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Experience, madness theory, and politics

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EXPERIENCE, MADNESS THEORY, AND POLITICS

DIANA ROSE



IN THIS COMMENTARY, I would like to do three things: First, reflect on Voronka's (2016) engagement with the critique of experience as a foundational concept and her answers to this; second, comment on how we, as both activists and user/survivor researchers, engage with other critical discourses emerging from excluded groups; and finally, offer some of my own perspectives and history as a user/survivor researcher and activist in the United Kingdom to illustrate the first two points.

EXPERIENCE

I agree with much of what Voronka has to say about the risks of relying on 'experience' as an unquestioned category and how those risks are embodied today in the increasing reliance on terms such as 'experts by experience' and 'people with lived experience.' In the United Kingdom, where I write from, many research projects now have what are called Lived Experience Advisory Panels and Voronka's arguments are timely, if equally rather unsettling, for this development.

Voronka engages extensively with Scott's 'The evidence of experience' (1991). Rereading it 30 years on, I was struck by its relentless post-structuralism. However, I also remember that many were deeply offended when it appeared—how dare she attack the authenticity of our experience? So, we must be careful, as indeed Voronka is. Appeals to experience on the part of service users are frag-

ile. Scott's argument is that history, in particular, but also other critical discourses, rely on experience as a foundational category that naturalizes excluded groups and identities, whereas these should be historicized. Historicizing experience means recognizing that subjectivity is produced through discourse. That is, subjectivity is shaped by language, the concepts it embodies, and the social institutions that structure it. Importantly, discourse entails power and it is *shared*. This does not preclude agency, but it does preclude free will and unfettered choice and means we are not unproblematic individuals. This is where I have difficulties with where Voronka's argument leads her. Her main point seems to be that using experience as a foundational category, even strategically, effaces the *differences* between us, renders them invisible and unspeakable—differences in response to distress and to the mental health system; ideological and epistemological differences; differences in respect of gender, ethnicity, disability, sexuality, and so forth. Although in one sense these differences *are* important, the logical conclusion seems to me to be that we are all different *as individuals* and so individual (albeit constructed) experience in fact creeps back in. For all the references to the *psy*-disciplines and the state and to the activism that resists them, we arrive at a point where the collective disappears.

Is there a role for survivor academics to tackle this issue? I would argue that there are parallels with activism and user/survivor groups. These

groups share, validate, collectivize, and thereby render more general the experiences that individuals bring to them. This is not to say that ‘individuals’ are ontologically prior to collectivities, but that the way madness is positioned encourages us to believe we are individually pathological and psychologically alone. Although not a post-structuralist, Harding (2008), writing about feminism and postcolonial studies, has a proposition that might be helpful. She suggests that academics can ‘study up’ (her quotation marks) the situations of women and racialized subjects, alongside political movements, to theorize those situations. They are situations of collectivities, albeit ones that contain differences. This concept of ‘studying up’ is to me a more productive move than an exclusive focus on the differences between us.

CRITICAL THEORY

The second issue for me is the engagement with critical discourses that have picked up and developed Scott’s critique of experience. These include feminism, postcolonial studies, queer studies, and disability studies. It is important to articulate our field with this theorizing, but I do not think we should underestimate how difficult it is. Texts in each of these bodies of work routinely invoke texts from the others—indeed, it is almost ritual. However, they hardly ever refer to madness. Madness simply does not figure. In his preface to *The History of Madness* (1967), Foucault wrote about how the mad had been silenced by the Enlightenment, silenced by a monologue of reason about madness.

I will be bold and contend that this silencing still holds, even in critical theory dedicated to marginalized groups. In the 1970s and 1980s, there were radical books about psychiatry, from Ingleby’s rather simplistic antipsychiatry volume (1981) to the much more sophisticated *Psycho Politics* (Sedgwick, 1982). But these were never referred to outside a small group of concerned with radical psychology and psychiatry. Feminist texts such as those of Busfield (1996) and Chesler (1972) had more traction, but they were trying to rescue women from being designated mad in the first place. Even Porter’s compendious history

‘from below’ of madness (1988) seems not to have had reach beyond a small niche. So, although it is admirable to engage critical theory, I am not sure critical theory wishes to engage madness or mad scholars. We may still be the ultimate Other, even in the eyes of scholars attuned to marginalization. This is not a question of ‘stigma’ or ‘discrimination,’ but a radical and probably unknowing refusal to see madness as political.

Voronka’s article is ambitious in respect of engagement with other critical texts and I have indicated difficulties that are not meant to foreclose debate. The alternative is to be more modest. The aim is to engage solely with the field of disability studies and reframe mental illness as a psychosocial disability. Jones and Brown (2013) make a trenchant critique of what they call the ‘clinicization’ of mainstream research. I return to this notion at the end of this article. Their answer is to eschew this as well as ‘biomedicalization’ and introduce the social model of disability including introducing it practically in the academic workplace. Boxall and Beresford (2013) make similar arguments in the United Kingdom, and these moves are consistent with our inclusion in the Convention on the Rights of Persons with Disabilities. So there is a tension regarding where best to engage—critical theory in general or the more circumscribed field of disability studies. I admire Voronka’s attempt and tend to support this move, but also believe the difficulties are considerable and have very fundamental historical roots.

THE USER MOVEMENT AND USER-LED RESEARCH IN THE UNITED KINGDOM

Let me start with a personal story that resonates with the narrative with which Scott opens her essay. That opening describes a gay, Black man’s first visit to a bathhouse in San Francisco in the 1950s. The scales fell from his eyes; he had an epiphany, although that term is not used. It can be imagined why this narrative opens the chapter only to be dealt a fatal blow immediately. In 1986, I too had an epiphany—or thought I did. It occurred during my first visit to a local mental health service user group during a time when my

treatment by psychiatric services was very poor. A fellow member stood up and related experiences similar to mine and then announced that she considered this treatment an abuse of her human rights. The scales fell from my eyes; I had an epiphany. Or so I thought, until I reflected on it. My reflection was that this ‘epiphany’ was no recasting to an authentic experience, but had been prompted, conditioned by a history of involvement in radical politics—feminism, the anti-apartheid movement in South Africa, trade unionism, and so on. The difference was that I had never thought of my ‘mental illness’ as in any way political before that meeting. But now part of a movement, I was already primed by a history to see it that way. This is not the only path, but the power of collectivism should not be underestimated (Rose, 2014).

To turn now to research, user-led research in the United Kingdom can be dated from 1996 when two empirical programs led by service users were established in nongovernmental organizations in London (Faulkner & Layzell, 2000; Rose, 2001). There were also initiatives from social policy, and some early conceptual writing emanated from this (Beresford & Wallcraft, 1997). The critical point to make about these early developments is that the coordinators and early authors were firmly embedded in the UK user/survivor movement, both locally and nationally. New understandings were also constructed around self-harm and voice hearing at an early date, again located in social movements. As far as we could, we took our research questions from the movement, shaped our research tools in ways aligned with movement principles, and wrote about our findings from the perspectives of those who participated in our research. It is important that this historical juncture in the United Kingdom saw the final moments of the old asylums so our ‘participants’ were a silenced group in a fundamental sense.

Twenty years later, the configuration is very different. There is a specific threat to the resources and infrastructure of user-led research as well as its standing (Rose, 2015). There is the rise of social media, which offers a very different route to validation, interpretation as well as theorization of the situations of service users and survivors. But I would like to finish with two points germane to Voronka’s argument.

First, she argues that in the context of diversity and difference only certain categories of service user/survivor are allowed to speak, either in a policy or academic terms. She worries that these are White, middle-class people (‘White heterosexism’) and that others, including those who cannot curb unruliness, are excluded. I agree that this is a problem, but we must be mindful that it is an argument often turned against us when we are faced with the accusation of being “unrepresentative.” Far from our good behavior and middle-class status making us the face of acceptability, it becomes a reason to ignore us. This is a Catch-22—you are articulate and so not representative so we will not listen to you; ‘ordinary’ patients are not articulate (but we think they are satisfied) so we cannot listen to them either. Everybody is silenced, again (Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2002).

Finally, let me briefly come up to the present in the United Kingdom and my own role. Jones and Brown’s (2013) critique of ‘clinicization’ hit home. It applies to a substantial part of my job description when I advise very mainstream clinical researchers on how to involve service users in their very mainstream clinical research. I do this in the full knowledge that the service users can make very little difference to the design or conduct of the research. However, perhaps they have to start somewhere and this becomes another reason for not playing lexical police with the term ‘experience.’ Independent researchers are less constrained and also tend to be more connected to contemporary user groups in England. However, I also have space to do my own research and writing, which is radically different than supporting conventional undertakings. Being made a professor has given me that space, even as in the process, I had to compromise principles. But I never forgot my political history.

REFERENCES

- Beresford, P., & Wallcraft, J. (1997). Psychiatric system survivors and emancipatory research: Issues, overlaps and differences. In C. Barnes and G. Mercer (Eds.), *Doing disability research* (pp. 67–87). Leeds: The Disability Press/University of Leeds.
- Boxall, K., & Beresford, P. (2013). Service user research in social work and disability studies in the United Kingdom. *Disability & Society*, 28, 587–600.

- Busfield, J. (1995). *Men, women and madness*. London: MacMillan Press.
- Chesler, P. (1972). *Women and madness: A history of women and the psychiatric profession*. New York: Doubleday.
- Faulkner, A., & Layzell, S. (2000). *Strategies for living: A report of user-led research into people's strategies for living with mental distress*. London: Mental Health Foundation.
- Foucault, M. (1967). *Madness and civilization: A history of insanity in the Age of Reason* (Richard Howard, Trans.). London: Penguin.
- Harding, S. (2008). *Sciences from below: Feminisms, postcolonialities, and modernities*. Durham, NC: Duke University Press.
- Ingleby, D. (1981). *Critical psychiatry: The politics of mental health*. London: Penguin.
- Jones, N., & Brown, R. (2013). The absence of psychiatric c/s/x perspectives in academic discourse: Consequences and implications. *Disability Studies Quarterly*, 33, 1.
- Porter, R., (1987). *Mind forged manacles*. London: Athlone.
- Rose, D. (2001). *Users' voices: The perspectives of mental health service users on community and hospital care*. London: Sainsbury Centre for Mental Health.
- Rose, D. (2014). Patient and public involvement in health research: Ethical imperative and/or radical challenge? *Journal of Health Psychology*, 19, 149–58.
- Rose, D., (2015). The contemporary state of service-user-led research. *Lancet Psychiatry*, 2, 11, 959–960.
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P., & Wykes, T. (2002). User and carer involvement in change management in a mental health context: Review of the literature. *Report to the National Coordinating Centre for NHS Service Delivery and Organization*. London: Institute of Psychiatry.
- Scott, J. W. (1991). The evidence of experience. *Critical Inquiry*, 17, 4, 773–97.
- Sedgwick, P. (1982). *Psycho politics*. London: Pluto Press.
- Voronka, J. (2016). The politics of 'people with lived experience': Experiential authority and the risks of strategic essentialism. *Philosophy, Psychiatry & Psychology*, 23, 3–4, 189.