

Monopolized Madness: A Critique of Mad Studies Through a Consumerist Lens

La folie monopolisée : une critique des « Mad Studies » par le prisme du consumérisme

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Abstract

This perspective piece surveys the peer-reviewed Mad Studies literature from 2013 to 2023 from the lived experience of someone who identifies as a consumer of mental health services. I postulate that researchers who self-identify as 'consumer' while engaging with Mad Studies may feel excluded because of its theorizing being steeped in anti-psychiatry and survivor scholarship, the depreciation of consumers' voice, and the vast under-representation of self-identifying consumers in the peer-reviewed scholarship.

Résumé

Ce texte fait l'enquête de la littérature de « Mad Studies » qui a subi une évaluation par les pairs et qui date de 2013 à 2023 provenant de la perspective vécue d'un individu qui s'identifie comme un consommateur de services pour la santé mentale. Je propose que les chercheurs et chercheuses qui s'identifient comme un consommateur ou une consommatrice pourront se sentir exclus de la littérature de « Mad Studies » en raison de théories empuées dans la scolarité des survivants antipsychiatriques, de la dépréciation de la voix des consommateurs et de la sous-représentation vaste de consommateurs qui s'identifient avec la scolarité évaluée par les pairs.

Keywords

Mad Studies, c/s/x, psychiatric survivor, consumers, anti-psychiatry

Mots clés

Les « Mad Studies », c/s/x, les survivants de la psychiatrie, les consommateurs, l'antipsychiatrie

Introduction

Mad Studies has come to prominence in the last twelve years since *Mad Matters: A Critical Reader in Canadian Mad Studies* (Lefrancois et al., 2013) was published. Mad Studies as a field purports to draw on the knowledge(s) and perspectives of consumers, survivors, ex-patients, and ‘the mad’ (c/s/x/m) and citizens who have direct experiences with psy-oppression and sanism (Beresford & Russo, 2016; McWade et al., 2015). Additionally, Mad Studies covers issues germane to the Mad movement (LeFrançois et al., 2016) and anti-psychiatry (Castrodale, 2017); the latter two groups, along with radical survivors, comprise the cynosure of Mad Studies scholarship (Diamond, 2013). This perspective piece begins by introducing how I choose to self-identify, followed by a discussion of terminology, the use of language, and what it signifies, including how it aligns with or diverges from Mad Studies approaches. Next, I discuss my findings from a literature review of how international Mad Studies authors self-identify in the literature published between 2013 and 2023. This paper concludes with a call for Mad Studies to stop dismissing the dissident voice of service user/consumer standpoints.

Throughout this paper, I use ‘consumer’ to refer to myself and others who consume mental health services and choose to write from, or align with, a ‘choice paradigm’ (Voronka, 2013) as opposed to the more common Mad Studies nomenclature of ‘survivor’ or hybrid terms, e.g., user/survivor or consumer/survivor. The term consumer is ubiquitously used in North America, while ‘service user’ pervades the United Kingdom. Burstow and LeFrançois (2014) argue the variance is more complex: “[I]n the British context, the term ‘service user’ may often be used to refer to politicized survivors of the psychiatric system, whereas in Canada the same term, ‘service user’ would tend to

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

indicate an uncritical and pro-psychiatry position” (p. 6). The two terms are essentially synonymous; however, ‘service users’ tend to encompass a broader subset of the disabled population – including anyone with a disability who currently accesses bureaucratic supports. According to some, the term consumer appears too ‘positive-sounding’ and hints that some semblance of progress has been obtained (Penny & Prescott, 2016). As such, the term ‘consumer’ has been a source of debate in the literature. Various, consumers who choose to identify with their diagnostic label: depoliticize their psychiatrized experiences and, through their consumership, reify the medical model of mental illness (Morrow, 2013); funnel profits into the pockets of the psy-regime; marginalize the perspectives of anti-psychiatry and survivors on madness (LeFrançois et al., 2013); or reformist consumers take, what Morrison (2005) claims is a “arch-conservative position” and “are seen by the more radical activists to represent the most oppressed psychiatrized group” (p. 169). According to Jones and Kelly (2015), “This characterisation illustrates how insistence on a continued need for care in the face of ongoing impairment can come to be framed as internalized deviance by more anti-psychiatric activists” (p. 45). Psych survivors and anti-psychiatrists see consumer investments in the mental health system as making divestments in their respective communities. I read this languaging of consumers’ relationship with the psy-complex as an attempt to smear and shame the consumer constituency – where the oppressed have “become oppressors or ‘sub oppressors’” (Freire, 1998, p. 27).

The broad, radical agenda of Mad Studies concerns consumers. The messaging from some survivor scholars and anti-psychiatrists is that psychiatry is a pseudoscience (Shimrat, 2022) that it causes neurological impairment through brain-disabling

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

psychotropics (Burstow, 2013) and must be made obsolete (Bouchard, 2019). Definitions of Mad Studies have underscored the connectedness of anti-psychiatry theorizing to the field (Eromosele, 2020; Gorman & LeFrançois, 2017; Lefrançois & Diamond, 2014) and that this ‘in/discipline’ (Ingram, 2016) is the “continuation of the anti-psychiatry project of activist organizing” (Menzies et al., 2013, p. 20). Concurrently, Mad Studies is an outgrowth of North American psychiatric survivor activism (Sutherland, 2017) and, overall, an exercise in ‘survivorship’ – that is, Mad Studies centers survivor knowledge, experiences (Kuppers et al., 2016), and analyses (Lefrancois et al., 2016). Survivor research has been touted as the “strongest expression of Mad Studies” (Sweeney, 2016b, p. 39). Indeed, the Mad movement was formed from the activist activities of psychiatric survivors; for instance, Toronto’s Mad Pride movement was initially named the ‘Psychiatric Survivor Pride Day’ and, by the 1990s, had emerged as a way to mobilize psychiatric survivors (Cameron, 2015). This movement originated from the radical roots of “survivor-led initiatives” (Beresford & Russo, 2016, p. 270), which sought to reclaim the term ‘madness’ as a positive signifier and make the experiences of survivors visible (Beresford, 2022). ‘Mad’ has become a ‘politicized identity’ (Reid et al., 2019) and “a signifier of a subversive standpoint” (Redikopp, 2021, p. 99). The Mad movement has also contributed to survivor-led/controlled research (de Brie, 2019). Unlike the consumer constituency, the psychiatric survivor and Mad often movements reject medical notions of their distress and do not consider themselves suffering from an impaired mind (McWade et al., 2015) or disability (Withers, 2014). Consumers use reclaimed terms such as ‘mental illness,’ whereas Mad Studies refuses to repeat regime terms (Burstow, 2013). Instead of reclaiming ‘Mad,’ consumers affirm and own their diagnoses derived from the

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

DSM-5; for example, I am ‘schizoaffective.’ I situate the etiology of my madness in both biomedical and social origins; this alone, I believe, places me outside the mold of survivor studies and anti-psychiatry. I maintain here that Mad Studies retains a monopoly on ‘Madness’ (as a critical field of knowledge production/dissemination) not necessarily hegemonically, but through its growing popularity as an international discipline, and enforced ideological consensus, while claiming to welcome consumer contributions, it has excluded consumers, while privileging anti-psychiatry, Mad, and survivor standpoints. Below, I will illustrate my point with several key examples from Mad Studies literature released between 2013 and 2023. I hope this article stokes reflection and debate, rather than the familiar criticisms: “He is policing identity claims;” “misinterpreting Mad Studies literature”: or, “is he an agent of the psychiatric sciences?”

Problem Statement

Mad Studies is known to advocate perspectives that transcend “consumerist service user involvement arguments” (Sweeney, 2016, p. 51) pursuant to knowledge “rooted in survivors’ own experiences” (Sweeney, p. 55). The exclusion of consumers’ voices and experiential realities from the corpus of the Mad Studies canon is evidenced in the forward of *Searching for a Rose Garden: Challenging Psychiatry and Fostering Mad Studies* (Russo & Sweeney, 2016). LeFrançois conceded in its opening pages that this edited collection was “wholly written by psychiatric survivors, with the exception of only three chapters co-authored in partnership with allies” (p. vi). The book’s co-editor, Russo (2016), remarked how they sought contributions from survivors and that the chapters were written by people “who absolutely resist medical explanation of their experiences” (p. 60). In Beresford’s introduction to *The Routledge International Handbook*

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

of Mad Studies, he confirmed that the editing team was committed to “access[ing] the widest range of survivor voices to create as full and inclusive a picture of Mad Studies as possible” by targeting submissions from the international survivor movement to produce a collection bringing “together the knowledge of survivors” (p. 10). From this alone, one could reasonably assume that Mad Studies is a sleight-of-hand term for survivor studies. In the special issue edited by LeFrançois, Beresford, and Russo (2016), they described their process of selecting articles for inclusion: “While selecting the abstracts, we did not wish to compartmentalize people crudely as survivors, non-survivors, or allies but aspired to include a spectrum of different topics” (p. 4). This suggests a ‘survivor’ bias, where survivor identity was the apparent standard for acceptable submissions.

Costa and Ross (2023) remarked that since the inception of Mad Studies, the field “has been criticized for being too radical or anti-psychiatry or, alternately, not radical or anti-psychiatry enough” (p. 2). This present perspective piece is the first to examine and critique the ‘in/discipline’ called Mad Studies through a consumer-centric lens. My motivation for authoring this paper began when I suspected in 2017 that Mad Studies was unsympathetic to consumers and wondered whether my brand of madness (or consumer) identity was even being considered outside the confusing use of appending the ‘-survivor’ suffix to ‘consumer’ or hyphenating ‘consumer/survivor’ to form a hybrid term. From this, I found my animus to survey the Mad Studies literature spanning 2013 to 2023 to confirm my supposition.

Sample

I sought out all double-anonymized peer-reviewed journals, books, and book chapters with “Mad Studies” in their title, subtitle, abstract, and keywords published from 2013 to

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

2023 using a Google Scholar search. The search included international publications so long as they were published in English. Grey literature, magazines (*such as Asylum Magazine*), websites (including *Mind Freedom, Mad in Canada/Mad in America*), zines, conference papers, theses, and dissertations were excluded because they are typically not subjected to anonymous peer review. This search turned up three edited collections: *Mad Matters* (2013), *Searching for Rose Garden* (2016), and *The Routledge International Handbook of Mad Studies* (2022). Nine chapters were identified in *Mad Matters*; fifteen in *Searching for a Rose Garden*, and twenty-three chapters in the *Handbook of Mad Studies* (see Table 1). Hundreds of peer-reviewed journal articles were searched, including seven special issues on Mad Studies. Forty-one papers included authors who self-identified (See Table 2). The 2023 volume of the *International Journal of Mad Studies* was searched. The sources identified in my search were read with the following research question in mind: Do the author(s) self-identify as a ‘consumer,’ ‘user,’ ‘survivor’ (or some hybrid term thereof), ‘ex-patient,’ or as ‘Mad’? The limitation of this search was the likelihood that several authors may privately identify with one or more of these identity groups but do not, understandably, self-identify as such in their work for personal or professional reasons. The tables supply authors’ surname, the year their article/book/book chapter was published, and the label they chose to self-identify with. Correspondingly, each article author’s full citation can be found in this reference list. Book chapter authors were excluded from the reference list. I was tempted to label authors who described past experiences with psychiatry as ‘ex-patients’ (e.g., Voronka, 2016; 2019) but opted not to. Nor did I include ‘trauma’ (e.g., Rubinsztajn, 2016) or ‘suicide’ (e.g., Ward of Ward & Poole, 2013), or ‘self-injury’ (e.g., Shaw, 2016) survivors in either table

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

under the survivor header because they refer to surviving self-harm and not iatrogenic harm.

Findings: Underrepresentation of consumers' voices in Mad Studies

This section discusses the conclusions drawn from the data set, which support my supposition that consumer voices have largely been absent in Mad Studies and reveal other gaps in the literature regarding modes of self-identification.

Firstly, despite several authors in Mad Studies framing the importance of their research for 'consumer/survivor' or 'user/survivor' audiences, among those who self-identified, only three authors used a hyphen or forward slash, e.g., as a user/survivor (Beresford, 2016; Faulkner, 2016; Poursanidou of Spandler & Poursanidou, 2019). Perhaps they were still 'users' but employed 'survivor' to account for surviving some unsavory aspects of psychiatry. All three researchers were located in the UK, which is why they used 'user' instead of 'consumer.' By so few authors identifying as user/survivors and that an overwhelming number of authors conjunctively link these two terms in the interests of coalition building, suggests to me an attempt to co-opt consumers into the significantly larger survivor swathe of Mad Studies. I eschew the hybridity of these two diametrically opposing terms because "they often have radically diverging points of view" on the efficacy of mental health sciences, treatments, and the necessity of involuntary committal (Wipond, 2013, p. 261). The insertion of hyphens and forward slashes cannot reconcile the tensions between these two groups (Menziez et al., 2013). The use of the '-survivor' suffix makes it challenging to untangle consumer views (and their relevance) in survivor-led research when it is misguidedly advanced as

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

‘user/survivor’ research. Likewise, hybridity makes “it difficult to locate and distinguish survivor projects” (Landry, 2017, p. 1441).

Secondly, only two authors self-identified solely as consumers of mental health services: Sexton of Sen & Sexton (2016) as a ‘non-survivor/consumer,’ and Procknow (2017; 2018; 2019a; 2019b). This lacuna reflects the absence of consumers’ voices in Mad Studies. Whether this omission is by willful design or by happenstance, it signals that Mad Studies does not draw on the knowledge and perspectives of consumers as advertised. McManus (2023) remarked on being a psychiatric survivor who consumes mental health care services. Thirdly, more authors self-identified as ‘Mad’ in the sample of journal articles than ‘survivor’ or ‘ex-patient.’ Interestingly, only two authors, Staddon (2016) and Weitz (2013) supplied a diagnosis, and self-identified as ‘survivor’; McMahon (2023), Poole in Ward and Poole (2013) and Reid and Poole (2013) supplied a diagnosis and self-identified as ‘mad’; and, Castrodale (2017; 2018; 2019), Wolframe (2013), and Liegghio (2016) provided diagnoses and identified as ‘ex-patients.’ Interestingly, all three —Clarke, Jones, and Mordecai (2023) — state their own respective mis/diagnoses without further identifying which Mad Studies constituent they identify with. Masters (2023) and Maylea (2023) discuss diagnostic experiences; interestingly, the latter, while detailing how medication had helped them achieve stability, felt compelled to say how they “cannot be a ‘consumer perspective researcher’ because [they] feel almost no direct connection to the ‘consumer perspective’” (p. 4). Contrarily, more contributors self-identified as ‘survivors’ in the edited collections. Perhaps, given the norm that scholars typically publish in peer-reviewed journals before progressing to book chapters, we will see more book chapters in the future authored by those identifying as ‘Mad.’

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

Fourthly, a few authors identified as disabled (Aubrecht, 2016; Davar, 2022; Iga, 2022; Kirihaara, 2022). Aubrecht uniquely self-identified as disabled and ‘mad-identified.’ Davar (2022) (India), Iga (2022) (Africa), and Kirihaara (2022) (Japan) discussed mad-specific matters in the Global South and Asia and had explicitly self-identified as psychosocially disabled. No authors in the Global North identified this way. Three explanations for this discrepancy are that members of the Global South find Mad terminology offensive (Beresford, 2022), non-applicable in non-Western settings (Davar, 2015), or simply that ‘psychosocial disability’ is the terminology used in international human rights instruments, such as the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

Fifthly, there have been inconsistencies with the way one labels themselves as a Mad person writing from the position of a survivor (de Brie, 2020) or those who have identified as an ‘ex-patient’ and written from the perspective of a Mad person (Wolframe, 2013). Authors should make these delineations clear because these inconsistencies make it difficult for readers, especially consumers new to this scholarship, to nuance the intricacies of c/s/x/m identities. Next, several authors included in the sample commented on their ever-shifting relationship with c/s/x/m labels. For instance, Davar (2022) first identified as a survivor of psychiatry (see also Davar, 2015) and then had a year-long stint claiming a ‘mad identity.’ She then started to identify as a childhood survivor of psychiatric abuse. Note: Her author biography from 2022 lists her as someone with a psychosocial disability. Reville (2013) relayed how his 40-year journey began by identifying as “a manic-depressive...an ex-inmate, a consumer, a consumer/survivor, a (psychiatric) survivor, and a Mad person” (p. 170). Admittedly, I mistakenly referred to

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

myself as a mad-identified psychiatric consumer in Procknow (2017; 2018), oblivious to the deeper nuances at the time. Blanchette (2019), however, “positively” identifies as both a “Mad scholar and a mental health service user” without trafficking much in these distinctions (p. 2). Lastly, some authors self-identify as users/survivors (Faulkner, 2016), whereas in other publications, they have identified solely as survivors (Faulkner, 2021).

Conclusions: Mad Studies and the Monopolization of ‘Madness’ Scholarship

No individual school, group, or person can claim ownership or define the borders of Mad Studies (Costa, 2014). Yet, Mad Studies theorizing has given ring-fenced attention to research advancing survivor theory and praxis. Mad Studies purports to draw on the knowledge of consumers. However, the reality is that survivor, mad-identified, and anti-psychiatry academics and their allies serve as its gatekeepers, deciding who (can)not contribute to its knowledge production. The field excludes consumers as contributors and originaries of Mad knowledge and subordinates consumers’ voices in pursuit of an exclusionary, pro-survivor praxis and identity politics. Even if this exclusion is unintended (which I do not believe it is), it risks pushing consumers out (Spandler & Poursanidou, 2019). I have often wondered if the Mad Studies project is merely a repackaging of survivor interests and an attempt to inject new life into a floundering anti-psychiatry movement (Burstow, 2014). Nevertheless, what of those ‘mad-identified’ (small ‘m’) who reclaim their ‘oppressive’ diagnostic identity, e.g., ‘schizophrenic’ or ‘bipolar’ as a badge of pride, who have experienced more pluses than minuses in their interactions with psychiatry? Spandler and Poursanidou (2019) propose that it is “entirely conceivable that people who feel they have benefited from psychiatry could have a positive contribution to the Mad Studies project” (p. 7). Still, consumers must fight for equality in Mad Studies. If

CRITICAL DISABILITY DISCOURSES/
DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

Mad Studies consensually does not relinquish its monopoly on 'Madness' scholarship, consumers could resist calling this supposed 'in/discipline' their disciplinary home.

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DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

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CRITICAL DISABILITY DISCOURSES/
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CRITICAL DISABILITY DISCOURSES/
DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

Table 1: How Mad Studies Scholars Self-Identify (Books/Chapters)

Author/Text	User/Consumer	Survivor	Hybrid (Consumer/Survivor)	Mad	Ex-patient or Disabled	Anti- psychiatry	Diagnosis Description
Routledge International Handbook of Mad Studies (2022)							
King		X					
Brosnan of Beaupert and Bronson (Ind. survivor researcher) Beaupert (experience)		X			X		
Campbell		X					
Canton (Mad activist in biography, Beresford refers to her as a survivor activist)				X			
Carr		X					
Davar (psychosocial disability)					X		
Kirihara (psychosocial disability) – Beresford said the author was involved in the survivor movement in Japan					X		
O'Hagan		X					
Reville (Mad activist) (Beresford calls him a survivor activist)				X			
Shimrat		X					
Sweeny of Sweeny and Taylor		X					
Tenney (Mad who conducts survivor research)				X			
Webb (Suicide survivor)		X					
Yeo		X		X			
Quiroz		X					
Penney (according to Beresford)		X					
White				X			
Taggart (Trauma survivor)		X					
Russo		X					
Iga (psychosocial disabilities)					X		
Armstrong and LeFrançois both 'mad activists'				XX			
Sharma					X		
Beresford		X					
Searching for a Rose Garden (2016)							
King		X					

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

**Beresford			X				
Roper (in intro discussed as survivor)		X					
Simpson		X					
Davar		X					
O'Hagan		X					
Sweeney		X					
Brown of Brown & Stastny		X					
-Sexton of Sen and Sexton identified as non-survivor/consumer	X						
-Sen 'lived experience with psychosis, PTSD, mood disorder' (Survivor, p. 170)		X					
Mead of Mead and Filson		X					
Landry from Landry & Church				X			
Bhakta		X					
* Faulkner (Intro - survivor researcher) (Chapter - user/survivor perspective)			X				
Prescott from Penney and Prescott					X		
Staddon (alcohol survivor)		X					X
Mad Matters (2013)							
Fabris				X			
Tam				X			
Gorman				X			
Reville (Mad activist)				X			
Poole in Ward & Poole				X			X
Ji-Eun Lee		X					
Weitz		X					X
Beckman in Beckman and Davis		X					
LeBlanc in St. Amanda & LeBlanc		X					

*Faulkner (2021), she identifies as a survivor researcher

** Beresford (2016) refers to Costa as survivor. In *Mad Matters* (2013), Costa had not self-identified as such.

CRITICAL DISABILITY DISCOURSES/
DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

Table 2: How Mad Studies Scholars Self-Identify (Journal articles/special issues)

Author/Text	User/Consumer	Survivor	Hybrid (Consumer/Survivor)	Mad	Ex-patient	Anti- psychiatry	Diagnosis Description
Bouchard (2019)				X			
Castrodale (2017; 2018; 2019)					X		X
Wolframe (2013)					X		X
Kalathil & Jones (2016)				X			
Lieghio (2016)					X		X
Procknow (2017; 2018; 2019a; 2019b; 2022)	XXXX			X (2017)			X
de Bie (2020)				X			
de Bie (2019)				X			
Clarke, Jones, & Mordecai (2023) all three authors state mis/diagnoses							XXX
Tavares (2019)				X			
McManus (2023) (a survivor and consumer of psy-services)		X					
Landry (2017; 2023)				XX			
Lüthi (2016)				X			
Jeppsson (2023)				X ("madperson")			
Masters (2023)							X
Kalathil from Kalathil & Jones (2017)		X					
Poole in Reid & Poole (2013)				X			X
LeBlanc in LeBlanc and Kinsella (2016)				X			
Maylea (2023)							X
Beresford & Russo (2016)		XX					
McMahon (2023)				X			X
Russo & Beresford (2014)		XX					
Aubrecht (2016)				X			
Kafai (2021)				X			
Kafai (2020)				X			

CRITICAL DISABILITY DISCOURSES/ DISCOURS CRITIQUES DANS LE CHAMP DU HANDICAP 10(2)

Heit in Koppers, Heit, Sizemore-Barber, & Preston (2016)		X					
Spandler & Poursanidou (2019) – Poursanidou is a user/survivor			X				
Douglas et al., (2021): four mad-identified mothers of disabled children				XXXX			
Haley (2018)				X			
Smith (2017) “mad-identified scholar”				X			
Golightley (2019)				X			
Newman et al., (2019) - Joanne describes herself as a ex-patient; Kathy as a survivor		X			X		
Snyder et al., (2019) “mad and non-mad educators”; “mad and mad allies”				X			
Reid et al., (2019) – “three of the authors of this paper identify as mad”				XXX			
Blanchette (2019) “Mad scholar”				X			