



INTERVIEW

Authenticity and the (in)visibility of service user representation

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Introduction

The problem of authenticity

Service user involvement in both research and pedagogy is both a goal and a value that institutions claim to support, including, in recent years, medical humanities programs. However, many people with ‘lived experience’ find a different reality in practice. Across disciplinary contexts, involvement aims are often tacitly undermined by epistemic double binds taking different representational forms: in the psy-sciences, the competing claims that those with lived experience are either “too disabled to play a meaningful role” or, conversely, “not disabled enough”; in the humanities, they are either “insufficiently mad” in the disruptive ways implicitly desired or, conversely, “too mad” to participate in disciplinary practices that demand a certain, arguably class-bound, creative or intellectual ‘ability’ (cf Thompson et al., 2012; Turner & Gillard, 2012; Ward et al 2010).

We argue that such dynamics can be illuminated in reference to the concept of ‘authenticity’ and its institutional performance, particularly when service user and survivors are invited to ‘tell their story’, either in professional, educational, or clinical contexts. Following Spivak (1988), we agree that many strategies of delegitimization are based upon an essentialism (i.e., fixed notions of what constitutes a particular identity) that reinforces existing inequalities. In the case of mental health politics, this surrounds certain expectations or prejudices as to what a ‘typical’ (or ‘authentic’) mental health ‘patient’ looks like or has experienced.

Nevertheless, without any category-based claim, bids for greater involvement are quickly undermined. In this vein, Voronka (2016) argues that using ‘strategic essentialism’, a term popularized by Spivak (1988) to advance the use of temporary or softly held identity characteristics as a platform to gain a foothold within powerful institutions even whilst recognising their limitations, risks submerging complex intersectionalities and “within group” differences, and potentially legitimizing unjust power structures. In a later paper (Voronka 2019), she goes on to illustrate the risks and realities of system cooptation and misuse of ‘lived experience’ accounts *even when* offered in a critical frame that makes the stakes of intersectionality and difference explicit.

Strategy and tactics

Clarke and Wright (2020) followed up Voronka’s (2019) concerns with a paper that argued that some of the difficulties identified could be avoided by making a distinction between ‘strategy’ and ‘tactics’. De Certeau (1984) calls ‘strategy’ ‘the calculation (or manipulation) of power relationships that becomes possible as soon as a subject with will and power (a business, an army, a city, a scientific institution) can be isolated’ (p. 35-6). Strategy is essentially a military term having to do with territories and the top-down imposition of forms of rationality and practice that exert an ongoing control over what De Certeau refers to as ‘users’ (i.e., ordinary people). By contrast, De Certeau (1984) defines ‘tactics’ as ‘a calculated action determined by the absence of a proper locus’ (p. 37). If strategy is determined by those with power, tactics are the operations used by those with little power who nevertheless find ways to subvert and adapt strategies to suit their own ends.

In reference to service user/survivor politics, Clarke and Wright (2020) argued that survivor narratives—self-accounting of dominant systems and their impacts--whilst vulnerable to cooption from vested interests, still form the locus around which resistance to totalising narratives can take place. One of the ways user/survivors can do this is by exploiting the cultural value of ‘authenticity’, whereby the neoliberal injunction to ‘tell your story’ is often used by the user/survivor to instead highlight existing structural deficits and inequalities (a practice Clarke and Wright term ‘tactical authenticity’). And while Voronka (2019) presents at least one cautionary tale of how even such explicit tactical strategies can be subsumed, Clarke and Wright point to greater collective possibilities of resistance. A limitation of this work, however, is a lack of more concrete detail and guidance regarding the practical ‘tactics of engagement’ that the service user/survivor might employ.

Article purpose and aims

On 23rd April 2021 we (the three co-authors) curated a session on ‘authenticity’ and service user involvement for the online conference “Medical Humanities: (In)visibility”, the Northern Network for Medical Health Humanities Congress 21-23 April 2021. This session took the form of a panel where the question of the politics of ‘authenticity’ in the current climate of service

user involvement and, particularly, surrounding identity politics was discussed. The panel invited questions and debate from online delegates attending the conference.

This article includes a transcript of the conversation from the panel session. We chose this format because we wanted to capture the liveliness of the discussion of the interview format. However, we have also edited the transcript to make it more accessible, provide greater context, and to systematically capture some of the issues (points of uncertainty) that emerged from the discussion. The original dialogue centered such questions as whether representation is a viable goal and, if not, how do we think about the spoken and unspoken (visible and invisible) aims of 'inclusion'. We also discussed 'tactics' of engagement that address the concept of representation itself. Following the panel interview, the article concludes with a discussion on existing work on authenticity and representation, the implications of this for service users and their allies, and possible avenues for future organizing and scholarship.

Authors' note and positionality statement

All the authors have lived experience of severe mental health difficulties. David was misdiagnosed and treated for schizophrenia for a year before receiving a more helpful diagnosis of bipolar mood disorder; Simon and Nev have diagnoses of schizophrenia. All three authors are involved in various ways in Mad activism and scholarship.

Authenticity and the (in)visibility of service user representation

Nev: Umbrella identity terms used in the context of mental health/disability are becoming increasingly broad, with language including (but not limited to) 'patients', 'service users', 'mad-identified', 'neurodiverse', 'lived experience' etc. This expansion in labels is partly due to massive growth in psychotropic prescribing, primarily antidepressants, meaning that, at any given time, substantial percentages of the population in many high-income countries will have experienced or used antidepressants. A further vector is 'diagnostic expansion', ie the adoption of new diagnostic labels and/or expansion of criteria for existing diagnoses, in turn increasing the 'psychiatrization' of an ever-larger number of people. Mad and neurodivergent identities may also be claimed by those who have never experienced services or, formally, been 'diagnosed' and, in this more bottom-up way, have expanded the community of individuals more traditionally identified as "users/survivors."

Whilst there are extraordinary possibilities to be gained from the deployment of these identity terms and assumptions (e.g., non-pathologizing, highlighting strengths and resiliencies etc.) there are also risks. And every time I find myself in a meeting pushing for greater user/survivor involvement—sometimes meaning even a single

other person in the room/meeting with a history of psychosis—I think and worry about these risks. Of course, if one does get those one or two people in the room, and they've only experienced psychosis through a particular class- and race-driven lens, the risks are still there.

David: A problem I think we are wrestling with is that we often find ourselves complicit in the very systems/dynamics we are invested in changing. To me, Voronka (2016) highlights risks and Clarke and Wright (2020) offer possible solutions.

One real-world example of the risks is how some thought-leaders with lived experience, particularly in the UK, have mobilized a constituency of people harmed by psychiatry in their efforts to completely discredit a significant role for biology in many forms of madness. Some of these lived-experience leaders are critical psychologists. While I am happy for anyone who can helpfully understand their own mental ill-health in terms that don't involve biology, some of us come to understand ourselves and our conditions as not very different from physical disability. It can be deeply ableist to exclusively center non-biological explanations for all mental health challenges (and anomalous experiences of consciousness) and to be critical of those who find these explanations helpful. Some of us find psychiatric diagnosis to be a useful way of framing our experiences, for instance, and still need to take psychiatric medication, and may experience cognitive (biological) difficulties. The similarity between some critical psychologists and the worst of biological psychiatry, i.e., having very fixed and inflexible positions on these issues, gets pointed out with some regularity in discussions on Twitter.

Simon: I think in many ways this is where De Certeau's (1984) notion of 'tactics' may be useful here, as well as his distinction between 'strategy' and 'tactics'. Take diagnosis for example. Diagnosis is the perfect embodiment of 'strategy' – it has been developed by clinicians and researchers, tied to money and power, developed, and distributed, by powerful institutions and imposed on service users, usually without their consideration. However, service users then use diagnosis in very creative and disruptive ways that repurpose diagnosis toward ends not originally envisioned (or sanctioned) by the developers of strategy. Service users take diagnosis and use it to leverage access to services, benefits, etc. They may also use diagnostic categories to support their own recovery or build community support practices around diagnostic labels, in person or on social media.

A related example here would be how the neurodiversity movement have reappropriated diagnostic labels such as autism and ADHD to help understand their differences (and not 'difficulties'!), to the point even of encouraging self-diagnosis (very controversial amongst medical professionals!), rather than resist or reject these labels.

- D: Regarding de Certeau's (1984) tactics vs strategies distinction: racism, sexism, sanism, ableism etc are deeply and consistently socially and structurally embedded and constructed, and so are clearly also power strategies in this sense. And insofar as identities arise around or in response to these dynamics, when they do so on an individual level, they must, to some degree, operate tactically except perhaps when they harness the power and/or go with the flow of the oppressive dynamics. Personal authenticity, in the sense of one's own charisma or passion or willingness to 'speak out' against oppression, is tactical.
- S: Yes. I think the point is that identity characteristics according to De Certeau (1984) are fluid and changeable in response to the development of 'strategy'. And I'm assuming it could be vice versa - strategy taking over 'tactics', say, big corporations take over the agenda of 'recovery' and enforcing it in a 'top-down' way, not according to 'users' but the dictates of strategy - capital, power, control etc.
- N: But then tactics re-assert themselves. This reminds me a lot of some of the seminal early writings within critical race theory and sociological theories of social movements more broadly--the give and take of co-optation, radicalization, resistance. None of what we're talking about happens in a vacuum: on Twitter, service users with a more biological self-understand do (already) push back; as do racially minoritized service users (in contexts where the claims in question are presented as color-blind, just for example). It's a dynamic space, that is; agonistic, pluralistic.
- D: Honestly what interests me most in our discussion is exploring the practical real-world significance of the things we're talking about. I recently had a conversation with a psychiatrist who mentioned being asked by the director of a psychiatry residency program to share their thoughts on the service user literature around lived experience involvement in psychiatry resident education. The psychiatrist confessed that they felt it necessary to say that based on the literature, the value of service user involvement was somewhat contested among service users themselves. I couldn't help but fear that this might result in less service-user involvement in the residency program going forward.
- An academic interest in interrogating, disrupting, complicating service user involvement that is can have unintended real-world consequences which could result in less involvement if mishandled. I think the risks Voronka (2016) names are real and avoiding them is important, but how do we describe them and possible responses in ways that don't foreclose the tactical opportunities Simon is

suggesting? How do we support space for disagreement, what Nev is calling “agonistic pluralism” without, in the world of administrative decision making, for example, undermining change?

N: I worry about this too. For example, there are vanishingly few permanent or (in the US) “tenure track” faculty with personal experience of a schizophrenia diagnosis that Simon and I are aware of. While I always go to great lengths to emphasize diversity and heterogeneity among folks with this label, I fully believe that it’s critical that “we” are included in psychosis research, early intervention in psychosis initiatives, etc. And when you have fewer people than one can count on two hands (maybe one?) I think we’re possibly putting the cart before the horse. Of course, one might also interpret Voronka’s concerns in this way—i.e. that strategic essentialism not only decenters intersectionalities of race, gender and class, but also the hugely variable landscape of “mad” experiences: an eating disorder is not depression is not schizophrenia, kind of thing—but practically, it seems like the risk of the larger Mad Studies discourse in which Voronka’s work is situated, goes the other way, i.e. with certain intersections mattering, while others drop out. In that sense, there’s still very much a (mostly unspoken) politics of ableism and inclusion at play.

S: Yes, I agree with this. Some diagnostic labels bring with them much more sustained levels of disability, which make it very difficult for some people to participate in the ways required by our neo-liberal societies. Plus, many of these labels are historically tied to power, racism and exploitation (‘schizophrenia’ being case in point here). Broad brush approaches to involvement—but also, ironically, critiques of involvement—often foreclose against these very real differences.

This extends to experiences of service use as well. Those of us who have been admitted to hospital under compulsion, for example, or received coercive treatments such as ECT, have very different experiences and perspectives than those who have had psychosis (or self-identify as ‘mad’) without experiencing discrimination and/or heavy psy-system involvement. I don’t think there’s enough recognition of this.

N: David, what do you make of all of this given your own—multiple—identities in this space?

D: I am struck by the tension between an organizing identity and personal experience and how that tension is heightened when I am called upon to be representative. Living at the intersections increases the discomfort if one identity significantly shifts the way in which another might commonly be perceived and experienced. As a

mixed-race, Jamaican, gay, invisibly disabled, cis man who made two attempts at migration as an adult before settling in Canada, I've had multiple, distinct opportunities to experience how I'm differently perceived and racialized. I have had to navigate community and employment as an outsider with different levels of social privilege in each case. I am keenly aware that umbrella identities are contextually constituted and thus representation always feels inauthentic, sometimes uncomfortably so.

When service users are called upon by institutions to be "involved" we must manage a range of internal and external dynamics. How much awareness, analysis and support we have in navigating these dynamics varies widely. We are naming representation as something that references power structures that operate strategically to control certain people and identifying a particular understanding of authenticity and tactical action as tools for coping with our discomfort and being effectual when we become a nexus for dynamics we can rarely be fully aware of.

- N: Risks of identity labels or claims may of course play out in situations in which user/survivors are invited to speak, train or consult--imposed by others, that is--but also self-representation (in the context of activist organizing or writing). I'm wondering what the risks that different forms of "curation" might take, i.e., externally imposed versus self-imposed curation? Is this part of what you're getting at, David, in invoking *self*-inauthenticity and discomfort?
- D: This is a really important distinction, I think. And really there are multiple forms of curation including: representation; culture; laws, canons, archives, histories, nosologies; ingroup norms (somewhat different from culture?); group dynamics - rejection, acceptance, validation, affirmation, ostracization etc. Medina (2012) discusses the communicative dynamics used by those in power which can have positive or negative effects: such as listening or silencing, granting or denying epistemic and hermeneutical opportunity. Belonging and reinforcement/validation of identity by others is a key ingredient in sanity from my perspective. So, one of the risks of how curation happens, particularly via group dynamics and personal communication, is that it can be destabilizing to mental health. That's certainly been my experience.
- N: So perhaps we're now talking about internal politics of exclusion and belonging or non-belonging...and how fraught this is within user/survivor/mad organizing....? Is the constant, if simultaneously unwritten, deployment of boundary conditions: this experience or person belongs, another does not not; or that, based on categorical

identities, this or that kind of experience is either assumed to be in play, or assumed not to.

- D: Yes, and it is very fraught. Coming from a past doing community-based health promotion in HIV and sexual health in the 90's I'm struck by how much more challenging mad organizing is.
- S: I agree that there are multiple ways barriers to involvement can happen. Too rigid boundaries around who is 'in' and 'out'; too fluid boundaries around who is 'in' and 'out'. Co-option and 'take-over' by those in power, in very exclusionary ways ('recovery' being the perfect example of this happening more recently, but we could also say the same to some extent with hearing voices groups). Representation taking the form of 'I am speaking for x group' when they're not (e.g., just telling their story without recognising their experiences are unique and may not resonate or include others). To return to the possibilities of "tactical authenticity" we began with, are there nevertheless ways of negotiating representation via authenticity?
- D: I think it may lie in the difference between people taking ownership of categories and categories being foisted upon us, and how that happens. We talked before about disability not being recognized as much within intersectional analysis (i.e., race and gender are central categories, maybe class, but not disability). I agree, and I would add that intellect and erudition can also be marginalizing. I am thus wondering about the academic space as a privileged domain. Medina (2012) suggested that hermeneutical responsibility and virtue is something that those in powerful positions need to strive for, but academia often fails in these demands. That is, in the sense that only certain people have even basic access to academic spaces but also, and perhaps because of this, those who do can be seen as inauthentic outside of academia.
- It is important to recognise that service user involvement is complicated and risky and there are good reasons for service users to decide not to be "involved". However, when our critiques and concerns about involvement are used to exclude us from decisions about us, that exclusion also carries significant risks.
- S: I think the point here is that 'authenticity' can be both strategy and tactic, depending on who's using it and what end it's serving. Trump used 'authenticity' particularly well, and perhaps even to disrupt the current 'strategy' of the neoliberal consensus, but in ways that redirected power to other (far more troubling) existing ultra-conservative power bases.

I think an authenticity grounded in a values-ethic that seeks to reshape the political landscape towards more ethical domains is different to the cynical, manipulative ploys of Trump and others. For us, I guess the question here might be: are we representing our own priorities, or those of the movement or the people we serve? Is it about ego (and, especially, our ego) or about engendering real, positive change?

D: Yes. And a practical way in which we can use authenticity to wrestle with the discomfort of representation is to look unflinchingly at that ever-present conflict between personal and collective goals and be willing to own up to the ways in which we are conflicted.

Intuitively I suspect that at least some of Medina's (2012) recommendations around hermeneutical responsibility could in fact apply internally to the manner in which we relate self and identity, the latter of which begins to introduce collective dynamics and a personal curation of identity that then coalesce through representation. I'm also really keen to shift the responsibility in these spaces from the storyteller to the host/listener per Medina (2012) and hermeneutic responsibility, but we may be leaving authenticity behind at that point?

S: I do wonder if it's a joint thing. There are some risks here, and I still think the emphasis is seemingly placed largely on the service user to enact change. The other extreme however is that we rely exclusively on people in the power structures to come round to our way of thinking on these issues. I see 'tactics', in particular 'tactical authenticity', as being part of the process. In very crude terms, sympathetic people in power hear our stories, resonate with our cause, and take issue with us with the things wrong with the system.

N: So basically, allies, in a sense, become part of a tactical series - that is, individual actors are decentered and the tactics play out across and between subjectivities. I also think, pragmatically, it's a reality that people already in positions of power either give up that power, knowingly and intentionally, or use that power to create real openings for those who have been historically excluded. Very practically: through mentoring, through mentored collaboration and support of actual leadership (in research, in policy, etc.) in the sense of control over decision making. Of course, a critic would say this is all still within the system (or the master's house), and of the system (master's tools). But...maybe...cracks that let the light in? The beginnings of an unsettling and disruption? Personally I would be nowhere—certainly not in a faculty position—were not it not for non-user/survivor senior mentors/allies who either took risks or made sacrifices on my behalf (and others with lived experience).

D: Yes, and I wonder if there is a degree of internalized sanism in mad-identified folks not going one step further and demanding organizational decision-making power, at least when we are not in the throes of madness. Ideally our service-provider CEOs and chief decision makers and department heads would be comfortable identifying as current or past service users. And that there should be individuals with these experiences in leadership roles. We need to recognize that this, in itself, will not guarantee positive change but it concerns me that we don't focus more on the goal.

I understand the personal core of privilege to be the ability to operate and assert entitlement (ie assert that individuals should be in leadership positions). Entitlement is a mindset used to translate privilege into power. Thinking again about the idea that "tactics operate without a territory of their own ... [and seize] the opportune moment": I can't help but think about mad-identified people operating entitlement, absent the strategic social dynamics that usually anchor privilege. The patient engagement zeitgeist could be our moment and more expansive understandings of the identity of madness could be a source of solidarity, albeit a solidarity with traps that need to be navigated with a skilful and humble understanding of diverse constituencies, openness regarding personal conflicts, and an active commitment to equitably share and shift power.

Discussion

In this article, we discussed the concept of authenticity as it relates to representation in service user involvement and Mad activism. The discussion originated with two key articles (Voronka, 2016 and Clarke & Wright, 2020) that explore the issue of 'strategic essentialism', a concept developed by Gayle Spivak (1988) to denote how certain characteristics or identities - in this context the qualities ascribed to service users/survivors/mad-identified people - could be used to gain a 'voice' within powerful institutions to facilitate more service user/survivor research. Whilst acknowledging the limitations of Spivak's (1988) notion of 'strategic essentialism' and some of the pitfalls of 'representation' – including speaking on 'behalf' of others, the dangers of co-option, exploitation etc – we also recognised that the notion of 'authenticity' still carries a lot of cultural weight and can be employed in various 'tactical' ways to advance the cause of increased involvement.

We think this discussion highlights two main implications. First and foremost, we identified that there is a plurality of views within the service user/survivor community and so 'representation' used to strongly advance a particular viewpoint can lead to exclusion and ableism. Indeed, the 'rhetoric of representation' identified by Scholz et al. (2017) and so often favoured by institutions may also be part of the problem of disempowering service user/survivors in leadership roles. Instead, shifting the language away from 'representation' and towards 'leadership', as argued by Scholz et al. (2017), may provide an important 'tactic' in legitimising service user and survivor involvement beyond tokenistic institutional

gestures. Certainly, it may avoid perpetuating some of the ‘myths of representation’ (Roper & Happell, 2006), if such leadership also strives for intersectional diversity along race, disability, class, and gender lines (Jones et al., 2020).

The second implication relates to the other side of the involvement coin: those in power who have the capacity to influence whether authentic involvement happens. In this article, we drew upon Medina’s (2012) notion of hermeneutical justice and the demand this idea places on those who act as potential gatekeepers for facilitating service user and survivor involvement. In this way, ‘tactical authenticity’ can also function as a way of winning over allies that can then support a foothold within institutions that can facilitate involvement leadership pipelines with greater diversity and inclusion (see Jones et al., 2020). Of course, as we repeatedly note, the struggle never ends—ongoing, clear-eyed critical reflexivity about every aspect of this—is imperative, as is the ongoing work of *collective* conscientization. Increased attunement to risks, costs and opportunities not only as individuals but (always) individuals-in-community.

Which brings us finally to the issue of research. How can these concepts support further research that is genuinely service-user and survivor-led? It is here also that the concept of authenticity can be useful in interrogating the supposed inclusiveness of research purporting to ‘involve’ service users. For example, does the research project in question genuinely seek to involve service users in all aspects of research decision-making, or is involvement relegated to a rubber-stamping of the choices already made by ‘senior’ non-service user/survivors? Does the research strive to include a wide range of service users, voices, or perspectives, or is involvement limited to a small homogenous group? Does the research include a detailed description of the involvement process, including the status of people with lived experience, or are these details absent from the methodology? If not, how, more pragmatically (or tactically) are those involved nevertheless strategically disrupting, unsettling, and complicating the work at hand? What kinds of relationships between and among user/survivors and allies, within these contexts, are in fact helping open new spaces for entrée? We believe such ‘tactical’ questions may help us to think, more realistically but not unambitiously, about the future of “involvement” and prospects for change.

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