

## **Storytelling: An Act of Resistance or a Commodity?**

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### **Abstract**

Telling our own stories of our experiences of distress and madness, of oppression and treatment, of survival and resistance, is a source of power for people who use or are forced to use mental health services. Storytelling has created a space for people, whose voices have been traditionally silenced, to be heard, affirmed, and to organise into collective action. However, recent trends suggest that these stories are becoming a commodity with mental health organisations and educational institutions using them primarily to promote their own agendas.

Many stories matter. Stories have been used to disempower and to humanise. Stories can break the dignity of a people, but stories can also repair that broken dignity. (Adichie, 2009)

We three women are activists (survivors, researchers, and educators) and, drawing from our experiences in the Scottish and Irish contexts, we discuss the need to constantly problematise what has been achieved through the user movement. We are frustrated because people who share their stories remain disadvantaged, often unpaid, unequal partners while organisations, professionals, and academics benefit through receiving funding and building a career path on the basis of user

involvement. While this is an unsettling position, we believe that we can make the best of it by being critical rather than cynical, by staying hopeful and engaged with the constantly changing demands of activism.

**Keywords:** stories, mental health, user involvement, survivor movement, co-option

## Introduction - Positioning Ourselves

This paper is a narrative exploration of the politics of storytelling in the context of mental health systems. We are informed by our experiences in Scotland and Ireland as people who have been invited to tell our stories (Liz, Anne) and invite others to tell their stories in our institutions (Lydia, Anne).

We are three white women with educational privilege which gives us opportunities to articulate our concerns. We are conscious that our experiences and thoughts are not representative of more silenced and absent voices.

Although the politics of storytelling by psychiatrised people has been discussed before (in particular by Costa et al., 2012), it continues to be a contentious issue. We are involved in a variety of Mad Activism, e.g. Critical Voices Network Ireland (Sapouna & Gijbels, 2016), the independent advocacy movement in Scotland (Sapouna & O'Donnell, 2017), research, and education. Yet in these spaces, storytelling is often unproblematized and depoliticised. Drawing inspiration from Costa et al. (2012), we consider the relevance of their critique to find ways to remain alert to the politics of storytelling in our different contexts. We start this discussion with each of us relating our experience of storytelling. We identify our hopes about the potential of stories to challenge mental health systems, and our worries about the appropriation of stories by the very same systems. Reflecting on our experiences of madness, advocacy, research, education, and activism, we identify the power of stories and our concerns about their co-option. This ambivalence towards storytelling remains a key feature in our discussion. However, as our conversation progresses we seem to regain our optimism about the potential of storytelling to challenge biomedical ideologies and oppressive power structures. We conclude with some suggestions about remaining hopeful about and engaged with the politics of storytelling.

**Anne**

I am an Irish woman who has lived in Scotland since the mid-90s where I became homeless, got a mental health diagnosis, and found collective advocacy, all within a year of moving here. Then, hearing other people tell their stories helped me feel less alone and more outraged. A good combination!

Service user involvement (SUI) seemed great at first, but I soon realised that a lot of it was very conditional on saying what funders and professionals wanted to hear. One of the first things I did when I became a service user group representative was to attend a big National Health Service (NHS) event where a very senior person pounced on me, delighted to see some 'fresh blood', telling me she wanted to hear from real people like me, not 'these activists'. At the same event, we were arguing for non-hospital crisis services. A general practitioner asked me what I would do when in crisis, and when I started telling him, he said "see how Anne manages it, we don't need a crisis centre!" before even hearing me out. These two incidents on one day made me very wary of my role as a service user representative in professional spaces and of "telling my story".

Since then, the increase in demand for people to tell their stories of distress, of stigma, and of recovery in ways which fit dominant ideas has worried me. I hear stories which are moulded to fit templates of grateful recipients of services, of taking individual responsibility, of combating stigma and opening up about suicidal thoughts to sympathetic family and professionals. These weren't the stories of people I knew; they didn't show the complexity of our experiences or the systemic problems we faced or the power of collective work.

I also manage a small project, part of an independent mental health advocacy organisation which provides mental health courses designed, developed, and delivered by people with lived experiences. Participants appreciate hearing our stories but I wonder how they actually make sense of those stories? And I wonder about the impact on us of telling stories of our experiences of distress, invalidation, and discrimination.

## **Liz**

My encounters with Irish mental health services commenced in 1989 and were initially involuntary. After a lost decade I became involved in service-user led research and advisory committee work. My initial excitement about the apparent revolution, heralded into Irish services in the 2000s by the adoption of the Recovery and SUI mantra, was fuelled by belief in the power of stories to effect change. But gradually it became obvious that it was often window-dressing, in spite of the best intentions of many committed allies. As an optimist I know we can influence individuals but given years of experience it seems systemic change is nigh impossible.

My research on power dynamics within SUI practice for a sociology PhD sparked an uncomfortable awakening (Brosnan, 2013). My whole life trajectory has been shaped by abuses of power (gendered, sexual, and religious) and so the dynamics in mental health services and in academia are uncomfortably familiar. I observe the same old games play out in forums with professionals; how recovery discourses mask the unseen, unspoken privileges conferred on “sane” professionals, while the token service-user is welcomed as long as she is not too “mad” or too angry and does not threaten the unspoken, invisible boundaries that determine how “things are done around here”. Similarly, narratives of recovery are welcomed as long as there is a redemptive feature for professionals: many participants in my PhD research spoke of hearing a story rejected because it was too negative, it did not give a “balanced view”. The satisfied service-user is welcome, they after all provide reassurance that “we can’t be doing everything wrong”. Of course, as the theorists of power (Foucault, 1980; Lukes, 1974; 2005) point out, power is most potent when the subjected believe the system is working in their best interests and that no alternative is possible. Most professionals (and the public) are caught up in this trick of hegemony: professional sanity (and avoidance of cognitive dissonance, see Cooper, 2007) depends on the recovery narratives underpinning their practice (Brosnan, 2012).

## **Lydia**

I have taught mental health in social work programmes in University College Cork, Ireland, for over 20 years. I started this work with a strong commitment to critical education and practice but soon realised the challenges of this task as students are expected to practice within dominant biomedical

systems. At the same time, I recognised my own limited resources to think and practice outside the box. Building alliances with the emerging user movement in Ireland created exciting new possibilities for engagement with critical practice (Sapouna, 2016).

A starting point of this process was SUI in education which included the sharing of people's stories of encounters with psychiatry in classroom and conference settings. I was very proud about this 'innovation', seeing such stories as a tool to challenge dominant understandings of distress. Indeed, students listened enthusiastically to these narratives, they appreciated the diversity of the experiences shared, and they saw the person beyond the symptom. These stories were an antidote to medicalization. However, even in these early days of my enthusiasm about SUI, I was uncomfortable with some students' fascination with a 'brave individual's' story at the expense of an interest in systemic change. I was also uncomfortable with the request, expressed by some students and many practitioners, for these stories to be more 'balanced' rather than, what was perceived as, constantly criticising service-provision. I was unsettled by the unequal status of the 'invited speaker' which gave no real recognition or power to those sharing their stories within education. Still, for almost a decade I was happy to 'pioneer' SUI in Irish social work education. The stories were educational, alerting future practitioners about how people experiencing distress want to be treated. I observed students becoming less preoccupied with diagnostics and instead developing a position of curiosity about the life-contexts of people who use mental health services. I observed students focusing on recovery, becoming aware of the impact of coercive practices and identifying the pursuit of social justice as a core element of changing mental health systems. People sharing their stories spoke about feeling affirmed and valued and, through their contribution, the authority of professional and academic expert knowledge was challenged, a welcome development! In many ways it seemed that stories had the potential to radically transform thinking and practice.

However, such stories are increasingly becoming mainstream within mental health institutions including education. And now I am even more uncomfortable! So what's my problem? Isn't this what I advocated for all along? Greater SUI in education? Co-production? It seems that when stories become part of mainstream discourses they lose their potential to be an agent of change. Many of these stories don't make their audiences uncomfortable any more. And I think this can be a real problem.

## Discovering the power of stories

While we all got involved in activism in different places and at different times, we were inspired by stories: from fellow activists, such as Judy Chamberlin in *On Our Own* (1978), Louise Pembroke on self-harm (Pembroke, 1994), Kate Millett (1990), and stories on the meaning of voice-hearing by Paddy McGowan, Noreen Fitzgibbon (The Irish Advocacy Network), Jacqui Dillon and Eleanor Longden (Hearing Voices Network, UK). We were also inspired by the less celebrated stories of people who, by struggling to tell their story, taught us the importance of being respectful of different positions and of listening to diverse voices. We usually hear, or are affected by, well-articulated stories of extreme coercion or successful recovery. Nevertheless, we also need to hear the stories of those who can't find the words to tell them, those whose experiences confuse us or challenge us because they may be far removed from our comfort zone. Through storytelling we can develop the art of listening.

**Anne:** I had listened to so many other survivors' stories which had inspired me greatly. I had been made to feel for so long that I myself had nothing to say. So being encouraged to tell my story was liberation. Being asked and being listened by fellow survivors gave me a sense that I mattered, my experiences mattered and my understanding of them mattered. But those experiences of having my own story of madness dismissed as 'one person's experience,' and of it being appropriated, silenced me again. I've been telling my story of activism much more freely (Sapouna and O'Donnell, 2017). It is only recently that I feel able to tell my own stories of my madness.

**Liz:** I found that I so under-valued myself that, like Anne, I thought either I had nothing original to say or that what I had to say had already been said before. Plus, my first attempts to write my story had been rubbished as 'just stream of consciousness' by someone I trusted, (wrongly as it turned out). This harsh opinion had wounded me so deeply I destroyed several years of notebooks and kept silent for years. It was through reading and listening to other survivors tell their stories that I began to believe my own story is valuable. That is why I both value and fear the power of stories. Now people come to me and say they value my work and my stories. Even professionals have come up quietly after classes to say my story reminded them of their own, but they don't feel in a position to share theirs.

**Lydia:** It is interesting that both Anne and Liz mention their feeling of having nothing worth saying as I felt the very same from my different position. Not belonging in the 'mad community', and also not being fully comfortable in the world of academia, I struggled with what I had to offer beyond

what is often perceived as 'vague' passion and vision. Stories of survivors articulating the importance of context, of 'what happened', of being treated with respect and dignity filled that gap. In this process of story-sharing I often found myself taking a step back with my role becoming effectively invisible/redundant. This is not always a comfortable place to be. But if this 'disappearing' is about 'creating spaces' it can be a political act (see also Church, 2013).

## **Questioning co-option**

So other people's stories have inspired us and being invited to tell our stories has felt very empowering. For many people, a request to speak to nursing students or to be interviewed by researchers or to speak at a conference may be the first time their opinion has been actively sought and attended to. Through telling their story, they believe they can make a positive difference, and be valued for experiences which were often invalidating and painful. Furthermore, inviting people to share their stories can also be a significant political act in terms of challenging dominant cultures in educational institutions.

However, what might be experienced as empowering has a dark side (Pascal and Sagan, 2016). As we have each described, we have become disillusioned by how we have seen something as powerful and transformative as telling stories becoming neutralised and co-opted (see Costa et al., 2012).

We see survivors' stories becoming commodities for mental health organisations and educational institutions to use primarily to promote their own agendas. These mainstream institutions claim to be involving service users, promoting recovery, and fighting stigma, but stories which do not fit their agenda are ignored and silenced.

Telling our stories has become compulsory in some contexts (e.g. professional education) and that is inherently disempowering: as the critical survivor group, Recovery in the Bin (RITB) put it "being made to feel like you have to tell your 'story' to justify your experience is a form of disempowerment, under the guise of empowerment." (Recovery in the Bin, n.d.)

People who share their stories remain disadvantaged, and are often unpaid, unequal partners. They often have very little say in how their story is retold or used, often as a substitute for meaningful

participation. In writing down our stories they can be used as material without our involvement or control, not recognising that stories are not static and nuances shift as our lives evolve and thinking changes over time. Without real influence over curriculum development and student assessment, SUI in education is tokenistic, and the practice of bringing someone in to tell their story to a class is patronising and meaningless. The lack of respectful conditions of participation was a strong theme in Liz's research with twenty activists engaged in SUI in Ireland, leaving many wondering if their efforts were having any impact (Brosnan, 2013). To date, there has been one part-time peer-academic post created in a one department in one University in Ireland. User/survivor research positions are even more precarious than postdoctoral research contracts in general. These concerns are also evident in mental health services, in particular in the arena of SUI. People are invited into SUI spaces without adequate problematising of the power dynamics inherent for service users in a hierarchical bureaucracy, dominated by bio-medical professionals. Narrating recovery stories at professional conferences or bringing common sense to bear on how proposed changes would impact grassroots people, are common activities that offer people a sense they are making a difference, a sense that grows increasingly elusive the longer someone is engaged with the system. Participants in Liz's research frequently reported a lack of meaningful recognition of the role that service users can contribute to culture change (Brosnan, 2013). Until the power structures that maintain the status quo are addressed, service users are limited in what they can do.

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At first, when we began our conversation about stories, we felt deflated and discouraged. However, as we talked to each other and to others, we found ourselves telling stories and we felt yet again the possibility of these stories. And in telling and listening to stories, we reawakened our belief in their radical potential and felt even more the need to challenge their appropriation.

Stories can bring to our attention to human rights violations in a way that facts and statistics can't. Such as that of psychiatric survivor Dorothea Buck (Buck-Zerchin, 2017), and her experiences of surviving the Nazi T4 programme. Her story brings the reality of the Nazi genocide of people who were diagnosed with mental health conditions to our attention in a way that facts and statistics can't. Psychiatry was complicit in this genocide programme, and in maintaining the Soviet order, and yet the learning is being forgotten. And these stories remind us that the UN human rights frameworks, which are being attacked relentlessly in the current political climate, were set up to ensure that the massive

violations that occurred in the early 20th century should never be allowed again.

All storytelling is political; there is no neutral story. Telling stories about experiences of mental distress and madness, of oppression and treatment, and of survival and resistance, is a source of power for people who use or are forced to use mental health services. Stories are part of how we - survivors and allies - resist the dehumanising experiences in the mental health system and reclaim our humanity, our subjectivity, our agency. Our stories affirm us as people. They help us create meaning where others see none and to help us channel our anger and rage into political action. They allow us to challenge bio-psychiatry and dominant understandings of human distress and to create alternative views; most importantly, they connect us with each other as we find we are not alone. This is the most significant potential of narrating our experiences; it builds community and allows a politicised, collective consciousness to emerge among psychiatrised people.

## **So what now?**

Whether it was the senior NHS person looking for 'fresh blood' from Anne, insisting she didn't want to hear from 'those activists' or Lydia's students who wanted the 'brave individual's' stories, or the professionals who welcomed the token, non-threatening service user who is 'not too "mad" or too angry' in Liz's research, the demand from 'consumers' of stories is for safe stories, for 'balanced stories', for stories which do not discomfort or challenge them.

But we all - service providers, researchers, educators, and policymakers as well as survivors and allies - need the stories which do challenge and unsettle us! Some of the stories Anne has struggled to hear are how some survivors have felt unwelcome or not listened to in the groups she has belonged to. Lydia struggles with stories of people who resort to seeking more coercion for family members because of issues of 'risk' and 'safety'. Liz struggles with hearing stories from people that justify coercion and contested practices such as seclusion and electroconvulsive therapy (ECT) because they helped them in the past, without believing other options are possible.

It is because our stories are so powerful that we are so concerned when we experience and witness the co-option and appropriation of our stories. But just because they are stolen from us, does not make the act of telling them invalid. In fact, it makes telling them even more important.

We believe that real change and real activism are grounded in and arise from the stories of the oppressed. And these stories are collective and diverse (including but not limited to poverty, domestic violence, abortion, legal guardianship, colonisation, genocide). As bell hooks (2014, 2003) reminds us, activism is grounded in the community of people who come together and learn from each other. By keeping a focus on community and by avoiding elitism, we will reduce the chances of the commodification of our stories. Other theorists of power and community (Gaventa, 2006; Cornwall & Coelho, 2007) speak of the need for collective spaces to resist the capture by the dominant worldview, the professionalization of development, of change, of resistance.

We need to tell and hear more stories which capture the complexity and messiness of our experiences; stories not of heroes - 'recovery porn' (Costa et al. 2012) - but the stories from people whose acute distress makes it messy to find a response (other than resort to coercion) because we know no better.

We need to hear more stories from people who are not like us. Those of us in the movement, as well as those in services, need to hear from people who are left out, overlooked, invisible, people who are not usually listened to. Our movement has been dominated by white people and the stories of people of colour are still not being listened to (Gorman et al, 2013; Griffiths, 2018). We need to hear from people with different experiences of distress and madness and people who have had different responses to their distress and madness.

We need to give more space for more stories. We need to be able to say, 'if you want my story for your students, pay me for my story.' And we need to give people space to say "no, I am not telling my story, not here, not now, not in this context".

## **Conclusion**

While this is an unsettling position, we believe that we, as storytellers and as people who invite storytelling, can make the best of it by being critical rather than cynical, by staying hopeful and engaged with the constantly changing demands of activism. Through our discussion we identified some ways to remain alert to the politics of storytelling.

We propose seeking out more diverse individual and collective stories and listening carefully

to those stories which challenge us to move beyond complacency. We also argue for the recognition, respect, and promotion of a broader range of Survivor narratives. These would include an understanding of the difficulties and struggle that people face every day, not just 'successful recovery' type stories (RITB principles). Essential in this process is a move from the rhetoric of equality to offering people proper conditions for participation, such as recognising that payment is also political, and providing genuine opportunities to influence education, policy, and practice. Ultimately we argue for the need to protect our own spaces for engagement and being alert to co-option.

We conclude with a brief reflection on the writing of this article. The three of us started this discussion because of our shared frustration with the use and abuse of survivors' stories within mental health services and education. However, writing this article required us to share our individual stories in order to talk about stories more generally. We had to decide what to share with each other, what to use, and what to discard. And in order to write a 'coherent' article we had to balance our individual views with the collective. And interestingly this story-sharing made us regain confidence in the power of collective stories to help us stay engaged with activism and the pursuit of social justice.

## References

- Adichie, C. N. (2009, July). *The Danger of a Single Story* [Video file]. Retrieved from [https://www.ted.com/talks/chimamanda\\_adichie\\_the\\_danger\\_of\\_a\\_single\\_story](https://www.ted.com/talks/chimamanda_adichie_the_danger_of_a_single_story)
- Brosnan, L. (2012). Power and participation: An examination of the dynamics of mental health service-user involvement in Ireland. *Studies in Social Justice*, 6(1), 45-66.
- Brosnan, L. (2013). *Service-user involvement in Irish mental health services: A sociological analysis of inherent tensions for service-users, service-providers and social movement actors* (Unpublished doctoral thesis). University of Limerick, Limerick.
- Buck-Zerchin, D. S. (2017). Bundesverband Psychiatrie-Erfahrener (BPE) e.V. Federal Organisation of (ex-) Users and Survivors of Psychiatry in Germany. Retrieved July 17, 2017, from <http://www.bpe-online.de/english/dorotheabuck.htm>
- Chamberlin, J. (1978). *On our own: Patient controlled alternatives to the mental health system*. New

York: Haworth Press.

Church, K. (2013). Making madness matter in academic practice. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies* (pp 181-194). Toronto: Canadian Scholars' Press Inc.

Cornwall, A., & Schattan Coelho, V. (2007). *Spaces for change? The politics of citizen participation in new democratic arenas*. London: Zed Books.

Costa, L., Voronka, J., Landry, D., Reid, J., McFarlane, B., Reville, D., & Church, K. (2012). Recovering our stories: A small act of resistance. *Studies in Social Justice*, 6(1), 85-101.

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings, 1972-1977*. Pantheon.

Gorman, R., saini, a., Tam, L. Udegbe, O., & Usar, O. (2013). Mad people of color: A manifesto. *Asylum*, 20(4), 27.

Griffiths, R. (2018). Kindred Minds: A Call for Social Justice, Retrieved March 22, 2018, from <https://www.nsun.org.uk/news/bme-mental-health-service-users-launch-manifesto>

Hearing Voices Network. (n.d.). Retrieved August 29, 2017, from <https://www.hearing-voices.org>

hooks, bell. (2003). *Teaching community: A pedagogy of hope*. London: Routledge.

hooks, bell. (2014). *Teaching to transgress*. London: Routledge.

Lukes, S. (1974). *Power: A radical view*. London and New York: Macmillan.

Lukes, S. (2005). *Power: A radical view* (2nd ed.). Palgrave Macmillan.

Millett, K. (1990). *The loony-bin trip*. Urbana: University of Illinois Press.

Pascal, J., & Sagan, O. (2016). Cocreation or collusion: The dark side of consumer narrative in qualitative health research. *Illness, Crisis & Loss*, 26(4), 251-269.

Pembroke, L. (1994). *Self-harm: Perspectives from personal experience*. London: Survivors Speak Out.

Recovery in the Bin. (n.d.). RITB – 20 Key Principles. Retrieved March 30, 2017, from <https://recoveryinthebin.org/>

Sapouna, L. (2016). Education for critical practice in mental health: Opportunities and challenges. *Critical and Radical Social Work, 4*(1), 59-76.

Sapouna, L., & Gijbels, H. (2016). Social movements in mental health: The case of the Critical Voices Network Ireland. *Critical and Radical Social Work, 4*(3), 397-402.

Sapouna, L., & O'Donnell, A. (2017). 'Madness' and activism in Ireland and Scotland, a dialogue. *Community Development Journal, 52*(3), 524-534.

The Irish Advocacy Network. (n.d.). Retrieved August 29, 2017, from <http://irishadvocacynetwork.com/wp/>

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