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# ‘Madness’ and Activism in Ireland and Scotland, a Dialogue

**Lydia Sapouna* and Anne O’Donnell**

## Abstract

Anne O’Donnell and Lydia Sapouna, based in Scotland and Ireland respectively, are activists and writers who have made long-standing contributions to the debate about mental health and recovery. In this dialogue they exchange analyses of the achievements and lessons to be learned from mental health activism that has resisted dominant narratives of mental illness and that has created innovative, collaborative and critical spaces for the exchange of ideas, experiences and enthusiasms. The dialogue seeks to evoke the distinctive styles of activism adopted in each context, the successes engendered and the kinds of dilemmas and tactical choices navigated. Ann and Lydia have initiated a process of reflection and exchange, and out of this they have constructed a dialogical piece that highlights key organisational issues for mental health activists and for community based social movements more generally.

**Keywords** Madness, activism, user/survivor movement, co-option, power

## Introduction

This conversation between a psychiatric survivor-activist and an academic-activist is focused on spaces and voices of resistance to the dominant biomedical mental health systems in Scotland and Ireland. We discuss the achievements and lessons to be learned from challenging narratives of mental ‘illness’ and from creating innovative, collaborative and critical spaces for the exchange of ideas, experiences, concerns and enthusiasms.

Through our initial correspondence we found that, despite our different backgrounds, we share similar values and perspectives on what we see as the politics of human distress and the mental health field. Furthermore, we are both strong advocates of meaningful user involvement in mental health.

We were therefore a bit concerned that all we would do when we did meet in person was to agree with each other, and that our conversation might be rather limited. We were wrong! We

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found that what we shared was very interesting in the context of different countries, backgrounds and current positions. This paper is based on our conversations in Edinburgh in June 2016. We identified shared tensions in our different positions, together with concerns and struggles to stay engaged with the movement in our respective contexts. These key themes form the basis of our paper.

**Positioning ourselves**

**Anne**: I left Ireland in 1988, aged 22, to live in London and then in 1993, I moved to Scotland permanently. I have been active in the mental health service user movement since 1994 when I first started using mental health services. Because I had some previous experience of political activity, it made sense to me to join with others who had experience of distress and mental health service use. That led to studying community education at Edinburgh University. More recently, I have become very active in the new field of Mad Studies. I currently work as a coordinator of a mental health, advocacy and recovery education project.

**Lydia**: I grew up in Greece during the post-dictatorship era, with 'the personal is political' as a key feature of my formative experiences. I did social work training in Athens in the late 1980s, the time of the so-called psychiatric reform in Greece which was fueled by the exposure of the horrific conditions at the Leros Asylum in 1989. I think the sense of shame and discomfort many of us experienced during that time has set the foundations to frame mental health care in political and human rights terms. Inspired by the work of Franco Basaglia and the links between the Italian psychiatric hospital closure and wider social movements (e.g. students and trade unions), I developed a keen interest in de-institutionalisation. When I moved to Cork, Ireland, in the early 1990s to do postgraduate research in this area, I was surprised to find that 'community' mental health policy and practice evolved, both geographically and ideologically, in institutional settings. For the past twenty years I have worked as a mental health educator in University College Cork (UCC), trying to promote critical thinking and practice skills for working with human distress.

**Anne:** So how has it been for you, as an academic training mental health workers on one hand and on the other, being someone who sees things in political and human rights terms?

**Lydia**: I would like to describe myself as an activist/academic but I am not sure how genuine this is! I struggle with managing the ongoing tension between my commitment to social justice and the expectation to prepare students for practice in a predominantly biomedical and

often coercive context. Developing systematic links with service users/survivors, advocacy groups, campaigns and like-minded professionals, has provided me with resources to think and practise outside the box. Such coalitions created possibilities to develop critical spaces both inside and outside the University within which to consider mental health practice. This has been an eye-opening but also unsettling journey.

**Anne:** So why is this unsettling?

**Lydia:** I increasingly position myself as an ally of the mad community, often at the expense of my academic or professional identities, whatever these mean! However, I am not a member of the mad community myself. While I have been through tough times, I haven't used mental health services. Kathryn Church's (2011) description of her position between the survivor community and the academy as 'familiar with both but uncomfortable in both' resonates deeply with me! So maybe it's about making the best of this position?

**Anne:** I have my own experience of similar discomfort, as I am a survivor activist, still dealing with mental distress, as well as being a paid worker in the advocacy organisation through which I have channeled most of my activism. It can be difficult to manage the different ways I am pulled as a worker and as an activist. The survivor community isn't homogenous - a view from outside is that I should be part of that community. I feel at home there but I also feel unsettled because some of my ideas are at variance with those of a lot of people in the movement. Of course my ideas have shifted and changed over time. So as you say, it's about making the best of this position by acknowledging the discomfort. By speaking about these tensions, we know we are not alone and we are better able to think critically together.

**What is happening in Ireland and Scotland?**

**Anne**: When I left Ireland, I had no sense that people with mental health issues were organising. So what has been happening?

**Lydia:** Indeed, the mental health user/survivor movement is a relatively recent development in Ireland. Up to the late 1990s most mental health groups were primarily consumer or patient organisations, concerned with self-help, resources and funding for services, and more recently with anti-stigma campaigns. The origins of the user/survivor movement can be traced to the Irish Advocacy Network (IAN) in 1999. IAN, a peer-run organisation, secured government funding in the early 2000s to provide peer advocacy in inpatient settings. Through IAN, peer advocates also make contributions to policy and management groups,

research and education. Overall, in the 2000s we see an increase in user representation in Ireland as a direct result of government policy through, for example, the establishment of consumer panels and the *Office of Service User, Family Member & Carer Engagement*. On the other hand, during the 2000s more grassroots groups such as MindFreedom Ireland and Madpride Ireland emerged, articulating a strong critique of human rights violations in psychiatry, highlighting the harmful effects of Electro Convulsive Therapy (ECT), psychotropic medication and forced treatment. More recently, in 2010, the Critical Voices Network Ireland (CVNI) was developed as a critical space to promote ideas and practice for a user-run democratic approach to human distress.

**Lydia:** My impression is that there is a stronger sense of collective action in Scotland. Can you tell me a bit more about it?

**Anne**: Well, the service user movement here in Scotland began in 1971 with the Scottish Union of Mental Patients (Roberts, 2009, p.16) but it didn't really take off until the late 1980s and early 1990s (CAPS, 2010). Care in the Community policy meant that service providers needed to consult with people using those services but, at the same time, people were gathering to share experiences and demand change. This meant there was some funding available for user groups in Scotland, so user-led organisations like CAPS, an independent advocacy organisation in the Lothians, and the Highland Users Group started. The earlier groups usually included people active in other movements and in political parties, so they had a sense of politics and of collective action. Scotland as a whole does pride itself on how collective minded it is. But this isn't always a good thing. For instance, there is a popular belief in the consensual nature of politics in Scotland which is much praised as being enabling and inclusive, especially in comparison with the more divisive practices of the UK government. But this can mean that a lot goes unchallenged. I think it explains why a lot of the time the service user movement in Scotland focuses on improving and extending services and not on direct challenges to psychiatry or to structural causes of mental ill-health. There are individuals who do critique psychiatry, they're just not part of the main discourse. We are on the whole cautious and we are also under-resourced. I think we should be demanding more from the state but that always comes at a cost! It's a problem common to most social and political movements.

**Lydia*:*** This is a very interesting observation. In Ireland also many mental health groups campaign for more resources, particularly as mental health services have been significantly disadvantaged during the recent recession, and consequent health sector cutbacks. But resources to do what? A preoccupation with lack of resources fails to see that the main

problem lies in the current service culture, and entrenched power imbalances between professionals and service users within mental health institutions. I think Sedgwick's (1972) work on psychopolitics is very relevant here. We need to take a political position about what type of care is needed rather than merely advocate for more resources.

**Anne**: Sedgwick has argued that 'the exclusion of mental health users from society can only be rectified by transforming the social, political and economic structures of late capitalism' (in Thomas, 2016, p. 7). However, while a lot of seemingly radical groups are against psychiatry, they don't necessarily appreciate or critique the wider political and social context.

**How political are service user groups?**

**Anne**: So from what we've been discussing, despite the differences in our respective contexts, we can see some key things in common in the service user movement. For example, the focus being either on service provision and funding on one hand, or on critiquing psychiatry and medication on the other, especially in Ireland. However these are not necessarily political positions.

**Lydia**: Yes, I think there is a lack of explicit political positioning within the Irish user/survivor movement. To make sense of that we need to look at the Irish context. In Ireland, as elsewhere, the user movement grew out of dissatisfaction with a system where people felt oppressed, voiceless and coerced. As Ireland has a strong institutional tradition, and the biomedical approach is still the dominant practice, we have a very powerful critique of biopsychiatry articulated by individuals and groups. This critique is focused on the overuse of medication, the damage caused by medication, forced treatment and specifically ECT, which can still be administered involuntarily once an individual is deemed 'unable' to consent by two consultant psychiatrists. Over the past fifteen years, people have come together in conferences and other community events, to share moving and powerful individual stories and experiences and generate a strong critique of coercive psychiatric practice. In these spaces some individuals have emerged as particularly 'gifted' in providing both inspiration and leadership. It is important however not to miss the voice of the less confident (and, as a result, less articulate) people in this process.

**Anne**: What about the voices of people who are saying things which are more critical, because they directly challenge people and structures?

**Lydia**: Often such voices are discredited as 'trouble-making' or just a 'rant'. This may be partly due to our limited capacity, or even limited knowledge-base, to do something

constructive with the discontent people experience. It is important to move towards a more collective storytelling, which incorporates a stronger political message beyond merely critiquing psychiatry and medication, thereby creating a context where critical voices can be more influential. The challenge is to build capacity to develop communities that are more active in promoting alternatives, in promoting hope, in promoting collective action. I suppose we need to start asking more questions about all forms of power, not just the power of psychiatry.

**Anne**: Ranting is necessary; certainly it was people getting angry who claimed the spaces in the first place! But ranting on its own is not enough - where does the analysis and the action come from? Maybe people don't feel that need or it's too difficult to do that. People don't have the capacity yet maybe because you can't just develop that capacity on its own. It's kind of an education thing! You need it around you, you need to be exposed to ideas, you need to be able to have discussions and you need to have your skills developed and that's again where a community development approach is crucial.

**Lydia**: I think community development can be very useful in making sense of power operations. It can help us develop an understanding of power distribution and provide a framework to claim power for a more democratic system of mental health care. However, we need to be careful not to reduce it to a technocratic intervention, a 'tool' for the development of services in the community without taking a critical stance towards service provision.

**Anne**: Having studied community education has given me ways to understand power and the dangers of progressive ways of working being co-opted into what you call technocratic interventions. I like that maxim, 'you start where people are at but you don't leave them there'; and the promise that every interaction is an educational opportunity for both the educator and the individual or group you're working with.

**Lydia:** So do you see a role for theory in all this? Very often activist groups take a rather hostile stance towards theory; what's your experience?

**Anne**: Yes, theory is crucial yet many people distrust it. But without theory, you act without thinking things through. Theory for me has been a guide and a tool for understanding what might be going on. The most relevant theory for us has been the *Powercube* (Gaventa, 2006) and especially how Liz Brosnan (2012) has applied it to an analysis of user involvement. To give a very brief overview of something quite complex and dynamic, the powercube has three dimensions – *forms*, *spaces* and *levels* of power. Basically, power operates in visible, hidden and invisible forms. Visible power is in operation when a government says they are consulting on a new mental health policy. Hidden power operates to decide what goes on the

agenda for the consultation. And invisible power operates to keep the real issues from our consciousness. And then there are spaces of power: closed space is where the decisions are made by those in power, invited spaces are where those in power invite others to participate on their terms. Claimed spaces are created by people who have something in common who want to speak up and make changes. Finally, there are levels of involvement, which in the case of user involvement, Brosnan has labelled as individual, operational and strategic. A person may be involved in their own care and treatment on an individual level, in how a particular service is delivered, i.e. on an operational level, and on a strategic level whereby the person is involved nationally and internationally in developing policy.

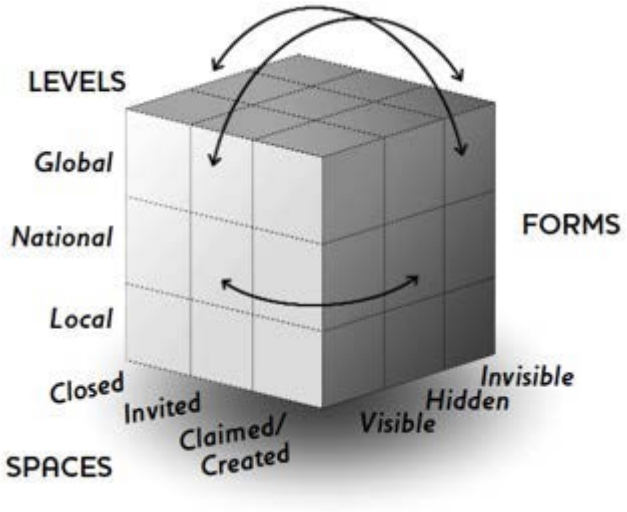


Figure 1: the power cube: levels, spaces and forms of power (Gaventa, 2006, p. 25 and http://www.powercube.net cited in Brosnan, 2012, p. 56)

We've found that thinking in terms of the Powercube has been very helpful in figuring out what we are doing: are we claiming space or are we being invited in? Is the power visible or invisible? Are we being involved operationally i.e. 'tell us how this service can be improved'? Or strategically? How do these different aspects interact? So for example, it seems to me that in Ireland the invited space has been strong but in Scotland, at least initially, there was as much claimed space as invited. But I think most space now is invited and it is hard to find the resources for claimed space - though it is more possible to do so online. And the closed spaces are still there and that's still where the real power lies, for all the fine 'Recovery' rhetoric (O'Donnell and Shaw, 2016). We need to develop and nurture our claimed spaces, because they give us the strength and focus to be able to work in the invited

spaces and not become absorbed in the demands of services and policy makers. And they also help us to make strategic decisions about what to become involved with, and why.

**Co-option of user involvement: a shared concern**

Throughout our conversation, the co-option of user involvement seemed to be a common concern…

**Lydia**: The provision of space for service user involvement in Ireland can be seen as the provision of an invited space, created in a top-down manner. The concept of user involvement has been institutionalised into Irish government policy and structures very quickly. It is particularly striking how comfortably the language of 'user involvement' has been adopted in traditional mental health systems while these systems remain, equally comfortably, under medical hegemony. For example, despite the rhetoric of user involvement in mental health care, research continues to raise concerns about the quality of such involvement, about tokenism, and about the lack of resources to support meaningful user involvement (McDaid 2009; Brosnan 2012). Brosnan's (2012, p. 62) research suggests that, like recovery, user involvement is 'incorporated into the official discourses without sufficient attention being paid to the complexities of the social justice issues inherent in the user-perspective and failing to problematise the power dynamics service-users must engage with if they choose to enter the new spaces into which they are being invited'. Brosnan also argues that the presence of service users at the table may suggest the democratic face of 'inclusive' practice while simultaneously legitimising the practices of the mental health establishment. Drawing from Nancy Fraser's (2000) ideas on social justice, we can argue that while there is talk about the 'recognition' of user experiences, leading to some level of 'representation' of service users at policy and management levels, there is no evidence of the 'redistribution' of power within mental health systems.

**Anne**: I recognise similar processes here in Scotland… some groups like CAPS started as claimed spaces, while other groups were created in order to fit into invited spaces. And when we don't appreciate or realise the difference between claimed and invited spaces, we don't recognise what is going on in terms of power dynamics, but wonder why we are running around responding to demands to take part in consultation but getting nowhere.

**Creating and claiming new spaces**

**Anne:** I am aware of the CVNI, which is a new claimed space in Irish mental health. Can you tell me more about it?

**Lydia**: The CVNI emerged out of a series of critical conferences organised since 2009 by the Schools of Applied Social Studies and Nursing and Midwifery in University College Cork. These conferences are unique as they are free of charge and involve survivors, professionals, academics and carers presenting, discussing and debating critical perspectives in mental health. From this, the CVNI emerged as a claimed space to develop ideas and act more collectively. It is a coalition of service users, carers, professionals, academics, national campaigning and advocacy groups, all looking for a mental health system not based on the traditional biomedical model. The idea is that the network now provides a democratic space with no hierarchical structures, open to everybody who wishes to join its discussions, mainly through a Facebook page.

**Anne**: Having been to a CVNI conference and joining the Facebook group, my impression is that it's uncritically anti-psychiatry, like many groups that seem quite radical, but actually aren't questioning or challenging wider power and political aspects. Are there people there who are looking beyond the narrower anti-psychiatry stance?

**Lydia:** Yes, the political views within the CVNI are very diverse and this is a challenge. As we discussed earlier, we need to move beyond a critique of psychiatry to a broader political critique. Our November 2016 conference is focused on activism and acts of resistance, thus recognising the importance of this broader political focus. Despite these challenges the CVNI has given a 'home' for people to get the confidence to articulate different opinions (Sapouna and Gijbels, 2016).

**Anne**: As I said before, we need to develop and nurture our claimed spaces - and I think there are new exciting developments which enable this, such as Mad Studies. This new field, both academic and activist, is a 'project of inquiry, knowledge production and political action' by people who identify as mad and our allies (LeFrançois *et al*, 2013, p. 13). As Lucy Costa (2014, n.p.) says 'maybe it's time we stop answering [user involvement] questions and have Mad Studies develop our own questions and research agendas'. It is definitely about claiming space! It feels more politically aware and more geared to both analysis and action than anything else I have seen in the international survivor movement in a long time.

**What keeps us going?**

**Anne**: So to summarise, we both operate in tense yet creative positions - me as a worker and an activist and you as an educator/activist. We are trying to balance the cynicism from our experiences and yet keep hope. So why do we do what we do? What keeps us going?

**Lydia:** I can't teach something I don't believe in. It is as simple as that. I consider myself lucky to be doing a job that combines a personal and political passion with the possibility to make a living!

**Anne**: But it can be an uncomfortable place. So what keeps you going in this uncomfortable place?

**Lydia:** Well, for a long time I was uncomfortable on my own. What can be done in formal education is rather limited and I soon realised that my own knowledge-base was inadequate. I was frustrated with the system, but I didn't have many resources to develop alternative ways of knowing and inquiring. Things started to change when I first connected with service user advocates and like-minded professionals. Through this process I expanded my ways of knowing and thinking and therefore I feel I have more to offer. So this is what keeps me going: a connection with a movement; a collective process of change. I suppose I made some contribution in developing a critical space within the university and I would like to see that continuing. As a next step it would be great to see Mad Studies in our University!

**Anne**: What keeps me going? Well, I have seen some small changes which helps keep me going. I feel a commitment to people and a community to which I feel an uneasy sense of belonging, and I want to continue to be involved in speaking out against injustice, even when I feel we can’t do anything else but highlight it. And, finally, I am very excited by Mad Studies from an academic and activist perspective …. even as I worry about its co-option.

**Lydia Sapouna** is a lecturer in the School of Applied Social Studies, University College Cork Ireland. She is interested in critical mental health research, education, community activism and in promoting meaningful, context-informed responses to human distress.

**Anne O'Donnell** is a community educator working in mental health advocacy. She has been an activist since the mid 90s. She is particularly interested in the political and social context in which mental health and mental illness are constructed, understood and responded to.

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