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THE INTERNATIONAL FOUNDATIONS OF MAD STUDIES

Knowledge generated in collective action

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Introduction

Besides contributing my own experiences and reflections on international activism in the mental health service user/psychiatric survivor movement through this chapter, I have also attempted to bridge the other contributions in this first section of the book. As editors, we want to demonstrate the centrality of political organizing of people with psychiatric experience in the emergence and further development of Mad Studies. The chapters that follow document different starting points and various directions of advocacy and political struggles of people who come together and organize themselves most often under the name of survivors of psychiatry or people with psychosocial disabilities. These accounts chart a non-unified, diverse movement and provide a range of standpoints. Operating under different socio-political circumstances, emerging at different points in time and with different priorities and terminologies – what all organizations and networks clearly have in common is their struggle for human rights. But there is also another, less explored aspect that I wish to focus on: the process of joint knowledge making that takes place alongside mutual support and political action. This way of generating knowledge is neither purposefully initiated nor represents an end in itself. Similar processes transpire in emancipatory and liberation movements that preceded the formation of Women, Black, Queer or Disability Studies. The constantly expanding and diversifying knowledge base realized by people who come together around a specific social justice issue is also key to understanding Mad Studies as activist scholarship that started long before the term Mad Studies was coined. The vast and collective body of knowledge assembled by people deemed mad themselves endures, deepens and grows regardless of its official recognition. Or as Brenda LeFrançois puts it:

Mad Studies […] takes place within or without academia, but never without community.

(2016: v)

I would add that Mad Studies also takes place with or without being named Mad Studies.
In this chapter, I explore some features of knowledge formation that I think are foundational for Mad Studies. In the first step, I describe the entry points and the geographies of the organizations I personally joined and my own processes of becoming that were taking place within and outside of those organizations. The remainder of this chapter describes the way I see the link between Mad Studies and our diverse political organizing and why I think that Mad Studies can (and should) do what our movements have not been able to.

Movements as a place to be

It is commonly being said that movements are made up of people. Less is being said about the ways in which movements also make us as people. That includes both those great as well as those not so great experiences and encounters which shape our background and become part of who we are. Like many other activist-authors I cannot write about our movement without writing about myself and my own commitment. The intimate link between our own lives and our political work and the impossibility to separate the two seems to be at the heart of all social movements as powerfully described by Alicia Garza, a co-founder of Black Lives Matter:

We inherit movements. We recommit to them over and over again, even when they break our hearts because they are essential to our survival.

(2020: xiii)

The first political group I joined was a feminist group at the Student Cultural Center in Belgrade, my home town in former Yugoslavia. I was 22 and my first forced psychiatric hospitalization and treatment were already behind me. As this was the only women’s group in the city at that time, the obvious focus of our work was violence against women. And even though we were welcome to share our own experiences under the slogan ‘personal is political’ I could only partially share mine. The mysteries and chaos of ‘personal’ somehow could not fit the clarity and straightforwardness of the ‘political’. The prevailing activist narrative did not really leave room for the option of becoming broken or losing one’s mind. This was acceptable for those ‘other’ women that we were supposed to support in sisterhood or theorize about. But the unspoken expectations of the ‘feminist self’ quickly made me understand that my own account of violence needed to be limited to a certain point and that I should keep its real ending for myself. There was some understanding of psychiatry as part of ‘patriarchal’ regime, but the actual personal experience of being diagnosed and forcibly treated was something better left undisclosed. Years later in the course of my employment as a counsellor in a shelter for women and children survivors of domestic violence in Germany, I faced similar impossibilities and saw how ‘political’ can edit or simply filter out parts of ‘personal’ that overwhelm and upset the ‘cause’ for which we have come together. I do not mean to undermine the sense of belonging and purpose that I found in women’s groups and organizations, but often I felt limits and longings wonderfully described by Dorothy Allison when she writes about sexual abuse:

Behind the story I tell is the one I don’t. Behind the story you hear is the one I wish I could make you hear.

(1995: 39)

Discovering and joining the psychiatric survivor movement came as a huge relief to me. Nothing seemed so mysterious and chaotic anymore that it couldn’t be shared, understood but also tolerated and sometimes even carried together. That instant easiness and normality
that I felt – if I may at all use such word in this context – opened up worlds for me. The first organization I joined was the European Network of (ex)Users and Survivors of Psychiatry that I am still an individual member of. What followed are almost 30 years of meeting different people, having all kinds of encounters and exchanges, including very intense and close ones. Even though constrained to one continent – the European Network was a meeting point of considerable differences in the early 1990s, probably more than today. One difference that I vividly remember was between Western and Eastern Europe, which then gradually dissolved with the political and economic changes that followed. The fact that my entry point into the movement was not local meant that from the very beginning I could see my personal experiences in a much broader framework. I didn’t have a cultural context to share and not even a common language. After all these years, the situation remained pretty much the same for me, meaning that I am always in a position to focus on other connections, sometimes very far away from historical and other circumstances in which I grew up. I can’t say that it was difficult to find such connections internationally. Intra-nationally though, things felt rather different. My immigration to Berlin accompanied by the struggle for residence and work permit turned me into a second-class citizen. In local survivor organizations I found myself part of an almost non-existent minority group within dominant German culture and among native speakers. I could share my experiences of madness and psychiatry but not the kind of acute existential struggles that I was going through. Those struggles lasted for several years and got their happy ending at some point, but my ‘comrades’ could not really relate to how that situation was affecting my mental and emotional state. In this matter I received far more understanding and support from my colleagues in the previously mentioned shelter where I worked. They didn’t know about my psychiatric history, but they knew the troubles I was going through as the majority were migrants themselves. Obviously, no matter how politicized each of these spaces was, there were always unspoken norms that encircled the realm of familiar and imaginable and ruled communication. I will later come back to this phenomenon and its implications for Mad Studies.

My involvement in the German survivor movement continues in different ways and with some breaks, but international settings still remain the most natural and comfortable for me. It is almost as if places without a particular geographical location offer me more grounding and feel more like actual places to me. Perhaps this comes from the coincidence that my discovery of the survivor movement and joining the European Network happened soon after the war broke out in my country. In the course of my first years as a member of the Network, Yugoslavia was falling apart while I was gradually building my psychiatry-free life elsewhere. Looking backwards, I can clearly see how international survivor activism actually offered me a home and helped me build that life. More than simply giving me somewhere to belong to when I was kind of displaced in every sense, the survivor movement also became the most important learning place for me. That ongoing learning is unlike any education I have received so far, including my latest degree in the field of Mad Studies. Yet certainly, things were not only cosy and rosy and this chapter will not turn into a love letter to the survivor movement. There were too many arguments, hurts, divides and bitter lessons learned as well.

My experiences of ‘international’ are confined to the organizations in the Global North. Here I do not mean personal contacts only but also published sources and older movement documents from those parts of the world. I have had encounters with activists from Asia, Africa and Latin America, but to a much lesser extent and much more through learning about their work than through actually working and thinking together. It seems to me that despite an always growing number of means to communicate and overcome geographical distance we are not really coming closer. Sometimes it feels that we are even falling further apart. When I read
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how Alicia Garza says that “[m]ovements are the story of how we’ve come together when we’ve come apart” (2020: xiv) – I wish our movement were such story. On local and sometimes country levels – it might be the case; globally it isn’t, with the exception of a few episodes of successful international action. This is of course just the way I see it. Coming together across geographical and other borders takes time, above all to listen and get to know each other and understand each other’s realities, if possible without applying one’s own cultural, political and other lenses. That is easier said than done in the speedy and profoundly divided world we inhabit.

But even though being aware of many limits and weaknesses of our political organizing at all levels, I cannot objectively judge the movement that has given me a home for many years or distance myself from it by any kind of rational decision. Distance grows with time and by getting closer to people whom the movement didn’t really offer a home and by understanding why that was. Distance also grows as I keep finding other connections and more ways to be and intervene in the world. Still, I cannot write about survivor activism from an unengaged place or as if it weren’t part of myself. I can also not criticize it as if it were a foreign body or without seeing my own doings as part of its many failures. To me, Mad Studies means a continuation of activism and political work that deepens and shifts that work to another level and entails a valuable chance to address the limits and failures inherent in many social movements. Mad Studies has the potential to stop us from falling further apart and help us connect on a different ground.

Overcoming single-issue politics

The most common failure of many social movements is their single-issue struggle, as famously expressed by Audre Lorde (1982). Here, the survivor movement is no exception. One reason for sure is ‘strategic essentialism’ (Voronka, 2016) exercised in many organizations by virtue of pushing forward one type of discrimination and oppression at the cost of all others. As we know, identities built around one form of injustice and the enactment of a collective self-definition are powerful emancipatory acts that can become a force to drive social change. But as we also know, such collective identities inevitably create a deadlock: they are never big or suitable enough to capture the many layers of social experience and therefore prove incapable of addressing them. The limitations inherent to identity politics commonly result in agendas that appeal to and are owned by the dominant groups within movements. Social justice movements can become places of injustice that create their own ‘others’. The second-waves of the feminist and the disability movements made that clear. Mad Studies holds the potential of being such a second wave, hopefully strong enough to revise and enhance the agenda of political organizing that began in response to psychiatric oppression. As contributions in this section show, that oppression operates differently across the globe: in places where psychiatry is just one among a number of institutions of colonial heritage, the movements unite around other, more pressing issues and kick off with broader agendas for change (see TCI Asia Pacific as well as contributions from Bhargavi Davar, Brenda Valdivia and Daniel Mwesigwa Iga in this section). Mad Studies opens up avenues to contextualize and de-center psychiatric oppression and avoid dead-end roads of identity politics.

Having said this – and even with the ‘mad’ adjective – Mad Studies does not imply embracing mad identity. For many contributors in this book and beyond, including myself – identifying as mad is not an option. It is important to remember this distinction for want of a better word and in the meantime not to confuse Mad Studies with the Mad Pride movement (see
Chapters 33 and 34 by Prateeksha Sharma and Colin King for deeper consideration of this critical issue). The human rights activist and author, Tina Minkowitz, points to the traps of ontologizing our experiences of discrimination or in other words – turning those experiences into who we are:

Paradoxically in naming the discrimination and calling attention to the needs there is a risk of a discriminatory, violent, and objectifying response, an essentializing of our identity that diminishes our full humanity. This is the challenge faced by every equality seeking movement and it is not the end of the story but, rather, is an ongoing call for humanity to grapple with injustice.

(Minkowitz, 2014: 131)

In another text that offers a comprehensive outline and discussion of different identities that emerge in relation to psychiatric experience, Minkowitz (2020) concludes that “we don’t need a complete theory of identities, we need theory that is useful for the purposes at hand”. Without this demand to serve a particular purpose and as a knowledge-making project, Mad Studies does not require the kind of strategizing typical of political action. This gives us an important opportunity to take a break from focusing on what is useful and invites us to further explore and get to the core of those uncomfortable and impractical questions that (we think) pose a threat to our collective action. This kind of joint effort could expand our understanding of political beyond claims for legal equality and help us develop a sense of togetherness that does not cement our relationship with psychiatry. I don’t mean this as a call to ‘overcome’ and ‘get by’ with experiences that determined us in so many ways. I mean this as a call to foster our ability to see, feel and act beyond those experiences rather than wed ourselves and our politics to the version of injustice that we were personally subjected to. On an individual level this means that if we are to re-write the stories of our lives, we need to break free not only from demographic categories that position and arrange us in the world but also from categories of our experiences that are making us into less of who we are and can be. After all, psychiatric experience is just one such category. However intense our encounters with psychiatric regimes are, however decisive for our life trajectories and no matter how central to our political organizing, the exclusive focus on psychiatrization remains insufficient and inadequate to understand the world we live in, let alone change it. This doesn’t mean that our movement does not matter or that our struggles for fundamental freedoms and human rights are outdated. Unfortunately, far and wide that is not the case. But it means that we can do more and do better and that Mad Studies might help us to move that way.

The words of Eli Clare, a queer disability activist and author vividly illustrate how none of us “leads a single-issue life” (Lorde, 1982):

Gender reaches into disability; disability wraps around class; class strains against abuse; abuse snarls into sexuality; sexuality folds on top of race … everything finally piling into a single human body. To write about any aspect of identity, any aspect of the body, means writing about this entire maze. This I know, and yet the question remains: where to start?

(Clare, 2015: 143)

Rather than having to prioritize any of these aspects, doing Mad Studies means freedom – and also responsibility – to start from nothing less than precisely that entire maze.
Situating first-person knowledge

Our movements are places where first-person knowledge or knowledge coming from our many experiences gets articulated, exchanged and gathered. This is more than sharing personal experiences. It is a joint process of making sense of the experiences that are commonly being psychiatrized and pushed into social exile; it is a process of legitimizing those experiences, giving them a status, finding a language to communicate them. The movement did not come up with any unifying theory of madness but it brought about many viable and sustainable answers on how to respect human crises and respond to them:

We may gain understanding from each other but no one should assume that we are all the same; that we react the same, experience the same and that the same things work for us. Being a mental health service user, in both positive and difficult senses, really is about the difference and the fact that we are all of us as human beings different.

(Beresford, 2010: 10–11)

In the course of many years of coming together, supporting each other and organizing we not only resolved many individual situations, we also found some important answers to broader questions faced by the societies we live in. We developed ideas, concepts and practices that profoundly challenge the ‘scientific’ evidence base, as well as conventional evidence and policy-making about us and our lives. Our movements gave birth to approaches and methodologies that are just and better suited to understand and respond to what is being diagnosed and treated as mental illness or perceived as madness. Though integral to political activism, these underpinning processes of joint knowledge production are often not recognized as legitimate epistemic practices.

In his outline of the history of the Japanese movement, Naoyuki Kirihara (Chapter 9) describes (successful) action against an amendment of the Japanese Mental Health Act that intended to further restrict the human rights of people with psychosocial disabilities:

We concentrated our biggest efforts on developing theories to oppose the Bill.

(000)

This is one of rare accounts that actually mentions theory building as part of political action. The intellectual labor that takes place as a matter of course in many groups and organizations is commonly not associated with theoretical work. This certainly has to do with our internalized institutional views about what such work looks like and who is designated to perform it. However, there are also powerful mechanisms in place that actively exclude our collective knowledge from the realm of social science. In her essay “Theory as Liberatory Practice”, bell hooks (1991: 4) describes devaluation and marginalization of certain types of knowledge as practice that serves to establish the academic notion of ‘theory’:

It is evident that one of the many uses of theory in academic locations is in the production of an intellectual class hierarchy where the only work deemed truly theoretical is work that is highly abstract, jargonistic, difficult to read, and containing obscure references that may not be at all clear or explained.

Rather than theorizing from ‘academic locations’, the processes of knowledge generation within political movements are situated in lived realities of their members. First-person knowledge
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does not emerge in an attempt to mirror different realities or come closer to social worlds in order to understand them better. Coming from within the reality that it seeks to understand, first-person knowledge has a different grounding and enables different epistemology than knowledge coming from any third-person, outside perspective. Kate Millet actually uses the term ‘reality model’ when exposing the wrongfulness of medical theories about us and our lives:

In other words, life is very difficult: death is hard to endure, bereavement, the death of love, love’s labour lost, hard economic times, lost employment, lost opportunities, the embittering frequency of every form of disappointment in life. This is a reality model, built upon reality. The medical model, on the other hand, is not based upon any reality, nor is it medical, though it uses the prestige of physical medicine and the reality of physical disease to mystify us and to command a general social consent, lay or legal.

(Millet, 2007: 32)

The value of insider perspectives in knowledge-making is attracting more attention in some fractions of social and even medical science that seek to involve multiple voices and come closer to lived realities that they study. But typically qualified as subjective, first-person perspectives are not seen as valid, self-sufficient knowledge-making locations. Such status is also commonly denied to perspectives from the first-person plural that are at the heart of political organizing: while they cannot be dismissed as subjective, our perspectives are being qualified as biased and over-involved. Collective first-person knowledge by its nature is in sharp contrast to academic dis-engagement, individualism and the competitiveness of social science. This incompatibility of jointly and horizontally (non-hierarchically) assembled knowledge with the academic notions of authorship and scientific ‘discovery’ is familiar to other scholarship that began outside of the ‘ivory tower’. In her above-mentioned essay, bell hooks (1991: 3) writes that “the production of feminist theory is complex, that it is less the individual practice than we often think and usually emerges from engagement with collective sources”

Movements are collective endeavors and so are their respective knowledge-making processes. The collective bodies of knowledge they produce involve the powerful fusion of ideas, histories and wisdom passed on among many different people, places and generations:

Movements do not have official moments when they start and end, and there is never just one person who initiates them. Movements are much more like waves than they are like light switches. Waves ebb and flow but they are perpetual, their starting point unknown, their ending point undetermined, their direction dependent upon the conditions that surround them and the barriers that obstruct them.

(Garza, 2020: xiii)

Knowledge gathered in organizations of psychiatric survivors and people with psychosocial disabilities comes as a result of many conversations and thinking together in order to act upon the issues that concern us. As distinct from places of education where people come to receive knowledge – our movements are places where people contribute their knowledge. Based on the initial premise that everybody has valid knowledge, we focus instead on what we can do with that knowledge, with what we know together. Knowledge making within movements is inseparable from acting upon what we know and this proximity between the two is very different from reserved and hesitant evidence-making patterns of social science. Mad Studies has therefore inherited considerable disillusionment in conventional and particularly in medical science and a lot of justified distrust in the notion of a knowing ‘expert’. If it is to stay true to
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its own self-conception of ‘activist scholarship’ (LeFrançois, 2016) Mad Studies must be careful about not turning into another third-person enterprise, that takes on the role of knowledge making about ‘others’. Mad Studies has good prospects to insist on the fact that everybody has ‘lived experience’ and that in that sense there can be no such thing as ‘us’ who know (better) as opposed to those (‘others’) whom we study. Building on the knowledge making traditions of our movements, Mad Studies opens up a space for each and every one to join knowledge production precisely from where and who they are.

Taking responsibility for our collective knowledge

In her essay “Mad Studies – What it is and why you should care”, Canadian activist and author Lucy Costa (2014) powerfully invites everybody to become part of, but at the same time not take ownership of, Mad Studies project:

Mad Studies has grown out of the long history of consumer/survivor movements organised both locally and internationally. [...] Together, we can cultivate our own theories/models/concepts/principles/hypotheses/ and values about how we understand ourselves, or our experiences in relationship to mental health system(s), research and politics. No one person, or school, or group owns Mad Studies or defines its borders.

At the time of writing, seven years have passed since Lucy Costa wrote this. In the meantime, the term Mad Studies has become more well-known and is branding itself inside and outside university courses. This also includes approaches to Mad Studies as an academic field that is by default separate from activism and at the most just seen in historical connection with our movements. I will come back to these developments in the afterword to this collection. Here I wish to focus briefly on the question of (non)ownership.

The fact that the vast body of knowledge of people deemed mad is out there, at everybody’s disposal certainly makes that knowledge an important and accessible emancipatory source for many. But it also readies that knowledge for distortion and co-optation of different kinds. We can’t pretend that we haven’t already witnessed and analyzed such developments (Costa et al., 2012; Penney and Prescott, 2016; McWade, 2016; Fabris, 2016). The truth is that our collective achievements are not being collectively owned. This means that the ideas and practices that we develop, continue to be detached from the contexts in which they emerge and disentangled from their original meaning and intention. The destiny of our collective first-person knowledge largely depends on those who make use of it. Putting a Mad Studies or any other kind of label on that body of knowledge will certainly not stop such projects. Also, collective ownership is still an uncommon concept and not easy to establish in the type of world we live in. But if we are to disrupt the long tradition of erasure of knowledge of people deemed mad, then we might begin thinking about taking more responsibility for what we know and what generations before us have assembled. By this, I don’t mean ‘defining borders’ or any bureaucratic act of ‘sealing’ ownership. One of the best features of our collective knowledge is its resistance to definition and control and the ability to always find itself anew outside such ambitions. What I mean is taking on the task of building on that knowledge base independently and regardless of the momentary agendas and currencies of psychiatry and mental health that surround it. Taking our knowledge responsibly means engaging in complex tasks of researching, connecting, extending and deepening the international pool of knowledge created by people considered
mad or disordered so that it gradually becomes more and more difficult to turn that knowledge into something else. I am aware that this implies a continuous battle on an extremely uneven playing field. What we are dealing with are not differences between perspectives and schools of thought. We are dealing with the systematic epistemic erasure that has lasted for centuries. The forms of epistemic injustice (Fricker, 2010) differ according to the historical epochs in the ways societies and their ruling regimes (mis)understand and approach ‘madness’. These traditions range from active silencing, ignorance, belittlement, re-interpreting, overwriting, appropriating up to the level of issuing glossy invitations to ‘co-production’ or subtle remaking of ‘survivor-control’ into ‘consumer-leadership’. It is without a doubt that these developments will continue with always more sophisticated methods but it makes a difference whether we stand in their way or seek to make some profit from what is on offer. In practice this is hardly ever a question of either / or and many times we find ourselves trying to do both. I am certainly not positioned to suggest any universal ‘right’ or ‘wrong’ but have a sincere hope that Mad Studies provides space in which we can leave the exhausting and risky subversion labor behind us and turn to further exploring, diversifying and deepening our first-person epistemologies to see where that will lead us. Indian activist and scholar Bhargavi Davar uses the powerful metaphor of unveiling when calling for our own responsibility towards alternative knowledge that is already there:

I think that it is important to open the veil created by medical professionals in mental health, and look what else is already there. Otherwise, we tend to become the perpetrators who we are opposing. We ignore who they ignore. We repeat their rhetoric. We become victims of ourselves. That oppression is more difficult to combat.

(WNUSP, 2014: 12–13)

Concluding remarks

Reflecting on my own experiences and personal learnings, I have attempted to explore in this chapter the processes of knowledge making that take place alongside activism and political action. Overshadowed by those more-pressing-things that movements are all about and by not corresponding to conventional understandings of ‘intellectual labor’ as well, knowledge-making traditions within movements of psychiatric survivors and people with psychosocial disabilities often go unnoticed. Generally, the ideas and concepts that we develop attract more attention than the joint knowledge-making processes that underpin them. However, the latter are the key to understanding Mad Studies and the potential contribution of this field. I have tried to highlight both the emancipatory aspects of these processes as well as their limitations and weaknesses, arguing that Mad Studies has a good chance of addressing these and moving collective knowledge making to another level. Most importantly, I hope I have demonstrated how the organizing of psychiatric survivors and people with psychosocial disabilities is central to Mad Studies and that this connection is not just a thing of the past. In my view, Mad Studies carries on the movements’ work without the constraints and beyond current political agendas, including our own. It is about valuing and deepening our own knowledge and continuing to learn from each other as well as from other liberation movements and scholarship. It is not so much about where we get to exactly in our different contexts but more about how we get there and who we become on the way. Our knowledge should of course keep traveling in all possible directions while Mad Studies and collective action remain organically intertwined. Different in their scope, both of these projects belong together and can only improve and strengthen each other. It is the responsibility of all of us to keep this link alive and mutual.
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Notes

1 This is a term used in the organizations that I was personally involved with. I often use the shortened form ‘survivor movement’ to express my own preference and affinity. None of the terms I use are meant as any kind of universal umbrella expression to subsume political organizing and stances described by other contributors to this book.

2 TCI Asia Pacific stands for Transforming Communities for Inclusion of persons with psychosocial disabilities – Asia Pacific. See more at https://www.tci-asia.org/

3 Besides oral histories that are kept alive within our respective movements there are also a number of written sources ranging from personal accounts, anthologies, newsletters and archives to research reports and conceptual work. What is considered to be the first written document of political organizing of people deemed mad dates back to 1620 (The Petition of the Poor Distracted People in the House of Bedlam). See the Opal Project (2007) for many more documents.

References
