and by choice. It affirms that resistance, refusal, or rejection of an invitation can all be generative too. It affirms that expressing and honouring our wants and needs and desires and peculiarities are radical acts, as dales so acutely pointed out during our collaborative creation process. It affirms that these are radical acts precisely because we are pathologized as wanting, and needy, and attention-seeking, and selfish, and these states of being are made to seem strange. It affirms that some days just don't work for working. It affirms that rest is vital, and that fallow periods fertilize the soil for new growth. It affirms the hard and the beautiful aspects of madness while forefronting collective and communal engagement (Cvetkovich, 2007; Wallin, 2013). It affirms that we are enough.

Maddened art, for me now, also inverts, reinvents, reimagines (Decottignies, 2016). It is not what you expect—all head-grabbing and crazy-eye making—as is in so much art about 'mental illness'. Rather, it is deeply sensory and fully embodied. It is synesthetic (and I don't only mean this metaphorically). It crosses wires, making lateral connections out of thoughts and states that are typically deemed incompatible or undesirable (like dissociation). It offers multiple invitations for sensory engagement, never forcing one singular story, experience, or reality. It is performative (Kuppers, 2005; Olsen, 2000): (re)presenting the repetitions through which we are

worn, and wear our selves, into relations with psychiatric systems, but also the multitudes of performances in which we can come to construct our selves otherwise (Spry, 2011a). It is excessive (Peers, Brittain & McRuer, 2012). It is seriously playful and playfully serious. It does not try to make you feel better. It makes space to share in the seemingly unsharable parts of ourselves.

In my work on Mad autoethnography, discussed in chapter three, I theorize Mad art and living as episodic and cyclical. Through this work, I have come to take to heart Spry's (2011a) assertion that there are some stories we are ready to tell, and some we are not. Spry (2011a) writes that autoethnography:

is an opening into the complex negotiations of meaning making with others for the purpose of adding alternatives to the single story; all personal experience is in concert with the political. You will know when it is time to begin making sense of a confusing or complex experience. You will know when it is time to tell the story. (p. 124)

This wisdom connects to webs of learning that were spun in my other research creation projects. I draw together the tenets of trauma-informed practice that prioritize choice and strengths-based approaches, along with the desire to create "brave spaces" as well as safer spaces (Arao & Clemens, 2013; Derbyshire, personal communication). In doing so, I have come to know that it is brave to choose not to tell a story that you are not ready to tell, just as it is brave to tell a story when you are ready to tell it. Through the process of making, of research-creating, we may be emboldened to tell stories—alternative stories—that we were not ready to tell before.

In and through collaborative maddened art-making, and home-making, I have come to be emboldened by community to share some of the stories we want our walls to tell. "We want the walls to come down. Or, if they stay up, we want the walls to talk, to tell our story. A story too

can shatter" (Ahmed, 2017, p. 222). In chapter four, I discuss some of the stories brought forth in our *Mad Home* collaboration. These stories were about multiplicity; dialogue about hard things; honouring our needs and desires; invitations into our discomfort; anti-pathologization; access; breaking as resilience; and crafting Mad sensory worlds. These stories are love stories. These stories shatter me, and then roll over me again and again in waves, washing up new pieces of smooth and ragged sea glass to add to my collection. These stories, this sea glass, decorate the webs of learning in this research-creation work further: connecting to the participatory and sensory worlds I crafted in and through my autoethnography; connecting to the calls to action around anti-pathologization, access, control, and choice in radical trauma-informed practice.

These stories taught me about mental distress, trauma, and harm as well. In crafting my fifth and sixth chapters, I have come to the assertion that, as much as possible, my maddened art and life works hard not to perpetuate or perpetrate harm. It is anti-oppressive and radically trauma-informed, making no jokes at the expense of those most targeted by overlapping systems of oppression. It recognizes that trauma can result in mental distress, and that some people are unequally subjected to harm, trauma, and distress. It works hard not to contribute to this unequal distribution, to disrupt and dismantle. It works not to pathologize, and thus individualize social inequities. It does not throw anyone under the bus, including our selves. It recognizes we fuck up, and will continue to, and that there is important work to be done with this fucking up. It makes worlds more accessible, and makes new homes too.

Although this chapter claims to be the conclusion, it is also a beginning, a new nesting doll: I continue the research-creation work of this cycle. These learnings bring me back to Chapman and Sawchuk's (2015) argument that "it is by *making* performance, *staging* events, *holding* workshops, *crafting* inclusive conferences, etc., that we have come to learn, profoundly,

about the systemic pervasiveness of ableism throughout our society and culture” (p. 51, emphasis in text). Out of this dissertation have emerged opportunities for literally "*staging* events" and "*holding* workshops" to mobilize these research-creation knowledges and practices (p. 51). This research continues its creating.

For example, in February 2018, I was invited to offer two workshops on Mad aesthetics for one of the most well-established integrated dance companies in Canada, who are embarking on a project with the local psychiatric survivor community. At first, in imagining what I could offer within these workshops, I was struck by deep unease. What could I possibly have to say about Mad art practices that wasn't already available to these artists? In building these workshops, I have come to recognize how my nesting doll projects of composing autoethnography, collaborative creation, and reflections on anti-oppressive trauma-informed practice are now nesting again within my Mad art and community praxis. In this workshop, I drew together: approaches to multiplying our subjectivities, and honouring our brilliant Mad sensory world-making capacities; discussions of radical intersectional understandings of trauma and mental distress; and practices of collaboration, choice, consent, performative invitation, and anti-pathologization. We made art with and from these learnings, and we made community through them.

I am not the only one in and through which this work continues to create. In response to reading the chapter on *Mad Home*, Nathan wrote the following to me:

You, in our friendship, and in this process, have helped me find within myself a decoder ring that connects me to my will to live.

And by live, I mean: create.

And by create, I mean: love.

And by love, I mean: everything.

I've come to find Mad art and community is my "decoder ring" as well, nested in the dolls that madly speak these beautiful twisty-treed love stories.

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## Footnotes

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<sup>1</sup> Sanism “refers to the inequality, prejudice, and discrimination faced by people who are constructed as ‘crazy’ within dominant culture” (Diamond, 2013, p. 77)

<sup>2</sup> Neurodiversity is a term referring to “the diversity of human brains and minds – the infinite variation in neurocognitive functioning within our species” (Walter, 2014, unpaginated). The Neurodiversity movement grew out of Autism Rights movement, but has moved to include other forms of neurodiversity, including that of those who have been psychiatrized, in its activism (Richter, 2014; Walter, 2014). This movement rejects the notion that Autism, and other forms of neurodiversity, are medical pathologies.

<sup>3</sup> Unfortunately, Giambrone’s (2011) article is in Italian and does not have an English translation available. I have gathered this information from the English abstract of the article.

<sup>4</sup> The focus on ‘individual differences’ in this definition of APA may already signal some disjuncture with social and political engagements with either ‘mental illness’ or disability. However, as I will discuss below, there are certainly scholars who take more social and political approaches within the field of APA.

<sup>5</sup> I have excluded the articles that do not deal directly with mad subjects, but instead argue for physical activity as a means of staving off mental illness, most especially depression.

<sup>6</sup> On crystallization as methodology in qualitative research, see Ellingson (2009); Richardson (1994; 2000)

<sup>7</sup> Koppers (2005)

<sup>8</sup> Spry (2011a)

<sup>9</sup> Gingrich-Philbrook (2005); Spry (2011a)

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<sup>10</sup> Spry (2011a)

<sup>11</sup> *ibid*

<sup>12</sup> Adams, Holman Jones & Ellis (2015); Spry (2011a)

<sup>13</sup> Denzin & Lincoln (2011)

<sup>14</sup> Conquergood (1998)

<sup>15</sup> Here, I am speaking critically of the ways that ‘trustworthiness’ is mobilized in autoethnographic research (as Adams, Holman Jones and Ellis, 2015, do), but also in trauma-informed practice. A key principle of trauma-informed practice is ‘trustworthiness’ (Fallot & Harris, 2009). However, Burstow (2003) argues that we ought to critically reflect on this key principle, as mistrust may be a vital survival strategy in the context of trauma and harm: one that should be validated and celebrated in radical trauma work (see the following two chapters of this dissertation for further discussion).

<sup>16</sup> Price (2011) specifically highlights the strategic, intentionally varied, shifting, ‘inconsistent’ use of pronouns as one way that Mad writing destabilizes subjectivity, Mad experience, and relationships to/with readers of Mad autobiography.

<sup>17</sup> Burstow (2005) would argue that these feelings, rather than being pathological ‘cognitive distortions,’ may in fact be a means of more accurately making sense of a troubled and troubling world.

<sup>18</sup> This is a dangerous game to play in the academy, and in neoliberal society more broadly: mania is prized for its hyper-productive potential (as long as it can be channeled, without too much disruption, to capitalist ends—see Martin, 2009).

<sup>19</sup> As Chandler (2017a, b) encourages us to do in relation to disability arts.

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<sup>20</sup> Thanks to the anonymous reviewers for their feedback on this piece.

<sup>21</sup> The audience was made aware that I was filming this public performance. I have obtained written consent from everyone I knew who was involved in the participatory activities within this public performance to post this video online and include their image. For people participating who I did not know personally, or could not identify, I have blurred their images in this video, as I could not obtain their consent to include their image. I have also captioned questions from the audience rather than include the voices of audience members I could not identify, and received consent to include captioned questions from people I could identify.

<sup>22</sup> CRIPSiE stands for the “Collaborative Radically Integrated Performers Society in Edmonton”. CRIPSiE is an integrated dance, disability and Mad art organization by and for people who experience disability and other forms of marginalization, along with their artistic and political allies. I am a co-artistic director for this organization.

<sup>23</sup> “EMDR” stands for “eye movement desensitization and reprocessing,” which “is an integrative psychotherapy approach that has been extensively researched and proven effective for the treatment of trauma and many other mental health problems,” and which involves embodied and sensorial practices (EMDR Canada, 2018, para. 1).

<sup>24</sup> Parallel play is a form of play that involves playing alongside others, without necessarily interacting or engaging in the same activity. “Even though it may appear that they don’t care about the presence of the other[s]...just try separating them and you will see this contact from a far is very important to them” (Child Development Institute, 2018).

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<sup>25</sup> the directions for our *Mad Home* zines included the instruction, composed by dales, that includes “This booklet is meant as a place to glue in the instructions that you want to take with you, or write your own instructions, or do whatever. We trust you”

<sup>26</sup> See Peers, Brittain, & McRuer (2012) for more on crip generativity.

<sup>27</sup> See Price (2011) for extensive discussions on reimagining participation within academic spaces as a practice that fosters Mad access.

<sup>28</sup> See Price (2011) for a discussion on reconceptualizing participation as an act of Mad access.

<sup>29</sup> Fluxus is many things. It is a performance art tradition, and a collection of loosely associated artists from across the world. It is also a set of ideas and practices and a “way of doing things” characterized by relationships to a vast array of considerations, including: “globalism, the unity of art and life, intermedia, experimentalism, chance, playfulness, simplicity...[and] presence in time” (Friedman, 1998, p. ix). It is also a “way of viewing society and life, a way of creating social action and life activity” (p. ix). One way of making art in this tradition is the Fluxus event score. We drew on the concept of the event score, or brief “proposal pieces, propositions, or instructions” (Friedman and Smith, 2002, p. 1), in composing performative invitations featured in *Mad Home*.

<sup>30</sup> LGBTQ2I is a short-hand general term intended to reflect the diversity of identifications surrounding sexual orientation and gender identity. LGBTQ2I stands for Lesbian, Gay, Bisexual, Trans, Queer, Two-Spirit, and Intersex. Other terms include LGBTQQIP2SAA (includes Queer, Questioning, Intersex, Pansexual, Two-Spirited, Asexual, and Allies) (Government of Canada, 2017; Hulshof-Schmidt, 2016)

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<sup>31</sup> PMR has been widely used as a therapeutic intervention or wellness modality for people diagnosed with: multiple sclerosis (Ghafari et al., 2009; Moriya & Ikeda, 2013); cancer (Kondo, Koitabashi, & Kaneko, 2009); burns (Tejas, Santosh, & Chaya, 2013); ectopic pregnancy (Pan, Zhang & Li, 2012); and various psychiatric diagnoses (Schroder, Heider, Zaby & Gollner, 2013; Vancampfort et al., 2013). Some of the purported benefits of PMR exercises include: reduced fatigue (Moriya & Ikeda, 2013); reduced anxiety (Navaneethan & Soundara Raian, 2010; Tejas, Santosh, & Chaya, 2013); reduced stress (Dolbier & Rush, 2012); improved quality of sleep (Francis & D'silva, 2012); lowered levels of pain (Tejas, Santosh, & Chaya, 2013); improved sport performance (Navaneethan & Soundara Raian, 2010); and improved well-being and quality of life (Ghafari et al., 2009; Pan, Zhang, & Li, 2012; Vancampfort et al., 2013).

<sup>32</sup> The following section is adapted from a paper developed in my sensory anthropology course in 2013.

<sup>33</sup> Interestingly, the normative framing of PMR-type movement exercises was highlighted in a dance work entitled “What’s Left of Us” choreographed and performed by Justin Manyfingers and Brain Solomon (performed in the Fluid Festival, Calgary, Alberta, on October 27 & 28, 2017). The work was billed as “Two 2 spirited ndns with only two hands between them. A gloriously deranged world of dance, storytelling, and the unexpected things that make you sexy” (Springboard Performance, 2017). This Indigenous crip dance performance included an extended voice-over of PMR-style movement and visualization instructions that juxtaposed the kind of body constructed by these exercises (one with two hands) with the onstage presence of these dancers with limb difference (both have non-normative left-hand formation and function).

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<sup>34</sup> Arguably this is a flattening of disability studies engagements with embodiment and pain. Nuanced engagement with embodiment and pain within disability studies is evident in the work of Thomas (2004), Clare (1999; 2017), Withers (2012), and others.

<sup>35</sup> Trigger warnings, or the practice of flagging class content as emotionally difficult, have become a hot topic of debate in academic circles concerned with pedagogy (Carter, 2015; Kafer, 2016). One position is that trigger warnings “constitute a ‘threat to academic freedom,’ ‘prioritizing ‘comfort’ over ‘intellectual engagement’ and presuming that ‘students need to be protected rather than challenged’” (Kafer, 2016, p. 1). Another position (which I will discuss more herein) is that trigger warnings are an accessibility practice, one that offers students the opportunity to consent to—and to emotionally prepare for—receiving content that may be trigger of trauma or emotional distress.

<sup>36</sup> Brave space is something that I learned about initially from JD Derbyshire.

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<sup>37</sup> Applebaum (2016) notes: “bell hooks writes that the word ‘racism’ ceased to be a useful term for her, and she began to use the term white supremacy as a descriptor for the reality of the everyday experiences of people of color. White supremacy, in this sense, does not specifically refer to groups like the Klu Klux Klan, who proudly parade their overt belief in the supremacy of whiteness, and the racial hatred and prejudice that accompanies this belief (but which in no way meant to minimize the danger of these groups). Instead the term has been appropriated to refer to the continual pattern of widespread, everyday practices and policies that are made invisible through normalization and thus are often taken for granted as just what is. Charles Mills points out that white supremacy is to race what patriarchy is to gender. White supremacy, as a form of oppression, is to be understood, following Iris Marion Young, as a structural concept that is reproduced by the everyday practices of a well- intentioned liberal society. The outcome of white supremacy has deleterious impact on the lives of the racially marginalized, while simultaneously affording benefits or privileges for white subjects as a collective. David Gillborn defines white supremacy as ‘a comprehensive condition whereby the interests and perceptions of white subjects are continually placed centre stage and assumed as ‘normal.’” White supremacy, therefore, presumes a conception of racism as a system of privilege that white people, often unwittingly, perpetuate in what seems to white people as common, unremarkable, and sometimes even seemingly ‘good’ practices and in the implementation of what seems to be racially neutral policies” (p. 4).

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<sup>38</sup> This is complex work: a danger is that by focusing on making whiteness obvious, we can serve to re-center whiteness when we may intend to do otherwise. Applebaum (2016) draws on Sara Ahmed to describe this danger further: “Sara Ahmed argues that ‘any project that aims to dismantle or challenge the categories that are made invisible through privilege is bound to participate in the object of its critique.’ This is not to imply that the project of critical whiteness studies should be suspended but rather that we must be vigilant about the ways in which projects of critique can be complicit with what they attempt to disrupt” (p. 3).

<sup>39</sup> Importantly, they do include a graphic at the beginning of the page that reads “~~29 stupid~~ harmful things.” By striking through the ableist term ‘stupid,’ I read this as an interesting practice of highlighting their own work of interrogating the implications of what we say or belief.

<sup>40</sup> Holladay (2000) writes: “My [white] skin color does not work against me in terms of how people perceive my financial responsibility, style of dress, public speaking skills, or job performance. People do not assume that I got where I am professionally because of my race (or because of affirmative action programs)” (unpaginated). Privilege means that you are not discriminated against because of your ability, size, or because your name doesn’t sound white, and if you are hired your success is not assumed to be the result of a ‘diversity’ hire (Holladay, 2000; Ridgeway, 2013). Further, with thin privilege, “you’re more likely to get a raise or promotion at work than someone who is fat” (Ridgeway, 2012). If you live with able-bodied privilege, you are much more likely to find housing you can access both physically and financially (Ridgeway, 2013).

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<sup>41</sup> Killermann (2014) points out that cis-privilege means: “being able to purchase clothes that match your gender identity without being refused service/mockered by staff or questioned on your genitals...Being able to purchase shoes that fit your gender expression without having to order them in special sizes or asking someone to custom-make them (unpaginated). Likewise, Ridgeway (2012) notes that if you are thin, “you can expect to pay reasonable prices for your clothing...You can expect to find your clothing size sold locally...You can expect to find clothing in the latest styles and colors instead of colorless, shapeless and outdated styles meant to hide your body” (unpaginated).

<sup>42</sup> To a lesser degree, cis-women encounter some similar barriers when navigating healthcare.

<sup>43</sup> I can reflect that going into a doctors’ office that has my mental illness diagnosis on file produces a similarly narrow range of possibility outcomes (my ailments must necessarily be in my head).

<sup>44</sup> Similarly, impairment, color, or gender non-conformity are not the primary ways you are defined by others. Additionally, **“You’re not made into inspiration porn: ‘People with disabilities are not here to inspire able [bodied] people or make them feel good about themselves. Inspiration porn not only objectifies people with disabilities by turning them into magic talismans, but it erases the very real issues many of us experience — issues for which nobody is offering accommodations...’”** (Higgins, quoted in Moreno, 2017, unpaginated, emphasis in text)

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<sup>45</sup> With regards to sex and sexuality, privilege means that you are not assumed to be unattractive or undesirable because of your ability (Moreno, 2017), nor because of your race, size, or gender. Killermann (2014) also notes that there is privilege in “knowing that if you’re dating someone they aren’t just looking to satisfy a curiosity or kink pertaining to your gender identity (e.g., the “novelty” of having sex with a trans- person)” (unpaginated). Sexual fetishism is also a concern for fat people (Ridgeway, 2012), disabled people, and people of color, and is another way we are objectified. Further, Cis privilege means that “strangers don’t assume they can ask you what your genitals look like and how you have sex” (Killermann, 2014, unpaginated). This rings true in relation to disability and fatness as well, where frequently people are asked if and how they can have sex (Ridgeway, 2012). Further, cis-privilege means that “you have the ability to flirt, engage in courtship, or form a relationship and not fear that your biological status may be cause for rejection or attack, nor will it cause your partner to question their sexual orientation” (unpaginated). There are echoes here regarding violence encountered by mixed-race couples.

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<sup>46</sup> Moreno (2017) states that those with able-bodied privilege are: “**able to see yourself represented in the media and pop culture:** People with disabilities are underrepresented — and erased — in media and pop culture. We’ve been left out, especially folks who are visibly disabled, except for those of us who are used as props or exploited for “*entertainment*.” Usually when disabled characters are incorporated into stories, they’re played by able-bodied actors. Even within the body positive movement, a *disproportionately small* number of people with visible disabilities is represented” (unpaginated, emphasis in text). Killermann (2014) similarly notes that with cis-privilege: “you have the ability to walk through the world and generally blend-in, not being constantly stared or gawked at, whispered about, pointed at, or laughed at...you can easily find role models and mentors to emulate who share your identity...Hollywood accurately depicts people of your gender in films and television, and does not solely make your identity the focus of a dramatic storyline, or the punchline for a joke” (unpaginated). Similar claims can be made around ability and body size (Ridgeway, 2012, 2013), as well as race (The Critical Media Project, n.d.).

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<sup>47</sup> For example, with some forms of privilege, you will not be unequally targeted by police. Holladay (2000) notes that “store security personnel or law enforcement officers do not harass me, pull me over or follow me because of my race” (unpaginated). Undoubtedly, disabled and mad people are also disproportionately targeted by police (Price, 2011). Likewise, Killermann (2014) writes that cis-privilege means you don’t “fearing interactions with police officers due to your gender identity” (unpaginated). Going further, parallels between white privilege and cis-privilege are evident in that “if you are murdered (or have any crime committed against you), your gender expression [or race] will not be used as a justification for your murder...nor as a reason to coddle the perpetrators” (unpaginated).

<sup>48</sup> With cis-privilege, you will not be stopped at borders because your identification does not match your appearance. Killermann (2014) also highlight the privilege of spontaneity that comes with being cisgender (and able-bodied as well): if you are “able to go to places with friends on a whim knowing there will be bathrooms there you can use” you experience privilege. See also Birch-Jones (2017) for more on LGBTQ2I travel-related issues.

<sup>49</sup> For example, Killermann (2014) notes that cis-privilege means that: “no stranger checking your identification or driver’s license will ever insult or glare at you because your name or sex does not match the sex they believed you to be based on your gender expression...You can reasonably assume that you will not be denied services at a hospital, bank, or other institution because the staff does not believe the gender marker on your ID card to match your gender identity” (unpaginated).

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<sup>50</sup> Unsettling is concept, methodological practice, and activist action discussed in Indigenous research that attends to both affective dimensions and material actions that disrupt settler colonialism and work towards decolonization (see Fortier, 2017; Regan, 2010; Snelgrove, Kaur Dhamoon, & Cornassel, 2014).

<sup>51</sup> van der Kolk (2014) notes that deeply feeling into discomfort is also a part of healing from trauma more generally, arguing that:

The challenge is not so much learning to accept the terrible things that have happened but learning how to gain mastery over one's internal sensations and emotions. Sensing, naming, and identifying what is going on inside is the first step to recovery. (p. 68)

<sup>52</sup> see DiAngelo, R. (2011) on white fragility.

<sup>53</sup> I am conflicted about the discourse of 'survivor' in relation to trauma, for a number of reasons. First, it hints at the notion that one is over the trauma, reinforcing the misconception that most trauma is a one-time event (rather than an ongoing insidious daily barrage), that the trauma has come and gone, that one can overcome it. At the same time, it also holds notions of agency, strength and resilience that resonate for me and for others I hold dear. (See King, 2004, for related and overlapping critiques of survivor discourses in relation to cancer)

<sup>54</sup> See discussion below on how the word 'pioneer' carries histories of colonialism and genocide

<sup>55</sup> This notion sparks a number of questions for me in the context of disability or madness and trauma: what are mad- and disability-culture related healing practices? What is the power of making connections to mad and disability cultures, and how do we heal in the context of these specific cultures?

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<sup>56</sup> The word 'pioneer' is frequently used to describe someone who has made an impact on a field, but this word carries with it histories of colonialism and genocide, where 'pioneers' stole land, invaded cultures, and enacted violence upon Indigenous peoples around the world.

<sup>57</sup> It is worth noting, here, that some of these qualities may be more or less difficult to develop for some folks, and some of the qualities highlighted are evidence of valuing neurotypicality in the practice of trauma-informed service. I would argue that there are likely many alternative strategies for creating meaningful trauma-informed teaching environments that demand different instructor qualities, and that folks may also be able to offer qualities and skills that are unique and equally valuable given neurodiversity.

<sup>58</sup> Polyvagal theory, developed by Stephen Porges, highlights 2 pathways of vagus nerve stimulation that activate our sympathetic and parasympathetic systems in different ways in response to stimuli. The different ways the vagus nerve is stimulated are correlated with different responses to stress (and trauma), including 'fight or flight' and 'freeze' reactions (see van der Kolk, 2014 for discussion on how polyvagal theory is applicable to our understandings of, and treatments for, trauma).

<sup>59</sup> All of these suggestions may be useful for some, but are also imposing of normalizing ways of being that for me do not validate the real coping mechanisms of altered sleep, eating, and energy expenditure that accompany this experience.

<sup>60</sup> Spry (2011a) argues performative autoethnography ought to avoid confessional narratives as well.

## **Appendix A: Loose Leaf**

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## Loose Leaf

Abstract:

A shuffle. Do you experience the following? Cigarette smoke and white cheddar popcorn. It's all in my pretty little head. Crinkling paper bedsheets. Excess. A woman who swallowed a fly, leaves and steel. A polka-dot collar. Blink... Side effects are a misnomer. An artist's manifesto. Non-linear. I want to be disjointed, unformed, messy, hurting, mad. Madness is both personal and political. Through an autoethnographic series of performative poetry and prose, Loose Leaf intends to evoke encounters with some of the affects, experiences, and politics of madness and psychiatrization. It works to offer both an embodied and theoretical engagement with one form of mad performance, and to compel readers to perform a form of mad reading.

Key Words:

Mad studies, Mad performance, psychiatrization, performative writing, autoethnography

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Print these  
pages.  
Shuffle them.  
Read.

## Cigarettes

I dig around in my overstuffed purse, my fingers grazing pens and steel clips and paper and lipsticks. The ritualized search for my fire-starter. I slip a cigarette, *Menthol Superslim*, out of the shiny package with the intentionally shaming photos on the front. Implied horrors of cancer, stroke, second-hand smoke, a malformed fetus... I inhale a burning flow into the back of my throat and taste copper medicine. My mouth grows dry as I roll menthol around on my tongue. A slow suicide is better than a quick one. ? .

The smoke erodes the university-educated veneer and exposes my roots. A slutty girl, a low class broad, a salute to my past. Where upward mobility was marrying rich. Where 99¢ soup made dinner each night. Where I dreamt of GAP t-shirts worn by wealthy kids. Where we scrubbed studio floors in exchange for dance classes. Where cigarettes were cheaper than prescription meds. Here, I learned to point my pinky finger down, balancing the long slim cigarette at the tip of my index and middle finger: a cultivated, gendered, grace. I drag. I drag.

I am brought back with a rush, a body flush, a concomitant regret. I smell like my father. I barraged him with shame, in chorus with the degrading photos on his cigarette pack, until his early death from a heart attack. I took up his habit a year after it killed him.

I will now choke my partner with my stench of formaldehyde and disgrace, clinging to me for hours, years. I am about to butt out, and to return to my partner who is dangerously allergic to smoke. Her throat tightens to a straw when I come near. My breath kills her breath. I will shower, and avoid her, to avoid having the cigarettes kill her too. This thought makes me want another. My cheeks blush, and I drag a little harder on my last puff... for now.

Insert thermometer into oral orifice here. ----->

Resist gag reflex

<----- Insert arm into blood pressure cuff orifice here.

Resist the command to run

Insert self into penetratingly steely stare of a triage nurse here.



She slices me up and brands me a crazy woman. Insert sinking in my chest orifice here. Crazy. Woman. Mistrusted. Dangerous. Faking. Flaky. Hysterical. It is all in my silly little head.

It's all in my pretty little head. Imaginary. An invisible friend. My body irrelevant. It's all in my head. Like intelligence. Like an aneurism.

A locked unit keeps me locked in, or out, of someone's reality. The walls bubble and wail. Relentless deep pressure. Screeching loud and dirty. Anesthetizing wash of pale blue paint chips away, revealing grating Pepto Bismol pink. It coats and curdles my guts.

Huddling under a gaping hospital gown and a paper-thin blanket, I wrestle to cover my thighs like a lady. My lover is my comforter, covering me fully with a grounding weight and the smell of home. Uniformly puffed-up police territorialize the hallways, eclipsing the match-box window. Oh Fuck. My lover soothes my jagged breath. She assures me that the cops aren't after me, but the indigenous man laying bloody next-door. My skin grows increasingly chilled, naked, and white.

I take my pills, like a good girl. The greyness lifts and the numbness sets in. My throat swells allergic at the bitter chalky disc seeping into my blood. I swallow hard, push the panic down past my sternum. If I just will myself hard enough...

There once was a woman who swallowed a fly  
I dunno why she swallowed the fly  
Perhaps she'll die

## The folding of days on days

My spotted dog Nugget launches herself onto my bed and laps at my face. I am running a fever. My breath tastes hot as it seeps up my throat into my mouth. My cheeks are heavy. My skin ripples, pricks, every hair standing on end. I draw the covers over my aching body, and Nugget's hard-lean against me is soothing. I am warmed by her offer of shared body heat. I sniff her feet: she smells of dirty river, mud and fun, white cheddar popcorn, comfort and love.

----- fold here -----

My spotted dog Nugget launches herself onto my bed and laps at my face. I am exhausted after a shitty night's sleep. Her insistence forces me into claustrophobic panic. My guts jump into my throat, and I am ready to throw her off the bed. She stinks faintly of urine and wretched meat breath. I clench my teeth and growl at her need to pee. As I begrudgingly pull on fur-covered sweats, her coarse discarded hairs needle their way under my skin. I am consoled only by the menthol cigarette that is coming my way.

----- fold here -----

My spotted dog Nugget launches herself onto my bed and laps at my face. The wet streaks she leaves creep and crawl as they dry, the hairs on my face spring to action. I freeze in terror. My German-Aussie Shepherd is a Korean spy. My body is revved by the psychiatric chemical warfare waged in my veins. I am nauseous, my mouth leaking. Beads of sweat break out on my lip. I need as far away from this animal as I can get. I kick her off the bed. Only then does my heart beat slow, my breath squeezing back into my lungs.

----- fold here -----

My spotted dog Nugget launches herself onto my bed and laps at my face. The laziness of this late Sunday morning is pierced by shimmering sun roasting my skin to toast. The birch tree's coin leaves twinkle with light. I drape my arm over her and stroke her barrel ribcage. She exhales a heavy rattling sigh of intimacy. My cheeks swell to draw my lips to a smile. Rest infuses my bones, and I bury my face into her luscious mane. I sniff her feet: she smells of dirty river, mud and fun, white cheddar popcorn, comfort and love.

F o (u) r l o n g m o n t h s

Of anger SWELLS

And knives turned inwards <-----

Plunged

D

E

E

And g P  
o hollow  
u d  
g e

I peel myself from my bed sheets, which have grafted to my skin and bleed as I pick them off, sticky with sweat. I recoil from myself, bones wincing, desperate to escape.

A waiting room clutters me with curling magazines

and a TV playing just beyond recognition

A doctor's office scratches me with crinkling paper bed sheets and plastic pillows

A prescription pad and piercing shadeless light bulb.

## Leaves and Steel

Yellow and red are scattered across the streets this morning, and flapping raven wings swell my belly as I crinkle-crush the hardened membranes of the trees' offerings under my feet. My long curly hair catches the tiny fragments of the cracked leaves and I dig them out with frozen fingers, so as not to be caught having rolled around on hard ground with soft flesh.

I am riveted by the musty detritus and salty sweat tingling smells of fall. My lover once laid me down in these leaves, on stolen mornings in the crisp air: our breath hanging dew in the sky, misting our cheeks. Our lips tangle and our teeth knock in our efforts to consume each other, driving chills to my core. The smell of fall(ing) clings to me all day.

I am riveted by the sun flickering off leaves next to the massive steel beams of the bridge. I have stared down hard at the rushing river far below, a familiar teetering on the edge, my hips pressed against the protective railing. I now look up at the never-ending sky and sway, full with the blossoming trees lining the water that has called me before. Something so hard and so soft juxtaposed. Gentle and sharp. Lips and teeth.

Dyke. Girl must be crazy. The words ignite possibilities in my chest and were spat in my face. The silent/screaming tirades of loved ones, of friends no longer friends, coat the ground in rot. And I am riveted to her still, to the leaves that were my home when we didn't have one to go to, when secrets masked spilling joy. Winter teeters on edge above me, yet the sun still reaches my bones.

Each crackle of the earth is a moment of cracking. Each time the river valley is painted in yellow and red I catch myself falling like leaves.

Muscles I didn't know I had clamp down with a vice grip, dragging my limbs along in a twitching and convulsing marathon. I chew aluminum foil. The ravens fill my belly with that

hanging

pause

just before the plummet: a weightless anticipation that sends trickling electricity to the tips of my fingers. Jump. And then the

drop.

Crushing gravity compresses my shoulders - squeezes out the last of my breath - I hit the bottom of the loop - gasp against the weight.

In the middle of the night the street lamps spatter everything in gold dust.

A shadow in the corner of my room flickers and catches my eye.

The stippled ceiling begins to bubble.

I curl up and peer through the slats of my blinds - surveying the streets for invaders.

I shrink inwards and peer out through the slits in my face.

My German shepherd X Australian cattle dog is a Korean spy - surveillance devices implanted in her polka-dotted collar.

I am (in) trouble.

## Performative Writing

When writing, Pollock (1998) urges us “to write in excess of norms of scholarly representation, to write beyond textuality... In other words, to make writing perform” (p.79). Much like research-creation recalibrates distinctions between the research act and the creative act, performative writing “collapses distinctions by which creative and critical writing are typically isolated” (Pollock, 1998, p.80). It troubles traditional texts, injecting creativity and play, as well as pointing to the performative nature of writing itself. It also draws us into alternative registers of knowing. “Performative writing evokes worlds that are other-wise intangible, unlocatable: worlds of memory, pleasure, sensation, imagination, affect and in-sight” (Pollock, 1998, p.80). Performative writing, like dance, offers me an opportunity to evoke the unspeakable aspects of madness.

What makes writing performative is not only its aesthetics, but also that the writing must *do* something: it must “perform a social function” (Pollock, 1998, p.76). McRuer (2006) argues that to Crip writing composition (which, arguably, performative writing can do) is to undermine the necessity to compose our writing (and ourselves) normatively. He states: “I argue for the desirability of a loss of composure, since it is only in such a state that heteronormativity might be questioned or resisted and that new (queer/disabled) identities and communities might be imagined” (p.166). I am interested in how performative writing might make (non)sense, shifting our relation to madness and sanity through text (see Price, 2011 for one such text). For example, Pollock (1998) refers “to the often smug tendency to privilege clarity in popular discourses of writing and education (how could anyone with any common sense not be for clarity?)” (p.77). Pollock goes further, citing Giroux, to argue that

‘clarity becomes a code word for an approach to writing that is profoundly Eurocentric in both context and content’ - writing that conforms to presuppositions about standard language use and neglects the historical, political and cultural specificity of diverse audiences or publics. (p.77)

Borrowing from Pollock and McRuer (2006), I argue that dominant ways of writing in academia are not only Eurocentric, heteronormative, and ableist, but also sanist. Thus, I employ performative writing in the hopes that it be disruptive of the sanist necessity of clarity. I intend to use performative writing (in the context of my work on madness and dance) following Mock (2009), as “an embodied practice that performs its own theory” (p.14). I attempt to theorize Mad by writing Mad. Pollock (1998), while not explicitly engaging with mad politics, nonetheless seems to equate performative writing to numerous mad affects. Pollock argues, for example, that performative writing is “*nervous*. It anxiously crosses various stories, theories, texts, inter texts, and spheres of practice, unable to settle into a clear, linear course, neither willing nor able to stop moving, restless, transient and transitive, traversing spatial and temporal borders” (p.90-91, emphasis in text). The author argues for the non-linear possibilities of performative writing, which resonate with Poole and Ward’s (2013) Mad critique of linearity as tied to “modernist assumptions privileg[ing] reason and rational truth” (p.98) (see also Cvetkovich, 2012). Theorizing/writing/exploring the generative possibilities of madness, I would argue, must be done through performative writing to some degree, in order to disrupt the sanist need for clarity and linearity within academia and beyond.

There once was a woman who swallowed a fly  
I don't know why she swallowed the fly  
Perhaps she'll die  
from the anti-epileptics  
for the depression  
from cutting the meds  
due to the seizures  
from the anti-psychotics  
which required anti-histamines  
for the throat swelling  
throughout the hypomania  
from the wrongly prescribed steroids  
for the allergic reaction  
from the anti-psychotics  
or the hypomania  
and the convulsions  
from the anti-depressants  
for the depression  
caused by the lack of serotonin  
caused by the childhood trauma  
caused by the father complex  
caused by the phlegm and liver Qi stagnation  
caused by the moral turpitude  
caused by the processed foods  
caused by the sedentary lifestyle  
caused by the poverty

She swallowed the spider to catch the fly  
I dunno why she swallowed a fly  
Perhaps she'll die

## An artist's life manifesto

### 5. An artist's relation to depression:

- An artist should not be depressed
- Depression is a disease and should be cured
- Depression is not productive for an artist
- Depression is not productive for an artist
- Depression is not productive for an artist

### 6. An artist's relation to suicide:

- Suicide is a crime against life
- An artist should not commit suicide
- An artist should not commit suicide
- An artist should not commit suicide

Abromovic, 2012

## ENDURANCE

This is an endurance piece.

I take my medication. My medication also takes me, sometimes for days/weeks/months at a time.

### Celexa

“headache, nausea, dry mouth, sweating, sleepiness or insomnia (sleeping is more likely), constipation or diarrhea (I wish SSRIs would make up their minds about these contradictory side effects), weight gain (if it happens the weight gain can be pretty bad for an SSRI), and assorted sexual dysfunctions . Most everything but the weight gain and bedroom problems usually goes away within a couple of weeks” (crazymeds.us, 2015a).

### Clonazepam

“It was the sort of hell one wouldn’t wish on child-molesting telemarketers who ignore the do-not-call list” (crazymeds.us, 2015b).

### Lamictal

“Rash, insomnia, itchy skin, lethargy, photosensitivity, memory and cognitive problems, rashes, and headaches that are sometimes really bad. Did I mention rashes and assorted other skin problems?... The lethargy and stupids usually diminish and may even go away” (crazymeds.us, 2015c).

### Latuda

“Movement disorders. Movement disorders galore. 20–40% of the people in the clinical trials had some form of movement disorder, mainly akathisia (severe, overwhelming restlessness) and the rate of side effects in clinical trials are *almost always* lower than real life. Nausea and other GI problems are common, but that’s often the case with any med you *really need to take with food*. Putting you to sleep (somnia) and making you feel tired throughout the day (lethargy, sedation) are also common, but Latuda’s an antipsychotic, so what can you expect? Since Latuda is used to treat depression insomnia and anxiety are popular side effects” (crazymeds.us, 2015d).

### Risperidal

“The usual: headache, nausea, dry mouth, constipation, sleepiness and lethargy or insomnia and way too much energy. Most everything of these go away within a couple of weeks, although the sleep & lethargy or insomnia & being wired may take a little longer.... Loss of libido, other sexual dysfunctions, swollen breasts, unexpected lactation (it’s especially unexpected when it happens to guys) and all sorts of other stuff related to increased prolactin and other hormonal wackiness... Plus discolored feces, and increased pigmentation” (crazymeds.us, 2014).

### Seroquel

“Seroquel is notorious for two things – making you sleep until next Tuesday, and leaving you with one hell of a hangover when you eventually wake up (crazymeds.us, 2013). “Headache, weight gain, nausea, dry mouth, constipation, sleepiness, general lethargy and not giving a damn about anything (emotional blunting). Combine the lethargy and blunting and you get what’s known as zombification... Infanticide - although the *lack* of Seroquel was the real cause of that tragedy” (crazymeds.us, 2015e).

etcetera...

Side effects are a misnomer – they are lived effects.

These drugs sustain me (?), but how long can I sustain them?

<blink> <blink>

"I think crip theory is a collective practice. First of all, I think that it is a practice that has been generated by a lot of queers, in one sense, partly because the workings of compulsory heterosexuality and compulsory able-bodiedness have been so inter-twined for more than a century. And it's really queer crips, crip queers, who have understood those workings really well. And hence, crip theory is this critical cultural practice that has been developed in a lot of queer communities, by artists, activists, and academics, writers of all kinds, poets, painters; many different kinds of cultural workers have put into practice what I think we can call crip theory. That said, I wouldn't say there is an absolute consensus on what crip theory is. I would say that in many ways it is something that's very much about excess. Compulsory heterosexuality and compulsory able-bodiedness generate sites of containment, where disability and queerness are managed, contained, kept quiet, kept silent. And crip cultural production has been about saying, "we're not going to stand for that," so to speak. 'We are going to generate visions of the body and desire and community that are in excess of attempts to contain and manage us.' And there is not absolute consensus about what crip theory is, because that generative excess has been so incredibly varied" (McRuer, quoted in Peers, Brittain & McRuer, 2012, p.148-149). "The world that thought to measure and justify madness through psychology must justify itself before madness, since in its struggles and agonies it measures itself by the excess of the works like those of Nietzsche, of Van Gogh, of Artaud. And nothing in itself, especially not what it can know of madness, assures the world that it is justified by such works of madness" (Foucault, 1965, p.289). "To write in excess of norms of scholarly representation, to write beyond textuality into what might be called social mortalities, to make writing/textuality speak to, of, and through pleasure, possibility, disappearance and even pain" (Pollock, 1998, P.79). "The largely unrecognized intelligence of dreams that many still see as meaningless and nothing but a discharge of excess energy. Madness is often, then, excessive action or difference witnessed by the stage sane" (Harpin, 2014, p.189). "Theatre appears caught in a paradox here between helping to correct 'faulty reasoning' and being dangerous in its potential for an emotional excess that may seize and overtake 'vulnerable' minds" (Harpin & Foster, 2014, p.11). "He currently feels in despair. Hopeless. No will to live. Sleeping excessively. Withdrawn. Tears and sadness, although the tears have reduced on the Effexor. He feels each day is another one to get through. His concentration is off, and his memory is poor. He is working as an actor, and coping with that" (Tighe, 2014, p.111). "The heroine is a madwoman possessed by a god or spirit or is frenzied with excessive emotions, she often carries a branch of bamboo as a sign of her disturbed state of mind" (Ishii, 1994, p.54-55). "Building on the excesses associated with larger-than-life musical form, singing and dancing about the ideas and emotions rather than merely feeling, speaking about, or suggesting them, the decision to turn Joy's depression symptoms into full-blown characters with whom she interacted meant that depression was not merely discussed or embodied by a solitary depressed character, but rather was hyper-embodied beyond her individual experience" (Johnston, 2010, p.210). "Weeping and lamenting, she succumbs to excessive grief" (Ishii, 1994, p.62). "The primary symptom of BDD is 'excessive' anxiety about appearance. What makes it 'excessive'? Basically if it makes you very distressed or interferes with your normal work or social 'functioning.' But adequate 'functioning' depends on your context—your class status, your work life, other people's expectations of you, how much you expect of yourself, and so on. And how much distress about your physical flaws is too much? These are very subjective criteria, and the diagnosis is always going to be both contextual and strategic" (Heyes & Taylor, 2010, p.181). "A woman who becomes mad through an excessive desire for vengeance directed at her husband, who has left her for another woman" (Ishii, 1994, p.62). "In today's global capitalist order manic traits such as drives to be productive are highly valued. But in the popular cultural imaginary this condition's 'excesses' are feared" (Chouinard, 2012, p.145). "By deliberately foregrounding and bringing together two extremes, two excesses, embodied by the classical ballet body and the disabled body, Newson forces the viewer to confront perfection and imperfection, those who cannot pretend and those who do not fit in" (Whatley, 2010, p.47). "A woman's touch was believed capable of debilitating and destabilizing men's bodies and minds...Contemporary physiological theories... held that an excessive loss of semen led to physical and mental degeneration - as well as blindness - in men" (Classen, 2005, p.71). "Fatness signified surrender of the disabled child's self to excessive appetites that could be restrained only through greater control of the already incapacitated body" (Rice, 2010, p.167). "Participants generally described mental illness in terms of depression, sadness, insecurity, hopelessness, or failure and avoidance of social interactions. Other indications of mental health struggles included domestic violence or aggressive behavior, alcohol or drug use, straying from religion, losing interest in work, and excessive sleep" (Simich, Maiter, Moorlag, & Ochocka, 2009, p.211). "Return Ophelia to childhood and thereby overlook the disruptive potential of her unconfined, wandering excess" (Harpin & Foster, 2014, p.13). "Art in the natural world occurs as excess" (Conrad & Beck, 2015).

When reading this, do you experience the following:

- A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased activity or energy...
- B. During the period of mood disturbance and increased energy and activity, three (or more) of the following symptoms (four if the mood is only irritable) have persisted, represent a noticeable change from usual behavior, and have been present to a significant degree:
  - 1. Inflated self-esteem or grandiosity.
  - 2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep).
  - 3. More talkative than usual or pressure to keep talking.
  - 4. Flight of ideas or subjective experience that thoughts are racing.
  - 5. Distractability (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)...
  - 6. Increase in goal-directed activity... or psychomotor agitation.
  - 7. Excessive involvement in activities that have a high potential for painful consequences... (American Psychiatric Association, 2013, p.124)

*Specify if:*

**With anxious distress:...**

- 1. Feeling keyed up or tense.
- 2. Feeling unusually restless.
- 3. Difficulty concentrating because of worry.
- 4. Fear that something awful may happen.
- 5. Feeling that the individual might lose control of himself or herself.

*Specify current severity:*

**Mild:** Two symptoms.

**Moderate:** Three symptoms.

**Severe:** Four or five symptoms with motor agitation. (American Psychiatric Association, 2013, p.149)

I find my father dead. Naked, cold, blue. Legs draped over the side of the bed, hand clutching heart, eyes wide open. Rigor Mortis. He pissed himself, and his flaccid penis is exposed. I jump on the bed and shake him. Scream. Call 911. I wait. Will this tightness in my chest leave with a few deep breaths? I get up, cloak his body in his ratty terrycloth bathrobe.

I find myself in my father's living room. The carpet is loud against my feet. The coffee table has razor sharp edges. I am nauseous. Hazy. My throat swelling and in a vice. The insides of my forearms and the backs of my knees are dangerously weak with uncertainty. I am coursing, raging, rushing with adrenaline and fear, shock and loss. Overcome with an all-consuming urge. I must move. I explode and collapse into dance.

Alone. Snot runs down my face, mixing with tears and guttural moans. I shake and jerk violently: jumping, over-extending, jamming my knees, hips, elbows, shoulders, ribs for lack of "proper" technique. I run into things. I stumble and trip. I break. I am naked. Conscious. Self-conscious. Judging my movements uncoordinated, sloppy, ridiculous, embarrassing. Then sights and sounds lapse and then fall away. All I sense is the weight of my body, the rolling intensity of grief spread through my chest. I revel in what I had judged ugly. I want to be disjointed, unformed, messy, hurting, mad.<sup>1</sup>

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<sup>1</sup> An earlier version of this paragraph has been published in Avner et al. (2014)

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