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Title: “Nothing about us, without us”: Negotiating the personal and professional as activists and academics who use drugs

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“Nothing about us, without us”: Negotiating the personal and professional as activists and academics who use drugs

> *“We need to tell our own stories. If we don’t tell our stories, people with power will tell our stories for us. And we won’t like what they say.” (Cameron in Boyd et al., 2017:5)*

In this special section we celebrate people who use drugs. However, unlike most publications featuring our voices, we also celebrate our positions as researchers and advocates for whom drug use is vocational. We are liminal subjects. Our identities are conflicting, incomplete, and may be too much and not enough, sometimes all at once. The tensions we, Nicole and Magdalena, experienced fitting in – but never fully – with our drug using and professional peers brought us together. We first met in 2019 via an email that read:

> I am contacting you with perhaps a bit of an unusual request: I have been on medical leave from Oxford since 2017, and now may return, albeit with apprehension. I have followed your work in earnestness, and greatly admire how transparent you are about your own lived experiences with hepatitis C and injection drug use. I too, have an extensive background of homelessness, illicit drug use, disordered eating, mental illness diagnoses, and complex trauma, all of which have informed my research interests and the theories/methods I employ.
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> To be frank, my first attempt at the DPhil was horrific - I began using substances almost immediately and was later sent to a private, psychiatric facility by my college to detoxify. As you may imagine, I am concerned about returning to Oxford. I can't predict with any degree of certainty how I will respond to being in an environment I associate so strongly with intensive self-destruction, and I am also unsure of how to maintain a reasonable degree of stability without having yet established a personal or professional support network. I am wondering, then, if you might be willing to open a dialogue with me about your own experiences as a researcher: primarily, I am curious about how your background has benefited you in a professional capacity, as well as any drawbacks you have identified to studying something with which you are intimately familiar.

From early on, our weekly conversations were more than professional mentoring. We bonded easily over our predilection for ‘intense self-destruction’ as well as our frustration with institutions that champion diversity in theory but only support it within tightly circumscribed bounds. Magdalena wrote to Oxford. Oxford did not, however, take Nicole back. Our friendship continued.

Today, our conversations still focus on inconsistencies we encounter as analysts of drug use – Magdalena in the academy and Nicole in policy – whose relationship with drugs may be less tidy than our work suggests. We do not ascribe to a 'disease model' of 'addiction' – the latter term also rankles. With others, we work to reject narratives of 'addiction' as merely destabilising, taking seriously the resurgence of pleasure as a scholarly topic of investigation in relation to using drugs of abjection (crack, heroin, methamphetamine etc). We know that normalising discussion of the way in which drugs are intensely and pleasurably embodied, experienced as both capacitating and sublime, is a crucial move in subverting dominant pathologizing narratives. Yet we are equally aware that for some (us included), drug use may have destabilizing features. It may not always be pleasurable. And while we are committed to troubling reductive framings of bodyminds as merely "afflicted," we cannot ignore that we too may sometimes feel this way. How, then, to talk about the complexities of drug use? How to acknowledge struggle without reinscribing the same essentialism that has shaped our life trajectories, while also inspiring us to pursue these careers in the first place? Most importantly, how do we present our own relations with drug use as unique while still making visible the universal barriers that people who use drugs may encounter?

An interest in these questions and how others respond to them was core to this special section call. We observe that those who are 'out' as using illicit substances may feel obliged to present the self as in control, capable and reliable – as thriving rather than surviving. Doing so is an important political statement and may require little effort for some. But what happens if drug use in everyday life becomes harder to negotiate? What if volition edges toward compulsion and we can no longer meet external demands? These queries were brought to the fore for Magdalena in the process of generating a collective history of a peer-led needle exchange in New Zealand, where she was reminded of her all too 'messy' drug use and subsequent dismissal as a peer volunteer (Harris, this issue). In co-creating this history, in being confronted by memory, she wondered how things might have been done differently. How might her precarity at the time have been better supported, or was it indeed unsupportable? An early aim of this special section, therefore, was to generate conversation about how people who use drugs can be optimally supported and sustained in their work even – and especially – when our use collides with professional and organisational priorities. In this way, the history of the peer-led Dunedin Needle Exchange (Harris, this issue), while perhaps esoteric in its specificity, provides a context to the call. In reflecting on the achievements of peer-led advocacy and activism, but also its tensions and challenges, Magdalena asks what scope there is "work with or even celebrate the messy intricacies of dedicated drug use", particularly among organisations experiencing a precarious legitimacy. In doing so, she notes how fine the line of acceptability can be for those hired, but also fired, due to their lived experience.

Contemplating this line - not just where people land on it, but who is authorized to define it - has informed every stage of the special section production. Our first challenge emerged even before receiving submissions. Specifically, our call for abstracts, wrapped in academese, may have alienated some for whom drug use is already a mechanism of exclusion. When she was confronted about this on twitter, Magdalena felt misjudged. Later, she agreed. Through this early process we were forced to consider why, in wanting to create a special section for and by people who use drugs, we imagined scrutiny from critical theorists working in the field. What - and whom - was compelling us to, as Carl Hart later remarked to Magdalena, wrap our words up in 'bullshit'? These tensions also emerged in working with the pieces submitted. How to navigate our expressed desire for methodological diversity and innovation in submission, from a range of people who use drugs, and the academic conventions underpinning what is deemed 'publishable'? Despite a desire to push against these conventions we were also a conduit for them, encouraging authors to create their 'best possible' work, to downplay their anger, and to 'play by the rules', in order to be taken seriously.

These uncomfortable dynamics – of needing to prove 'worth', of deferring to respectability in order to be heard – also resonated throughout pieces received, aiding our understanding of the processes at play. PhD candidate Danielle Russell (this section), for instance, describes her disenfranchisement while living with injecting related wounds. In vivid detail she traces systemic and interpersonal barriers while accessing care and, in so doing, she elucidates what we know already: "paternalistic concern, silent judgment, or outright and obvious disgust" may not just be received from medical providers. If we aren't careful, it may come from colleagues, too. Decisions about disclosure are thus contingent upon identity: for early career researchers (Russell, Frank, Luongo, Zampini et al.) our precarity is inescapable. We are reminded of it constantly, and while disposability is woven into the fabric of academia, people who use drugs are particularly prone to feeling like double agents. For established academics also, disclosure may precipitate precarity and – with few role models to be guided by – appear an insurmountable challenge. Ingrid Walker, for example, shares the following statement, also rectifying it through her contribution: "My four decades of illegal drug use, whether claimed or unspoken, wholly informs my life and my work. Yet I have struggled to make that knowledge explicit in my scholarship."

We are, however, not completely bereft of role models. Carl Hart, one of the most well-known and celebrated academics to openly disclose stigmatised drug use, closed the 26th Harm Reduction International Conference in 2019 with a provocative call to arms. Referencing the gains and sacrifices of the civil rights movement to end legalised racial discrimination, he enjoined those with lived experience to 'out' themselves – to engage in collective civil disobedience against the persecution of people who use certain substances. A casual mention of the people he works with as more difficult to manage than his heroin use, operated as a strategic exemplar of such outing. For ‘high functioning’ professionals, such as Hart, to assert managed use of drugs irrevocably tied to scripts of marginality, compulsion and despair, offers a corrective to discourses coupling drug use and dysfunction. Likewise, in this section, Zampini et al. ask “whether researchers and other people with privilege are responsible for being open and honest about their drug use.” As they note, this can have “positive consequences, including its potential to dispel myths about who uses illicit drugs, moving away from stigmatised or stereotyped representations as well as linear, flat, totalising labels and understandings”. This special section provides an invitation to such an ‘outing’ but with perhaps a more uncomfortable remit. Rather than purely a celebration, a correction to pervasive narratives of dysfunction and marginality, we have asked for reflections on tension, on unmanageability – both personally and as embedded within institutional frameworks. Not all of us are ‘high functioning,’ at least not all the time.

Nicole grapples with this in her piece (Luongo, this issue). She employs autoethnography to examine how the academy, ostensibly a space for interrogating deviance, may not be able to embrace it. Extending critique of the ‘brain disease’ model of addiction (Heather et al., 2018; Keene, 2021; Lewis, 2017; Fraser et al., 2018), Luongo illustrates how the medicalization of substance use is reified through language to pigeonhole those with non-normative or aberrant behaviour as in need of medical intervention. This description of institutionalized responses to uncontrolled substance use highlights how practically reliant academia is on biomedicine – a stark departure from its deployment of theoretical innovations. In so doing, Nicole also approaches inquiries about “the line” not just from the perspective of having others decide that she has crossed it, but also as one who disagrees with decision-makers about what the line is made of. Her use of Mad Studies in this analysis is a welcome extension of critical drug scholarship, and in doing so Luongo troubles the myth of the stable, unified self and prompts us to consider whether loss of control while using drugs may also be a way to reclaim it, albeit unconsciously.

While Danielle and Nicole are nascent academics, submissions from those farther along highlight that most people who use drugs are susceptible to some degree of epistemic violence. This concept, introduced by postcolonial theorist Gayatri Spivak (1988), refers to how marginalized populations are prevented from speaking for themselves about their own interests, or not heard in doing so, due to others claiming to know their interests better. On this, David Frank (this issue) recounts an interaction with a ‘disbelieving doctor’ in which he has to draw on scholarly credentials while seeking reprieve from benzodiazepine withdrawal.

Not only does Frank render the physical anguish of withdrawal palpable, he illustrates how suffering is compounded when practitioners call us unreliable narrators (see also Russell, 2021). The dismissal of intimate knowledge by those tasked with alleviating bodily and psychic distress is a common violence visited on people who use drugs. Each of us knows this feeling, but the manifestations of stigma may be less dire if we can, as Frank does, cite scientific literature when forced to self-advocate.

Submissions from those who *can* self-advocate because they are viewed as leaders in drug-related knowledge production, interrogate how we got here. For example, Ingrid Walker, Associate Professor of American Studies and acclaimed author of *High: Drugs, Desire, and a Nation of Users*, explores the conditions under which we collectively and officially 'know' about drug use. She asks, "whose gaze frames people who use drugs — and why are some people who use drugs able to pass completely out of that frame of reference?". As a white tenured academic, Walker possesses the social capital to choose if, when and how to disclose her use. This relative privilege protects against much of the collateral damage sustained by oppressed populations who use drugs, but it can reproduce the processes that cause damage in the first place. Specifically, Walker argues that misunderstandings about drug use are recursive: stigma prohibits disclosure, which in turn circumscribes 'what we know' about drugs within a frame of reference that is limited to those who have no choice but to be 'out.'

Walker also notes the relative paucity of voices from people who use drugs in academic processes of knowledge generation about drug use. While people who use drugs may be invited on as research participants, this renders them 'subjects,' their voices and personhoods reduced to 'data' to be filtered, coded, and grouped thematically. In these cases, whether analytic interpretations are also informed by the researcher's personal experience is difficult to discern. As noted by Ross et al. in a recent related publication, such non-disclosure by drug use researchers can seem "contrary to some core academic principles, such as transparency in data collection and reflexivity in the research process" (Ross et al., 2020:268). Yet, while advocating the academic and activist benefits of 'coming out', the authors of this piece refrain from making transparent their personal relationship with drug use. The only reference to this decision, "our article is not a confessional", conjures well-grounded fears of academic opprobrium for "self-indulgence" in disclosure (Mykhalovskiy, 1997); somewhat at odds with Ross et al.'s call for "honest reflection in the field" (2020:281). The difficulty of drug use disclosure is once again rendered palpable, albeit inadvertently. Walker, with others in this collection, also provide stark examples of disenfranchisement upon disclosure irrespective of palpability. She admits to heroin use in a hospital setting, and akin to experiences documented by Frank and Russel, her authority is negated when: "My identity as a drug user trumped any other information about me, in a moment of testimonial injustice with the ER nurse". This is common among those who use drugs of abjection, and it elicits doubt about how and in which directions to advance collective meaning-making.

Stephen Wakeman addresses this doubt directly. Framed as "part reflexive commentary, and part methodological instruction manual", his article (this section) reviews the application and potential value of autoethnographic research methods for doing drug research. Because Wakeman's early work includes people who use heroin in a housing estate in North West England, his own experience of heroin use in similar estates grants him an embodied recognition of the physical cues and speech patterns observed from his participants. Attunement to the unspoken enhances the depth of his analyses and also protects against victimisation. It is possible for 'subjects' to become comrades, but as Wakeman notes, this transition is not given. About his 'representational dilemma' as a *former* drug user, he writes:

> I use my experiences of heroin addiction to question dominant understandings of the phenomenon and the role of choice and control within it. However, in doing so I run the risk of pathologising others and, by imposition, presenting my case as *the* case through which all others ought to be understood.

Thus, advocating for autoethnographic reflection among researchers about the way in which their drug use impacts on their work is not a reification of 'insider' experience. Wakeman's analyses are guided by personal experience of, but also distance from, heroin use. This distance, and his position as a researcher, inevitably evokes hierarchy because of the status ascribed to both.

Also as researchers and participants, Zampini et al. situate their article in the context of a participatory action research project in which they and their 'subjects' enjoy the pleasures of drug enhanced dancefloors. Invariably, this is complicated, and they articulate the challenges of melding their 'personal, professional, and political' standpoints. Foremost within this is acknowledgement of how social and cultural privilege act to insulate the authors from the structural violence that is visited on those less able to hide their use and/or excluded by types of drugs they consume. Like Walker, they also note the isolation of academia: *Doing* research, as an activity or practice (hence the suffix verb "doing"), gets conflated with identity, defining what a person *is*. This is akin to drug use (wherein one becomes a 'PWUD' or another, less diplomatic term) and the perceived incompatibility of these two practices-cum-identities can feel impossible to reconcile. As co-author Anthony Killick states, "the tension between these two parts of "my identity" can give rise to a feeling that I am some sort of stowaway in my job, that I will soon be found out and thrown overboard." (Zampini et al., 2021). Despite this, Zampini et al. affirm the value of self-disclosure for countering the ‘institutionalized isolation’ of academia, and for allowing academics to find ‘political collectivity’ that may eventually transcend it. Crucially, and foremostly, they advocate self-disclosure as a political stance – necessary to close the false divide between ‘expertise’ and ‘experience’, one which acts to “perpetuate hierarchies of knowledge, of deservingness, of moral status and of credibility”.

Hierarchies of knowledge, deservingness, moral status and credibility are classed and racialised, with different drug types also thus ascribed. Disclosure of ‘club drug’ use, as favoured by Zampini et al., has very different resonances to disclosure of heroin, crystal methamphetamine or crack use, for example. Administration through injection, and the visible traces of this practice, is particularly reviled. In this section, Lindy Clapp and co-authors poignantly relate the scramble of women who inject drugs to borrow or buy long sleeve shirts prior to court appearances and ask “if the day will come when those of us who have track marks will be able to show our arms in the summer without fear of being discriminated against”. As activists and professionals in Appalachia, U.S.A, a region hit hard by the twin crises of overdose and poverty, to not conceal or express shame around drug use is a professional liability. Lindy, for example, “was told that the most common presenting symptom for an anaesthesiologist who is using drugs is overdose death,” and while it may be impractical to resist expectations of abstinence when one’s income is at stake, succumbing to them also “den[ies] the policies, power relations, and historical contexts that shape subjectivities” (Clapp et al). On this note, Clapp et al. take issue with the term ‘lived experience.’ It is not just temporally narrow but applying it indiscreetly “risks losing the contradictions and shifts within people’s inner worlds.” Also narrow are the parameters within which people with ‘lived experience’ are expected to share their knowledge: *What people ignore when they ask Lindy to present is that their experiences with drugs contributes to their current success.”* In other words, what is not asked of people who use drugs is as salient as what is. Abstinence-only frameworks simplify and obscure. They also beget secrecy, and in bravely announcing their relationship to drugs, Clapp et al., with Walker and other contributors to this special section, dilute the “extreme representations of illegal drug use [that] dominate our cultural imagination.” (Walker, 2021).

Finally, Simon et al, (this section) provide a trenchant critique of dominant drug treatment systems while interrogating the mechanisms by which these are evidenced and changed. As activists from the United States’ Urban Survivors Union (USU), they illustrate how methadone dispensing requirements exacerbate risk and trauma among communities eviscerated by the ongoing North American drug toxicity crisis. They note that structural vulnerability is compounded by the Covid-19 pandemic, and throughout, the uneven adoption of flexible methadone provision by clinics has proved the urgent need for reform. Put simply, “it takes a pandemic to get a take home.” Yet despite being uniquely positioned to delineate the empirical evidence needed to advance public health and human rights, the authors feel disempowered by collaborative attempts with research academics. Specifically, the institutional review board (IRB) processes needed for ethical clearance preclude many people who use drugs from identifying as researchers, and vice versa. The resultant inability to “belong to multiple categories at once” (see Souleymanov et al., 2016) automatically places USU members, some possessing graduate degrees or in the process of acquiring them, on the bottom of the researcher-subject hierarchy, which is internalized by all. Damning is the lament, “they appeared uninterested in what we had to say or our research questions ...These researchers did not seem to want what we envisioned: a true collaboration where their infrastructure worked hand in hand with our unique insight”’ (Simon et al., 2021). In detailing these tensions and power imbalances, including within community based participatory research (CBPR) projects, Simon et al. call for a new paradigm of community *driven* research (CDR) and provide recommendations for its instigation. In finally conducting their own research to address community driven research questions, they reflect on its benefits:

> Participating in a research project led by people with lived experience gave our members a chance to speak out without fear or hesitation. It reminded every single member that their voices matter and their stories and experiences have value. (Simon et al., 2021)

Community driven research can empower people who use drugs because the questions formulated matter to the community and arise out of their collective knowledge and experience. Simon et al.’s quote above, on the importance of *being heard* and having community stories valued, resonates with the introductory quote to this editorial: *“We need to tell our own stories. If we don’t tell our stories, people with power will tell our stories for us. And we won’t like what they say”.* This excerpt is from a poem by Sandy Cameron, activist and poet in the Downtown Eastside, Vancouver. Boyd et al. (2017) include it in full, as a guiding impetus for research and action instigated and carried out by the SALOME/NAOMI Association of Patients (SNAP) to fight for the rights of people who use opiates, including through access to heroin-assisted treatment (HAT) and, more recently, user-owned and operated compassion club models. The poem continues: “When we tell our stories, we reach out to each other, and build community”. This special section has provided just one format, among many, for those stories to be told. We asked not only for celebratory stories, but those of discomfort, to understand the difficulties people who use drugs in academia and activism can face in negotiating drug use as it intertwines in their personal and professional lives.

Because many will never disclose, and are within their right to do so, we were honoured to receive contributions from some ‘outing’ themselves in public for the first time. Other articles describe conditions in which ‘outing’ is moot, and coming together in this special section, submissions likely confront rather than console. The questions we began with remain unanswered, and now they are further complicated by considerations around inclusion, exclusion, and the extent to which we were best suited to introduce them in the first place. This may have been the point: experiences of drug use are not homogenous. Our disparate points of entry into debates on policy, research, and authorship are as diverse as our identities, and to expect cohesive ‘solutions’ to problems we can’t uniformly define would have been naive. We remain unsettled. We also know we have reproduced some assumptions about what it means to be a person who uses drugs by virtue of publishing in an academic journal. Many of our peers and comrades will never read this special section. Moreover, amidst the daily, gruelling battle for survival, they may not care to read it, or have the tools to do so. The ‘we’ referenced herein is partial. However, during production, we – Magdalena and Nicole – may have expanded onlookers’ perspectives. Reviewers who exclaimed that submissions by activists were not sufficiently ‘academic,’ or, conversely, that submissions by academics were too personal, were one group who was forced to grapple with pre-existing beliefs. We would like all readers to do the same. We aim to reach a point where positive stories of drug use are so normalized that ones that are less positive, or imbued with chaos, grief, and pain, are not seen as reflecting the inherent properties of drugs. Only then will consent – around use, abstinence from using, reduction of use, increased use, or treatment for use – truly be accessible.

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