Why Mad Studies Needs Survivor Research and Survivor Research Needs Mad Studies

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Abstract

Mad Studies and survivor research are emerging fields of enquiry whose goals and boundaries are continually being shaped. This paper aims to explore intersections between the two fields and argues that fostering a stronger relationship could bring strengths to each. In section one, I outline points of intersection between Mad Studies and survivor research. In section two, I discuss why I believe that Mad Studies and survivor research need one another. Mad Studies gives survivor research a framework through a theorized radical counter-discourse to biomedical psychiatry and a model for conducting research beyond consumerist service user involvement arguments; survivor research offers Mad Studies preliminary thinking around the ethics and means of knowledge generation. In the final section, I explore our positioning within and beyond the academy. I conclude by discussing the potential benefits of a stronger relationship and posing questions for our future relationship.

Keywords: Mad Studies; survivor research; survivor perspectives; critiques of psychiatry; alternatives to psychiatry

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Mad Studies and survivor research[1] are both emerging fields of enquiry at an early and exciting stage in their histories. The meaning and potential of each—and in particular the former—are continually being shaped by passionate protagonists in ongoing dialogue and praxis. Costa (2014) has written that no single "person, or school, or group owns Mad Studies or defines its borders," and the same is true of survivor research. Consequently, this is an exploratory, rather than a definitive, paper. Its aim is to explore some of the potential points of intersection between Mad Studies and survivor research, and outline why I believe that Mad Studies and survivor research could, and indeed should, foster a strong relationship. I don't claim an authoritative voice. Instead, I hope that these early and evolving thoughts on the potential value of a strong connection between Mad Studies and survivor research will spark a continuing relationship and debate.

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[1] I have elected to use the term *survivor research* to signal the unique identity of our research approach. Alternate terms include *survivor-controlled research*, *survivor-led research*, *service user-controlled research*, and *service user-led research*.

Section 1: Exploring Points of Intersection
Between Mad Studies and Survivor Research

Toward Definitions of the Emerging Fields of Mad Studies and Survivor Research

Mad Studies and survivor research can both be considered emerging fields of inquiry. In the United Kingdom, survivor research began to formally take shape around the end of the 20th century, with two major programs of survivor-led research established in national charities[2] (Faulkner & Layzell, 2000; Rose, 2001). A major milestone was reached in 2004 with the publication of *The Ethics of Survivor Research* (Faulkner, 2004) and again in 2009 with the publication of *This is Survivor Research* (Sweeney, Beresford, Faulkner, Nettle, & Rose, 2009). In the United States, early survivor research projects have been traced to the late 1980s, although there is far less survivor research activity in the United States than in the United Kingdom, and no edited volumes or key publications (Jones, Ostrow, & Kelly, 2015).

Survivor research can be considered the systematic investigation of issues of importance to survivors, from our perspectives and based on our experiences, leading to the generation of new, transferable, knowledges. Typically, survivor research constitutes a departure from standard biomedical research in two key ways. First, rather than being located within dominant positivistic research paradigms, survivor research is located within a broad qualitative paradigm and as such is based on the assumption that all research "is inevitably based on who we are, how we come to each other as researchers and/or the subjects of research, and the essential 'subjectivity' of human relationships, including research relationships" (Beresford & Rose, 2009, p. 12). Key to survivor research, then, is the transformation of research relationships so that research "subjects" become research participants and partners, and develop a sense of ownership over the research (Russo, 2012; Sweeney, 2010). Second, survivor research often, though not exclusively, explores issues that collectively have the potential to constitute an alternative to biomedical psychiatric discourse (Russo, 2012).

In *Mad Matters,* Reville (2013) posed the question, "Is Mad Studies emerging as a new field of enquiry?" He dated his awareness of the first use of the phrase *Mad Studies* to Ingram (2008) and described how Mad Studies emerged at Ryerson University in Toronto from the fall of 2004. The United Kingdom's first Mad Studies course was established at Queen Mary University in Scotland in 2014, and there is now also a course at Northumbria University in England. The publication of *Mad Matters* in 2013 (LeFrançois, Menzies, & Reaume) and the presence of a Mad Studies stream at Lancaster University's Disability Studies Conference in 2014 (McWade & Costa, 2015) further demonstrate the growing profile and presence of Mad Studies. Although Mad Studies is at a very early stage in its development, and is emerging in different ways in different places, it has nonetheless been broadly defined as

> an umbrella term that is used to embrace the body of knowledge that has
> emerged from psychiatric survivors, Mad-identified people, antipsychiatry

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[2] See Sweeney (2009) for a reading of the development of U.K. survivor research.

academics and activists, critical psychiatrists and radical therapists. This body of knowledge is wide-ranging and includes scholarship that is critical of the mental health system as well as radical and Mad activist scholarship. This field of study is informed by and generated by the perspectives of psychiatric survivors and Mad-identified researchers and academics. (LeFrançois et al., 2013, p. 337)

Crucially, it has been described as incorporating

all that is critical of psychiatry from a radical socially progressive foundation in which the medical model is dispensed with as biologically reductionist whilst alternative forms of helping people experiencing mental anguish are based on humanitarian, holistic perspectives where people are not reduced to symptoms but understood within the social and economic context of the society in which they live. (Menzies, LeFrançois, & Reaume, 2013, p. 2)

The extent to which either Mad Studies or survivor research achieves this critical/radical vision will be explored later in this section.

The Centralizing of Experiential Knowledge

From the early definitions above, the overlaps between Mad Studies and survivor research become immediately apparent. Most notably, both provide hope for the creation of radically new knowledges based on survivors' own experiences that collectively pose a direct challenge to dominant biomedical psychiatric orthodoxies. This is in part because both Mad Studies and survivor research centralize experiential knowledge—described by Webb (2008) as first-person knowledge—over and above scientific or third-person knowledge (see also Russo, 2012). For instance, the editors of *Mad Matters* have explained

Mad Studies takes as its principal source, inspiration, and raison d'être the subjectivities, embodiments, words, experiences, and aspirations of those among us whose lives have collided with the powers of institutional psychiatry. By definition and design, Mad people and Mad culture *occupy the analytic core*, and they/we embody the very spirit, of Mad Studies … without the foundation of critical knowledge and action built up over many years through the grassroots advocacy of psychiatrized people, a viable field of Mad Studies would be unimaginable. (Menzies et al., 2013, p. 14; italics added for emphasis)

This is a crucial point. Traditional biomedical research privileges objectivity, neutrality, and distance from the research topic (Beresford, 2003). Consequently, "Despite taking people as its central subject of interest, psychiatry is a discipline based on the exclusion of first-person knowledge" (Russo, 2012, para. 6). This means that the direct experiences of survivors can be denigrated as mere anecdote, as the lone or extreme experiences of one or more (angry) individuals. Both Mad Studies and survivor research turn this on its head. Based on our experiences of madness, distress, and psychiatry, we explore our priorities, our perspectives, our views on what heals and harms, (ideally) without censorship. We do so without attempting an artificial objectivity or distance from our research subjects, but

through reflexive inquiry based on participatory and partnership approaches with research participants.

Menzies et al. (2013) identifed this centralization of survivors' experiential knowledge as one of 10 common themes currently emerging within Mad Studies (see pp. 13–18 for a full account of the 10 themes). As Mad people and culture are placed at the "analytic core" of Mad Studies, survivor research can in some senses be understood as the strongest expression of Mad Studies, where our research is conducted within a radical framework. This suggests that survivor research and Mad Studies are already closely connected.

Within Mad Studies, the privileging of experiential knowledge often occurs within a "survivor frame" in which allies bring themselves—their experiences, beliefs, and personhood—into the research explorations and relationships (Church, 1997). Church (1997) further stated, "In forming their movement, psychiatric survivors begin from 'I', from their own story in relation to the power and authority of the mental health system." Likewise, both Mad Studies and survivor research typically begin with the *I*. For instance, the development of research questions or topics for exploration tends to arise from the researcher's or scholar's first-person experiences (e.g., Webb, 2010). Robust approaches such as reflexivity, critical autobiography, autoethnography, and storying can be utilized to interrogate the *I* and its interconnections not just with the experiences of others, but also with broader institutional, societal, and theoretical levels of understanding (Church, 1997; LeFrançois, 2013; Poole & Ward, 2013; Poursanidou, 2014; Webb, 2010). Within the move from individual to collective levels of knowledge—that is, the move from *I* to *We,* researchers and scholars don't seek evidence of our own truths, views, or experiences reflected in the lives of others, but instead move reflexively between a critical understanding of our own experiences, the points of intersection and departure with others, and the interconnections and implications at broader levels. Thus, accusations of bias relating to the conscious shifts between *I* and *We* are simplistic and misleading.

Emergence from and Connections to Social Movements and Activism

Mad Studies is intrinsically connected to, although has not directly emerged from, the social and political movements of people who have experienced madness, distress, and psychiatry; whereas survivor research can be said to have emerged more directly from the survivor movement, at least in the United Kingdom, where key movement figures have used their research skills to further the movement's emancipatory visions (Rose & Beresford, 2009; Sweeney, 2009). Perhaps unsurprisingly there are examples of both Mad Studies scholars and survivor researchers turning to an exploration of survivor movements in their work (e.g., Diamond, 2013; Wallcraft, Read, & Sweeney, 2003).

As a consequence of these connections to local and national networks and movements of survivors, both Mad Studies and survivor research are heavily bound with activism. Indeed, in the introduction to *Mad Matters*, the editors stated, "We represent Canadian critical Mad Studies as an emerging, and increasingly vital, field

of study and activism" (Menzies et al., 2013, p. 3). For instance, the unfolding of Mad Studies at Ryerson University and the work of its tutors and scholars reveal that it is inherently intertwined with local community action and organizing (e.g., see Landry & Church, 2016). In his foreword to *Mad Matters*, Beresford (2013) observed that the book offers hope that Mad Studies will be a discipline that determinedly connects with activism and change. Abstracted academism is unlikely to be of much use. Studies must go with practice to make up praxis (p. ix). In a similar vein, writing as a survivor researcher, Beresford (2009) has explained,

> I identify as a survivor researcher. But … I do not see myself only as a researcher. I also see myself as an activist, a writer, a campaigner and, I hope, an educator. I say this because I think that it is important to see being a survivor researcher as part of a constellation of things that I—and that we— need to do together in order to bring about change. (pp. 178–179)

Similarly, survivor researcher Wallcraft simply stated, "I am a mental health researcher and an activist" (2009, p. 132). Thus, neither Mad Studies scholars nor survivor researchers are content to interrogate or generate knowledge for its own sake, but seek for their work to hold transformative and social justice goals. Indeed, one of the key ethical imperatives of survivor research is its commitment to change (Faulkner, 2004). For instance, Webb's interrogation of the field of suicidology and development of counter-theory, based on his first-person experience of suicidality, is not just a doctoral thesis (2006) and published book (2010), but also an extensive web resource (http://thinkingaboutsuicide.org) aiming, among other goals, to reach people currently contemplating suicide and to encourage communities to engage more honestly and openly with suicidal feelings. Similarly, following on from her doctoral research, Staddon (2013, 2016) has produced theoretical papers on a social model of alcohol use while also establishing a charity to support women who use alcohol in her local area.

Both Mad Studies and survivor research also have links to social movements beyond that of psychiatric system survivors. Rose and Beresford (2009) have explained,

> Survivor research can also be seen as part of a broader development of research from a wide range of service user movements, including those of disabled people, older people, and people with learning difficulties. This research can, in turn, be related to feminist, black and community development research committed to supporting the rights and liberation of people facing discrimination and oppression. (pp. 3–4)

Similarly, Costa (2014) has stated, "The methods, and approaches for research are drawn from other educational fields such as women's studies, queer studies, critical race studies, legal studies, ethnography, auto-ethnography (again, just to name a few)." Thus, both can be located within broader sociopolitical struggles and emancipatory goals (for more on this see LeFrançois et al., 2013).

Inclusivity and Anti-oppressive Practice

A further key point of intersection between Mad Studies and survivor research is that both must question the extent to which they are inclusive, or acting in ways that prevent inclusivity, and both must confront, interrogate, and accept the racism, sexism, homophobia, and other forms of oppression that can manifest through our institutions, activities, and attitudes (see Gorman, saini, Tam, Udegbe, & Usar, 2013; LeFrançois, 2013). This is undoubtedly a difficult process. Its starting point must be an honest and self-critical reflection on the extent to which we all, as individuals and as groups, can act to prevent inclusivity and to further oppressions. As Diamond (2013) has reflected,

> It is important to recognize, acknowledge, and change the ways in which dominant cultural values are left unquestioned or unchallenged within spaces that strive to be anti-oppressive and inclusive to all psychiatrized and Mad people, even when this means examining our own ways of thinking, behaving, and relating to others in demanding and difficult ways. (p. 71)

As a working class, heterosexual white woman, I experience the privileges my whiteness and sexuality confer; I have an imperative to consider the ways in which these privileges affect my peers, my research, and particularly my research participants. This demands honest conversations, an openness to criticism, and a willingness to embrace change. It also means interrogating the ways in which my whiteness, and the whiteness of universities as institutions (where I am located), manifest through my work and interactions, and the ways in which this can operate to prevent inclusivity. In "Mad People of Colour—A manifesto," Gorman et al. (2013) wrote,

> Audre Lorde taught us that when white people don't confront their own racism, they blame people of color for "being angry." We know why we are angry. Racism, sexism, and class oppression make us angry. We know why people attack us for being angry. Guilt, entitlement, and a refusal to work with us fuel your attacks.

Rather than deflecting our guilt, entitlement, and exclusionary practice onto those who are excluded, LeFrançois (2013) has questioned why white people want to be seen as good and right:

> By questioning my relationship to the discourse of "goodness as whiteness," I disrupt it as I challenge you to disrupt your own self narratives of goodness and rightness. What is this desire to see ourselves and to be seen by others as good and right?

LeFrançois (2013) continued that through critiquing our lived experiences of the manifestation of "goodness as whiteness" and confronting racism and white privilege, we may be better able to engage in radical activism and scholarship that is inclusive, anti-racist, and anti-oppressive.

Within U.K. survivor research, Beresford and Rose (2009) have observed that much survivor research is conducted by white survivors with research by black

survivors often under-resourced and marginalized; this is despite the particular discrimination and oppression faced by black survivors within the U.K. psychiatric system. A decade ago the first review of survivor research concluded that a further review of survivor research from the perspective of black communities was needed (Turner & Beresford, 2005), yet this has still not occurred. In moving forward, it is critical that black scholars and researchers have a central and integral role in survivor research, rather than research from and with black communities being viewed or treated as a sideline or "add on" to the main activities of white protagonists. All Mad Studies scholars and survivor researchers who are white must take ownership of this. The same, of course, applies to research with and by other marginalized communities.

The Shared Lack of Resourcing

Mad Studies and survivor research are both in dire need of funding (Beresford & Rose, 2009; Costa, 2014; Jones, Harrison, Aguiar, & Munro, 2014; Jones et al., 2015). To date, there have been very few funded survivor-controlled studies, despite service user involvement being a requirement of some funders, particularly in the United Kingdom where survivor research activity tends to be concentrated. Likewise, Mad Studies operates with minimal resourcing, as Burstow and LeFrançois (2014) have observed,

> Activism and radical scholarship has worked to produce alternative knowledges, usually without research funding and certainly without corporate sponsorship, all amidst the dominance and privileged positioning of psychiatric and pharmaceutical discourse. (p. 14)

This is a crucial issue because it limits our ability to develop and progress both in terms of the knowledges we can generate but also in our thinking around the processes, parameters, and ethics of our inquires.

Survivor Ownership and the Role of Allies

While the obvious points of intersection outlined above set the scene for clear parallels between Mad Studies and survivor research, two key observations can be made. First, the extent to which Mad Studies scholars and survivor researchers work with allies varies. The editors of *Mad Matters* have written,

> We are not locating "Mad Studies" as originating solely within the community of people deemed Mad, but also as including allies, social critics, revolutionary theorists, and radical professionals who have sought to distance themselves from the essentializing biological determinism of psychiatry whilst respecting, valuing and privileging the Mad thoughts of those whom conventional psychiatry would condemn to a jumble of diagnostic prognostications. (Menzies et al., 2013, p. 2)

Thus, it can be said that Canadian Mad Studies did not stem from, nor is it "owned" by, survivors or any other group. Instead, survivors are located at the analytic core (Menzies et al., 2013, p. 14) with allies occupying an important supporting role, a role that has developed partly through the significant contributions

of critical psychiatry and anti-psychiatry to Mad Studies theorizing. Within the United Kingdom's Mad Studies Network, Mad Studies is understood as a collective of those who share a common interest in "making and preserving space for mad people's knowledges and histories within the academy and within services" (Mad Studies Network, 2014). This sense of "preserving space" for survivors conveys a different articulation of the role of allies to the Canadian understanding, as it implies that survivors are not inevitably located at the analytic core. Worryingly, this weakening of the centralizing of experiential knowledge has the potential to open the door to the co-optation of Mad Studies by allies and others.

Conversely, survivor research is at the far end of a continuum of survivor involvement in research that typically also includes consultation, collaboration, and co-production (see, for instance, Hanley et al., 2004). There are places along this continuum and outside of survivor-controlled research for survivors to work with allies, most valuably through co-produced research (e.g., Gillard, Simons, Turner, Luckock, & Edwards 2012). Within the specific context of survivor research, we might work with allies to gain research or topic expertise, for mentorship, to help secure funding, or to co-author works; but these partnerships are often secondary to the research relationships among survivors (most notably between survivor researchers and survivor participants). Crucially, this means that the parameters, ethics, methodologies, and emancipatory vision of survivor research have been generated almost exclusively by survivors (drawing on broader influences; see Sweeney, 2009), a key point of difference from Mad Studies. Yet it should be noted that survivor-controlled research is rare when compared with other forms of survivor involvement in research, and it remains true that our involvement in research is often seen as an "interesting add-on" (Ostrer & Morris, 2009, p. 80).

The Radical Potential of Mad Studies and Survivor Research

The second observation to be made is that the extent to which either Mad Studies or survivor research can and should offer a radical critique of psychiatry is currently contested in the United Kingdom. Canadian Mad Studies emerged as a site for the development and expression of critical and radical counter-discourses to biomedical psychiatry and psychopathology, forging a space for and representing "all that is critical of psychiatry" (Menzies et al., 2013, p. 2). However, the United Kingdom's Mad Studies Network (2014) recently worked collectively to produce shared principles as a starting point for discussion and to inform future work. Principle number 6 reads, "We do not seek to impose new orthodoxies on anyone, but at the same time we support critical thinking about the medicalization of madness and distress."

The varied comments on the shared principles web page reveal that the extent to which U.K. Mad Studies should challenge biomedical psychiatry is debated. Some Mad Studies scholars feel that spaces for survivors who reject biomedical models of madness and distress are few and far between; they believe that there is a need for any existing spaces to be protected and nurtured. Others fear that a focus on radical critiques of psychiatry will result in the imposition of new orthodoxies on survivors, and that this will divide us, ultimately harming the most marginalized. Survivor

research has long shied away from such potentially divisive debates by avoiding the adoption of any single model—radical, critical, mainstream, or otherwise (although it does claim to contribute to an alternative discourse—see below). To many this is a significant source of strength, as it means that all of our varied experiences and perspectives are embraced in line with the principles of the survivors' movement. However, while this is important, it has also undoubtedly hindered the development of survivor-led theories of madness and distress, with the consequence that:

> In its absence, different theories *about* us continue to be created, some of which come closer to understanding our experiences than others. We tend to favour some of these and to reject others but none of these theories have come from a systematic and thorough investigation of our own knowledge. (Russo, 2012, para. 91)

Russo (2012) provided further reasons as to why survivor researchers have failed to develop our own theoretical models of madness and distress, including survivors' resistance to the imposition of new models or orthodoxies (arising from negative experiences of psychiatric labelling); the need to focus on human rights first and foremost; the lack of independent survivor research institutes and, therefore, the lack of capacity to thoroughly investigate survivor knowledge; and the lack of resourcing for survivor research. However, she warned,

> If our accumulated knowledge is not to be appropriated by anyone whatsoever for their own purposes, then it is high time to develop our own framework … In this way [survivor-controlled research's] collective echo may become louder, stronger and impossible to ignore. (Russo, 2012, para. 94–95)

I agree with those who argue that survivors and allies need positive, dedicated spaces within which to explore our own theories about, and approaches to, madness and distress. If U.K. Mad Studies were to dilute the critical and radical focus of the Canadian approach as relayed in *Mad Matters*, it could represent the weakening or loss of an unparalleled opportunity to challenge the domination of biomedical psychiatric models through the development of our own theories and approaches. Moreover, Canadian Mad Studies is comprised of both scholarship and activism; it is difficult to envisage how activism can be maintained while biomedical psychiatry is uncontested. In saying this, I don't wish to simplify the complex and highly sensitive issues involved, nor to stifle debate, nor to encourage division. Instead, I want to suggest a need for safe radical spaces while acknowledging the complexities involved, and in the hope that we can find our points of commonality and solidarity across difference. In acknowledging the diversity of identities, experiences, and perspectives that make up Mad Studies, the editors of *Mad Matters* have considered:

> How to represent and promote this spectrum of Mad involvement, while maintaining a critical edge and resisting a decline into liberal relativism, remains a political and ethical challenge requiring resilience, reflexivity, the willingness to adapt, and a collective vision of the Mad movement as a living, and constantly evolving, field of political engagement and struggle for social justice. (Menzies et al., 2013, p. 11)

In moving toward this we can draw on Diamond (2013), who has described how people situated within three broadly identifiable constituencies of the Toronto survivor movement (psychiatric survivor, Mad, and antipsychiatry) might move toward solidarity across difference:

> Important questions to consider are: How do we react to these differences? And how do we come to the realization that these political visions can work together to serve the interests of human justice? There are no easy answers to the complex process of bringing people together; but we must grapple with these difficult questions, as everybody is needed if we are going to make changes in the direction of eliminating sanism and psychiatric oppression. (p. 73)

Diamond (2013) then proposed a new working paradigm that could enable survivors with different perspectives to find their points of commonality, foster empathy, and cultivate solidarity without compromising their own principles (see her chapter in *Mad Matters* for a full description). U.K. Mad Studies could, like Canadian Mad Studies, evolve as a radical project that seeks points of connection with other constituencies. This would enable us to protect the radical space within, while seeking commonality, empathy, and solidarity across.

Section 2: The Rationale for Fostering a Strong Relationship Between Mad Studies and Survivor Research

As I have said, I believe that Mad Studies and survivor research should cultivate a strong relationship. This is partly driven by the excitement I felt on reading *Mad Matters*—on wanting to be connected to something with such huge, radical potential—but also because of an ongoing frustration at the limits of what survivor research alone is able to achieve. In this section I propose that Mad Studies and survivor research should foster a strong relationship so that each can be reinforced by the strengths of the other.

A Counter-Discourse to Biomedical Psychiatry

A key rationale for a strong relationship between Mad Studies and survivor research is that the former gives the latter a framework through its theorized critique of biomedical psychiatry and the development of critical and radical counter-discourses. At present, survivor research tends to focus on areas that advance choice, control, and empowerment, and, to a lesser, extent survivors' own understandings of madness and distress and of survivor-led or informed support. We often—myself included—claim that collectively, our research represents a challenge or alternative to dominant biomedical psychiatric discourses (e.g., Beresford & Wallcraft, 1997; Sweeney, 2016; Wallcraft, 2009). For instance, in their seminal text, Beresford and Wallcraft (1997) described five key ways in which survivor research both subtly and overtly challenges the dominant biomedical paradigm. These are: (a) concepts of distress and crisis are used rather than mental illness; (b) social and spiritual models of understanding are favoured over medical explanations; (c) hearing voices and other devalued perceptions and experiences are seen as having a number of possible explanations, rather than being constructed as symptoms of an illness; (d) psychiatric

treatments are sometimes described as abuse or torture; and, (e) medical concepts, language, and labels are often seen as damaging and inappropriate. They then described key survivor research studies that have focussed on alternatives to dominant biomedical models: Pembroke's (1994) work on eating distress and Lindow's (1994) research into self-help alternatives. Nearly twenty years later, we can add a number of important streams of survivor research to this, such as Staddon's (2013) work to develop a social model of alcohol use and related charity and Webb's (2010) research and activism around suicide.

Alongside this, survivor research has always had an—often uneasy—focus on people's experiences of existing services. Examples of such research include Rose's (2001) work on User Focussed Monitoring, Gould's (2012) exploration of service users' experiences of the U.K.'s Care Programme Approach, and my own research into service-user-defined and -experienced continuity of care (Sweeney, 2010). Within this we may, through adopting radical or critical survivor standpoints, focus on aspects of our findings that challenge dominant psychiatric discourses (for example, my doctoral research included a secondary grounded theory analysis of the role of fear in people's lives; see Sweeney, Gillard, Wykes, & Rose, 2015). However, the primary focus is often people's experiences of, or evaluations of, the current system rather than the development of our own models or theories. Moreover, the research issue being explored has often been identified by non-survivors, for example, where survivors are invited to contribute to a larger study by exploring people's views of a particular treatment or service.

There are a number of potential explanations for this. Partly, as Beresford and Wallcraft (1997) have stated, "The psychiatric service system is unpromising ground for reform, but many survivors are held within it. It cannot be ignored" (p. 79). This means that we often research the perspectives and experiences of people within the system. While this can be achieved by adopting a radical approach from the outset, such approaches are rare beyond master's and doctoral work. This is in part because most survivor researchers currently lack the seniority to generate research bids or questions from radical survivor perspectives, and so our research is often conducted in response to or alongside a mainstream question; most often, "What about this service could be improved from the perspective of its users?" This is in contrast to the more radical question, "What about this service is causing its users harm?" Secondly, funding for any research controlled by survivors is hard to come by, even more so when the approach is radically different to or challenging of accepted psychiatric orthodoxies. This means that even senior survivor researchers can lack the freedom to explore the topics that they want to in the way that they deem most appropriate. A further reason is that our research occurs within the context of the survivors' movement which has evolved as a "broad church" accepting all people's views and models; while this has increased inclusivity and minimized conflict, it has also limited the extent to which survivor research adopts a unifying, radical vision (Beresford & Wallcraft, 1997). Consequently, we can be reluctant to conduct research or adopt positions that exclude service users who adopt a biomedical or illness model in explaining their distress or who, alternatively, may believe in conducting studies that contribute to improvements to the current system. This

means that "commitment to change" in survivor research is often broadly interpreted; albeit within an emancipatory paradigm that aims to empower survivors and challenge our exclusion from knowledge generation and wider society.

For many survivor researchers this is a difficult position to be in. We do not want to exclude or impose new orthodoxies on people who do not share our views, but at the same time, many of us (though of course not all) believe passionately in the rightness of furthering alternative models and theories based on an understanding and exploration of trauma and social causation from first-person experiences. It is easy to see then why Mad Studies holds such appeal. Rather than independent survivor research studies being undertaken without a shared unifying goal or vision (beyond empowerment), Mad Studies has the potential to offer a unifying theoretical framework that has as its central goal the critique of biomedical psychiatry and the development of critical and radical counter-discourses. It is partly for this reason that the possible dilution of Mad Studies' radical potential (described above), so that it comes to mirror the "broad church" approach of survivor research, is so worrying.

Moving Beyond Service User Involvement

In the United Kingdom, involving survivors (or service users) in research has become a requirement of much research funding; at the very least, researchers must provide justification where they are not proposing to involve survivors in their research. Arguments posed for the involvement of survivors have typically been defined as ethical and research based. The ethical arguments are premised on the fact that survivors are the ultimate recipients of psychiatry and therefore have a right to be involved in psychiatric research, particularly that which examines the experience, validity, and effectiveness of interventions and services. In addition, involving survivors meaningfully in research is said to increase skills and confidence, improve employability, enable survivors to explore the issues that are important to us and our broader communities, empower survivor researchers and participants within and beyond specific research studies, and challenge the exclusion of survivors from knowledge-making by demonstrating that we are capable agents of knowledge generation. Research-based arguments revolve around the notion that the presence of survivors in a study will in some way lead to improvements. For instance, it has been argued that research questions that are grounded in first-person experiences are better able to reflect people's realities and priorities; survivor participants are more likely to be candid in interviews to peers, increasing data validity (e.g., Clark, Scott, Boydell, & Goering, 1999); data interpretation is altered through the involvement of survivors, increasing validity, applicability, and relevance (e.g., Gillard et al., 2010); and survivors are best placed to recruit from and disseminate to survivor communities (with improving recruitment rates a major goal of much mainstream research; e.g., Clinical Research Network for Mental Health, 2014).

Many—though by no means all—of these arguments can be seen to fall within the consumerist model of welfare provision wherein the involvement of survivors and other stakeholders is aimed at increasing the efficacy and effectiveness of services and treatments, and the satisfaction of service users (Beresford, 2002). In this respect, survivor research can take an important lesson from Mad Studies. This

is because the drivers for and demonstrations of Mad Studies provide a model for conducting research beyond "service user involvement" arguments. Instead, on reading *Mad Matters*, one is struck by how much greater the demands of Mad Studies are than this. Mad Studies scholars demonstrate what survivors and allies can achieve when first-person experiences are foregrounded in critiques of biomedical psychiatry based on the right of survivors to generate and own our own knowledges. If survivor researchers—myself included—were to follow the demands of Mad Studies, it might give us greater impetus to conduct research that furthers the development of our own knowledges, rather than becoming involved in mainstream research that seeks merely to access our views of existing services. This is not to belittle the social and economic drivers behind our tendency to focus on less radical goals as I outlined above, including significant barriers to survivor research such as the discrimination operating against it, the lack of funding for it, and the lack of a quorum of survivor research leaders or of a survivor research institute (Turner & Beresford, 2005). Nor is it to undermine some of the excellent activity in collaborative and co-produced research (e.g., Gillard et al., 2012) or the vital work of, often warrior-like, survivor researchers who fully engage with mainstream and co-produced research, for all the ethics and research-based reasons outlined above. Moreover, it is not to minimize the important contributions of allies who have developed critiques of biomedical psychiatry (e.g., Bracken & Thomas, 2005; Fee, 2000; Hammersley, Read, Woodall, & Dillon, 2007), or survivor researchers such as Webb and Staddon who have developed their own counter-discourses. It is instead to urge us to generate knowledge that comes from and is owned by the survivor community where such possibilities arise, and to work to create future opportunities wherever we can.

Advancing Thinking on the Ethics and Means of Knowledge Generation

Mad Studies has the potential to offer survivor research a counter-discourse to mainstream psychiatric orthodoxies, and a model for survivors generating our own knowledges beyond service user involvement arguments. But what might survivor research offer Mad Studies? In her report of the Mad Studies stream at Lancaster University's Disability Studies Conference, McWade (2014) listed a number of questions that arose across the week including, "What are our ethics?" and "What should mad research methodology be?" (para. 2, item 2)

Survivor research has the potential to offer Mad Studies some preliminary thinking around the ethics and means of knowledge generation. Firstly, and most saliently, survivor researcher Faulkner's (2004) report entitled *The Ethics of Survivor Research*, based on research with survivor researchers, described the key ethical principles underpinning our approach:

- *Clarity and transparency*: being open and clear, particularly with participants.
- *Identity*: disclosing a shared identity with participants during the research.
- *Respect*: respecting and listening to participants' views.

- *Equal opportunities*: ensuring people from diverse or marginal communities are heard.

- *Theoretical approach*: being open about the theoretical underpinnings of the research.

- *Accountability*: clarifying the relationship between the research and wider society, and taking a sophisticated approach to accountability to other survivors.

- *Empowerment*: challenging stigma and ensuring participants' voices are heard.

- *Commitment to change*: conducting research that in some way contributes to change. (Faulkner, 2004, pp. 3–8)

To this we might consider adding *"Participation/ownership*: providing opportunities for research participants to become fully involved in the processes of the research, and in particular data interpretation, leading to a sense of research ownership" (Russo, 2012; Sweeney, 2010). Faulkner and Tallis (2009) explained that the principles in part emerged from survivors' negative experiences of being "research fodder" for mainstream psychiatric research. This "smash and grab" style of research proliferates in academic psychiatry, whereby the researcher extracts what they want from the participant in the way that they want to, with little regard for the potential impact on participants, and typically without being heard from again. It is integral to the identity of being a survivor researcher that our research in no way resembles this smash and grab. Fundamentally, this means that relationships with research participants are transformed so that they become respectful and empowering, enable people's full participation, and ultimately create a sense of ownership over the research. Indeed, Faulkner and Tallis (2009) explained that the broad aims of the principles included "to adjust [the research] relationship, to include more people in the thinking and doing that constitutes research, and to give participants more rights within an overall framework that is more respectful and ultimately more empowering" (p. 57). Ten years on, the report remains a principal departure point for discussions around ethical research practice.

Secondly, survivor researchers have progressed thinking around methods and methodologies for our research. Early survivor researchers "took their research agenda from the priorities for the movement, and developed methodologies appropriate to the questions that arose for them" (Rose & Beresford, 2009, p. 3). This tended to result in a focus on a range of qualitative and survey methods to enable exploration of first-person knowledges. We now also employ advanced quantitative and mixed methods where it is deemed appropriate (e.g., Jones et al. 2014; Rose et al., 2009; Sweeney et al., 2012). Jones et al. (2014) have argued that conducting quantitative survivor research studies can combat the notion that our research is inevitably "soft" or "subjective," or the presumption that survivors are incapable of statistical analyses (a discriminatory position that I have faced). They have further argued that without advanced statistical training, survivors will be unable to exercise meaningful decision making within many collaborative research studies. They explained,

> We ground our own call for increased quantitative academic training in the belief that the reverse "cooptation" and radical reconfiguration of "the master's tools" can in fact be a highly effective means of navigating and affecting complex power–knowledge relations. (p. 369)

Survivor researchers have developed methods that are unique to our community, at times by reconfiguring "the master's tools" (see Lorde, 1984/2007) so that traditional scientific methods come to have a participatory survivor focus. Examples include a model for generating survivor-led outcome measures (Rose, Evans, Sweeney, & Wykes, 2011), and methods for conducting survivor-focussed systematic reviews (Fleischmann, 2009).

However, the key point to be made is that "survivor-controlled research defines itself much more through its core values and principles than its allegiance to any particular methodology" (Russo, 2012, para. 24). The broad aim is to employ critical and emancipatory methodologies—using whichever methods are most appropriate— that challenge survivors' exclusion from knowledge generation and society more broadly (see Sweeney, 2009). In this sense, our research should advance the emancipation and empowerment of survivors throughout the research process and through the research output. This has strong echoes with critical theorists who describe their research as a political activity wherein social knowledge is constructed through an understanding of power and oppression:

> Critical research can best be understood in the context of the empowerment of individuals.… Research thus becomes a transformative endeavour unembarrassed by the label "political" and unafraid to consummate a relationship with an emancipatory consciousness. (Kincheloe & McLaren, 2002, p. 140)

Both Mad Studies and survivor research can also be seen as political activities first and foremost. For instance, in their introduction to *Mad Matters* Menzies et al. (2013) stated,

> By advancing a program of Mad Studies and Mad activism, we are flagging this book politically, and we are knowingly taking up a subversive standpoint relative to the governing paradigm of psychiatric "science." (p. 11)

Similarly, I have argued that adopting the explicit identity of a survivor researcher is a political statement meaning that we want to challenge dominant ideas that are about mental distress and about us (see Sweeney, 2016), while consumer researcher Roper (2016) has claimed, "Partnerships in psychiatry are political." As a consequence, the survivor research approach to methods selection is akin to that of the pragmatist who selects the method most appropriate for exploring a particular question (Morgan, 2007); but crucially, this occurs within a broader transformative emancipatory paradigm (Mertens, 2003) that foregrounds first-person knowledges. This means that survivor research has the potential to bring Mad Studies a methodological pragmatism, as well as novel approaches to the development and use of critical methods that centralize first-person knowledges, often within traditional scientific methods. Moreover, survivor research's focus on empiricism could

represent an important counterbalance to the heavily theorized aspects of Mad Studies, broadening both its potential outputs and audiences, but also its ability to make claims to truth. This is not to undermine the important research that underpins much Mad Studies theory, but to lend a greater focus to empiricism. Indeed, survivor research has thus far developed fairly narrow research practices, such as health services research and autoethnography, while the research underpinning Mad Studies is more broadly conceived, including literature reviews and analysis, storying, and law and policy critiques. In describing potential learning from survivor research for mad research methodology, I am referring to this fairly narrow definition of empirical, data-driven research. Survivor research could in turn draw lessons from the broader definition of research that has evolved within Mad Studies.

Section 3: Mad Studies and Survivor Research Within and Beyond the Academy

In this final section I explore two related issues facing Mad Studies scholars and survivor researchers: our positioning within and beyond the academy. Although I focus predominantly on survivor research (as this is where my experience lies), these are nonetheless shared issues with which our constituencies must grapple. Doing so from a position of connection may help us to navigate a path through these complexities. In describing these issues, I draw on the work of Jones et al. (2014), who have outlined two approaches to fostering greater research autonomy and control for survivors: community-owned participatory approaches and training and support for survivors within academia.

Although my focus is on two key issues, Mad Studies scholars and survivor researchers are likely to face numerous challenges as our fields emerge and evolve. While an extended discussion of these is beyond the scope of this paper, I would like briefly to raise some potential questions before moving on:

- How do we understand our (fuzzy) borders and embrace uncertainty?
- How do we nurture and protect critical and radical spaces while respecting plurality and difference?
- Drawing on Diamond (2013), how do we build solidarity across constituencies?
- How do we ensure that we have a solid base from which to grow?
- How do we secure funding for the work we believe in without compromising our values?
- Drawing on Jones et al. (2014), how do we nurture a future generation of researchers and scholars within and beyond academia?
- How do we, as survivors, relate to allies?
- How do we ensure that our work is relevant and accessible to survivors and others outside of academia?
- How do we prevent or challenge the co-optation, appropriation, and debasement of our knowledge?

- Drawing on Liegghio (2013), how can we combat epistemic violence?

For a broader perspective on key questions currently emerging for Mad Studies, see McWade (2014).

Mad Studies and Survivor Research in the Academy

Both Mad Studies and survivor research tend to be located within academia, despite the fact that very few academic institutions host either Mad Studies courses or survivor research studies. This placement within universities can bring some important advantages.[3] Perhaps most significantly, it confers a legitimacy and status that enables us to claim parity with other research and teaching faculty, particularly where we gain higher research degrees (Straughan, 2009). This means that our knowledge has the potential to stand on equal terms with that generated in the mainstream, notwithstanding the context of epistemic injustice (see Liegghio, 2013) and the academic (ab)use of survivors as material (Wilson & Beresford, 2002). As Wilson & Beresford (2000) earlier stated,

> it is almost as if service users and their knowledges are viewed as a resource to be ignored, trawled, plagiarized or co-opted in order to support academics' theorizings as and when it suits them. (p. 562)

There are also a number of important practical benefits that arise through our placement in universities, such as access to library, administrative, estate, information technology, and other resources; indeed, universities function to fully support the conduct of intensive research and pedagogy (Jones et al., 2014).

Situating Mad Studies and survivor research within academia also brings significant challenges. First and foremost, departments or research groups that fail to bring in sufficient money (most notably through research grants or student fees) are unlikely to survive the current climate of neoliberalism and austerity. This inevitably creates significant tensions as the critical and radical work of survivors and allies may struggle to be lucrative, leading to the potential dilution or concealment of our values. Furthermore, universities are excessively hierarchical institutions, as Beresford (2015) has described,

> The academy is as tied to rank as the army, with as clear a hierarchy—from temporary research assistants to senior professors. It is as discriminatory as mainstream politics, with a dearth of black women tenured professors and a growing bottom layer of low paid ancillary staff increasingly marginalized by modern outsourcing economics. (para. 2)

This culture can permeate pedagogy and research through top-down decision making that excludes the full and meaningful participation of survivors. For survivor research specifically, many of us are unable to occupy research leadership positions, as we lack the qualifications and/or relevant experiences that are typically a prerequisite for leading funding bids (Jones et al., 2014). This means that our ranking in the hierarchy of research players will be limited, with important consequences for

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[3] Of course, not all academic survivor researchers choose to work within or affiliate themselves with a university.

our ability to have an impact on research. Alongside this ranking of research players, universities, particularly the most prestigious, tend to be highly competitive, with collaborations at times precarious and political. It can sometimes feel as though the ultimate goal of research is to secure more publications in higher impact journals leading to more research funding, greater personal status, and enhanced employment security, rather than to have any real impact on people's lives. However, this may owe more to the realities of neoliberal academic life than the personal values of researchers, as Jones et al. (2014) have argued: "Incentives inherent in the political economy of the academy [force] even well-intentioned researchers to focus on the exigencies of academic publication, individual funding, tenure and so forth" (p. 362).

The drive toward more and better publications and grants can lead to a damaging emphasis on projects over people, with junior researchers (often the positions occupied by survivors) typically expected to carry very demanding or unrealistic workloads. A further issue is that universities, particularly the most prestigious, can exhibit a nervousness around survivors' voices, creating a proclivity to control and censor. This can limit our freedom to conduct the research we are committed to, using the methods we deem most appropriate; more worryingly, it can lead to the dilution or misrepresentation of our research findings (Sweeney, 2016). These issues are not confined to survivor research: Church and colleagues have described some of the challenges of Mad Studies pedagogy being managed within the university (e.g., Landry & Church, 2016).

Within this culture, it is vital that survivor researchers and Mad Studies scholars hold on to the ethics and values of our practices. If we came to mimic mainstream university cultures—that is, if we found ourselves becoming hierarchical, competitive, and disconnected from people's lives—we should, perhaps, consider proceeding no further. In reflecting on her time as an activist, survivor researcher Wallcraft (2009) has written, "I learnt that survivors can be each other's best friends or each other's worst enemies" (p. 135).

In collaborating as researchers and scholars, we should extend the same care and concern to one another that we demonstrate toward our research participants. Seeking commonality and solidarity within and across our constituencies to strengthen our relationships may further help ensure that our work is not corrupted by academic cultures.

But is this battle for an ethical academic practice worth having? Beresford (2015) has written,

> We can see the survivors who are already advancing mad studies and disability studies within universities as an advance guard of a new kind of academic. This is an academic true to the founding principles of academia—to explore and share new knowledge, while equally committed to the aspirations of new social movements to advance people's human and civil rights and challenge disadvantage and disempowerment. (para. 8)

In the pursuit of our emancipatory goals, survivor researchers and Mad Studies scholars have a right to claim our space within academia, but must do so while continuing to fight the most damaging aspects of its dominant culture.

Getting Out of the Ivory Tower

Related to our positioning within universities is that Mad Studies and survivor research can both be perceived as ivory tower academism. Similarly, "some psychiatrized people feel that antipsychiatry is, and perhaps always was, too far removed from the lived experiences of psychiatrized people, given that the constituency's roots are in part embedded in the academic and professional realm" (Diamond, 2013, p. 72).

This is a clear challenge. Survivor researchers and Mad Studies scholars should continue to nurture links between academic research, grassroots activism, and praxis, and ensure that our research and pedagogy retain transformative, emancipatory, and social justice goals. In *Mad Matters*, Reville (2013) provided an adaptable recipe for the emergence of Mad Studies:

1. Find a way into the academy.
2. Find your way around.
3. Build alliances.
4. Bring in Mad students and teachers.
5. Find your way back out into the community again. (p. 179)

Survivor researchers and Mad Studies scholars must continually seek paths back to the community. There are numerous potential ways of achieving this; and each scholar, researcher, group, department, location, study, course, and so on is likely to favour a different approach. One method is to build strong links with local survivor-controlled grassroots organizations. For survivor researchers, this might include evaluating their work; researching topics they identify as priorities (in partnership); holding meaningful information, dissemination, and consultation events; supporting or creating networks of local survivor groups to significantly inform university research and teaching activities; and building local research capacity, for example, through supporting research funding bids led by local survivor groups, training people in research skills, and offering the use of library and other resources. Another route back to the community is to conduct research studies in partnership with local and national survivor-controlled organizations. For instance, in the United Kingdom there are a number of organizations with a keen interest in research who often partner with university-based allies and survivor researchers on funding bids (e.g., Emergence; the National Survivor User Network [NSUN]). In outlining his personal approach, Reville (2013) has described delivering numerous talks in the community as well as making his work available on YouTube. Similarly, Webb's work is available on a dedicated website (thinkingaboutsuicide.org), while Staddon has taken her research work into the community through the development of new practice (see Staddon, 2016). There are, of course, many additional innovative and creative ways of seeking paths back to our communities.

An alternative approach is for survivor research to move out of the academy altogether. Jones et al. (2014) have described a number of advantages to this including: (a) a genuine shift in power relationships away from rigid hierarchies; (b) embedding research in the transformative visions of the survivor community; (c)

challenging presumptions regarding who is capable of producing knowledge; and, (d) contesting the notion that intellectual spaces are only to be found within universities. However, they have also described a number of significant barriers to community-based survivor research including: (a) the struggle for acceptance and legitimation; (b) the lack of capacity and resources; (c) the potential lack of technical knowledge, limiting meaningful relationships with external researchers; and (d) prohibitive access to funding born of a lack of credentials, affiliations, connections, credibility, or knowledge of funding streams. Jones et al. (2014) go on to describe public (open) access to research, university provision of services to the community, and the development of independent technical assistance centres as possible means of increasing the viability of community-owned survivor research.

Moving out of the ivory tower may be particularly important when we consider our ability to develop counter-discourses to biomedical psychiatry grounded in real experiences and grassroots practice. As Jones et al. (2014) have stated,

> Community-owned user/survivor research holds the potential of facilitating the exploration of, and generation of knowledge about, true alternatives to the mainstream mental health system as well as alternative conceptualizations of madness. (p. 363)

Making a related point, Menzies et al. (2013) have written,

> Mad Studies will have little meaning if it cannot offer some sense of an alternative, some measure of hope that the present can be endured and overcome. To stay relevant and grounded … is the key practical, ethical, and political challenge confronting critical scholars, writers and activists in the realm of "mental health." (p. 18)

For these reasons and many more, it is crucial that survivor researchers and Mad Studies scholars continue to seek paths out of the ivory tower.

Conclusion

In this paper, I have proposed that Mad Studies needs survivor research and survivor research needs Mad Studies. I have suggested this in part because I believe that developing a relationship between our fields could bring strengths to each. As argued, these potentially include the ability to develop and interrogate: (a) a counter-discourse to biomedical psychiatry; (b) a rationale for survivor activity in knowledge generation beyond consumerist service user involvement arguments; (c) robust ethical practice; and, (d) the development of unique empirical approaches that strengthen our claims to truth. Each of these strengths has the potential to enhance the legitimacy, credibility, and standing of Mad Studies and survivor research. This is an important issue in an age of neoliberalism and austerity, and given the under-resourcing of both disciplines (although it would be naïve to assume that our ability to claim equal access to funds is likely to be enhanced any time soon). It is important to note that there are a number of important shaping contexts for the relationship between our emerging fields, including our siting within academia and the community;the presence of epistemic injustice; and the ongoing co-optation, appropriation, and debasement of our knowledge.

This paper has been exploratory rather than definitive, with the aim of considering points of intersection between Mad Studies and survivor research, why we should foster a strong relationship, and some of the key issues currently facing our fields. The intention has been to open, rather than close, dialogue. In moving forward, there are a number of questions that collectively we might wish to consider, including: What might a strong relationship between Mad Studies and survivor research look like? Do survivor researchers and Mad Studies scholars want to develop a strong relationship? What might the anticipated and unanticipated difficulties and complexities be? Should our primary concern be facing outward—toward the community—rather than across, to other academic fields? Ultimately, the aim of considering these and similar questions is to strengthen our ability to develop and explore our own theories and knowledges about madness and distress in a scientific and cultural climate in which biomedical psychiatry rules.

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