Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Exploring the Threats to Sociable Scholarship: An Autoethnographic Viewing of Participatory News Making

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Abstract

Sociable scholarship is the activity of engaging in, and disseminating academic thinking through social media as part of a commitment to be held accountable by the communities a scholar serves. Doing so has both benefits, such as increasing the people impacted by an article, and drawbacks, like ad hominem attacks. In this piece, we use collaborative autoethnography to explore common threats to sociable scholarship. We are activist scholars who are recognised internationally as experts in our field and as committed activists for social change. Marewa is a community psychologist and long-time advocate for reducing the harm caused by smoking tobacco; Cat is a Fat Studies scholar and fat activist who works to ensure fat people have the same rights as non-fat people. We reflect on our own experiences with a specific venue, Facebook Live, to share tips and tools for managing negative encounters, and suggest that universities have a responsibility to protect staff who engage as public intellectuals in digital spaces.

Keywords: sociable scholarship, activist academic, Web 2.0, social media

Global social media is being used by communities to demand and enact the changes they want. To stay relevant, scholars must engage in these new public spaces (Pausé & Russell, 2016). This requires a willingness to debate with the very people we 'study': community practitioners, our critics, and other activists or scholars with opposing views (as well as with traditional journalists). Tensions arise for scholars unskilled in or unfamiliar with the culture of social media. Pausé and Russell have called for research identifying the barriers for academics' use of social media.

Using an autoethnographic approach we discuss the threats to sociable scholarship. Recognised as 'activist' scholars, we are frequently called upon by the media for comment. Individually we have both participated in a

new format being trialled by a national television channel in New Zealand: a panel discussion livestreamed to Facebook that draws on audience comments in real time.

Marewa, a community psychologist and long-time advocate for reducing the harm caused by smoking tobacco, was called upon to debate if cigarettes should be sold in pharmacies only. On the panel were a tobacco control advocate arguing for the proposal and a smoker arguing against Government intervention. Whilst an uncomfortable experience for Marewa, this case is instructive for our purposes of illustrating the risks of sociable scholarship.

Cat, a Fat Studies scholar who studies the impact of fat stigma on the health and well-being of fat people, was invited to give a taped interview about whether the fat acceptance movement encouraged obesity; on the panel were a plus size fashion blogger and a fitness campaigner. Cat was dismayed when her interview was edited to a single comment and taken out of context; it is yet another risk of sociable scholarship, but also an opportunity to consider ways for scholars to mitigate the potential harm.

The incidents examined illustrate the importance of 'performing' ethically. As scholars we must protect our professions' reputation. We also have a duty as public servants to diligently perform our role as social critic and conscience, which includes responding to public requests for our expert opinion and to serve as educators. That includes responding positively, workload permitting, to media requests for evidence-based information and opinion, including to participate in being interviewed. But, what are our obligations when the platform for communication is commercially dependent upon an adversarial performance? How are we to respond to abuse? The participating audience wanted real, as opposed to alternative, facts, expert versus lay opinion. They saw themselves as the 'lay voice', the community, in these formats and were rejecting of a lay voice claiming 'expert' space. The comments on the show Marewa was in, revealed an expectation of value, not just infotainment. The audience wanted to have their say, and they expected to be given arguments for and against that they could adjudicate.

Background

Web 2.0 tools, such as Twitter, Tumblr, Facebook, and others, have created large holes in the walls of the Ivory Tower. These forms of social media allow for lay people to create knowledge, challenge existing paradigms, and engage in debate with scholars about their scholarship in public forums for the world to see. Communities themselves are able to use social media tools to push their demands into public spaces, force those in positions of power into public debates, and enact the changes they want to see. Scholars often find themselves in the centre of these spaces, especially ones who are committed to pursuing social justice through their scholarship.

Many academics embrace these new forms of engagement (Pausé & Russell, 2016; Veletsianos, 2013). They write about their work on blogs and online magazines like The Conversation. They host platforms on Twitter and Facebook, and join academic networking sites such as Academia.edu and Research Gate. And new scholarships have arisen to explore these new activities; Veletsianos (2013) and Weller (2011), for example, have explored how technology is transforming how some academics engage in their scholarship.

There are threats, however, when scholars engage in sociable scholarship. Some of these threats are familiar, like the tensions that may arise when scholars engage in activism. Or the tensions that arise when engaging with the mass media, as noted by McCormack (1965) in the middle of the twentieth century. Other threats are new, such as whether scholarship done in these social media spaces "count" for anything within the traditional academy. It also requires scholars to have the language and ability to speak on their work with others who may not have

the same background knowledge in the field, or consideration for their status as experts. For many, these threats are perceived as barriers to engaging in sociable scholarship. For others, the desire to engage exists, but uncertainty as to how to proceed, or respond to threats, remains.

Weller (2011) has called upon scholars who are engaging in digital scholarship to share their experiences, and bring to the light the affordances, tensions, and threats. And Veletsianos (2016) has echoed this call for scholars doing this work to build an evidence base about the ways these technologies are used and *experienced* by scholars. We both are regularly invited by national media to give comment on our respective topics, and have watched as mainstream media within New Zealand has begun engaging more with social media. For this piece, we will use our experiences as participants in a new format being used by a national New Zealand television channel's news show, Newshub Live on Facebook Live.

Cat was invited to give a taped interview about whether the fat acceptance movement encouraged obesity. On the panel were a plus size fashion blogger arguing for fat positivity and body autonomy and a fitness campaigner who was disgusted by the idea of fat positivity and believed it to be harmful. Viewed over 80k times, with over 550 comments, this first episode of Newshub live on Facebook was consumed widely within New Zealand. Marewa was called upon to debate if cigarettes should be sold in pharmacies only. On the panel, viewed over 22k times, were a tobacco control advocate arguing for the proposal and a smoker arguing against Government intervention. Viewers posted over 600 comments on the show at the time and afterwards.

Sociable Scholarship

Sociable scholarship refers to the way that scholars use social media, specifically Web 2.0 tools, to conduct their research, disseminate their research, and are held responsible for their research. Sociable scholars may be considered a subset of digital scholars, defined by Weller (2011) as "someone who employs digital, networked and open approaches to demonstrate specialism in a particular field" (p. 4). Sociable scholars embrace the affordance of Web 2.0 tools, in allowing users to create their own content and co-construct content with an untold amount of others with whom they are physically disconnected. Veletsianos and Kimmons (2013) have identified a networked scholar as one who uses digital neworks to promote their work and engage with others. We see sociable scholars as similar to both digital scholars and networked scholars, but unique in their motivation to engage in sociable scholarship. What drives a sociable scholar is their commitment to social justice, and their invitation to be held accountable by the communities they claim to serve.

Scholarship is changing in the age of social media (Pausé & Russell, 2016). Many scholars are embracing social media as a way to engage in research collaborations, disseminate their work to large audiences, and support and interact with the very communities they are studying. Others use social media to live Tweet conferences, maintain blogs, share syllabi, engage in debate, live stream teaching or research presentations, and crowd source help for professional activities (Veletsianos, 2013).

Faculty who engage in sociable scholarship report numerous benefits, including engagement in international networks, collaboration, and faster feedback from peers on their work (Crookes, 2016; Gruzd, Staves, & Wilk, 2012). Promoting scholarship through social media increases the impact and reach of the research (Green, 2015; Puustinen & Edwards, 2012), and allows for academic research to become part of conversations outside of academia (Lupton, 2014; Maslen, 2011). It also allows for engagement and interaction, in real time, with individuals across the world (Daniels, 2013; Pausé & Russell, 2016). These interactions allow for scholars to learn and ben-

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efit from the experiences of other scholars, but also the experiences of those being studied (Pausé & Russell, 2016). It provides a platform for scholars to use their voices to highlight social justice issues, unpack commonly held myths, and fulfil their role of critic and conscience of society (Pausé & Russell, 2016).

Engaging in sociable scholarship necessitates that the scholar be visible online, but being visible online opens the scholar up to engagement and interaction with (and criticism from) lay people, and opposition in one's sector and the press. Faculty identify a variety of threats they associate with sociable scholarship, including issues of privacy, time pressures, user error, and plagiarism of their unpublished work (Gruzd, Staves, & Wilk, 2012; Lupton, 2014; Veletsianos & Kimmons, 2013). The exclusion of sociable scholarship from promotion and tenure consideration is another concern; "scholars' digital participation may at times stand in stark contrast to and defy the evaluation metrics traditionally used to judge their work" (Veletsianos, 2013, p. 648). Many have called for the inclusion of sociable scholarship in traditional evaluations of academic performance (Biswas & Kirchherr, 2015; Pausé & Russell, 2016).

Other concerns include the blurring of professional and personal boundaries and coming under attack online (Gruzd, Staves, & Wilk, 2012; Lupton, 2014; Veletsianos & Kimmons, 2013). Being attacked is experienced most often by women, through sexual harassment, rape threats, and death threats (Lupton, 2014), and is especially worse for women in marginalized groups (fat women, women of colour, etc.) (McMillan Cottom, 2012). This is true for women outside of academia also. It is a common experience shared by women who engage online, regardless of their employment (Graham, 2017).

In a 2015 survey of 21,399 faculty members from across tertiary institutions in the United States, participants reported being concerned about scholars being attacked for social media activity, but did not report this influencing their own professional social media use (Straumshein, Jaschik, & Lederman, 2015). It is worth noting that most of the faculty surveyed did not report engaging in sociable scholarship. In contrast, Lupton's (2014) survey of 711 academics from around the world (most respondents were from Western countries) who engaged in sociable scholarship did report that their social media use was influenced by their awareness of the threats of being attacked/taken out of context/being put in a position that would damage their credibility as scholars or jeopardise their careers. The threats of career jeopardy to those who engage in sociable scholarship can be very real. Online engagement has resulted in academic faculty being reprimanded (including suspensions, being disavowed in the press, and being denied an appointment) (Sugimoto, 2016); the Board of Regents in Kansas, Nebraska, approved a policy in 2013 that gave senior administrators in the state universities the power to fire academic staff for their social media use (Lupton, 2014); this was condemned by the American Association of University Professors (2013b) as a "gross violation of the fundamental principles of academic freedom" (para 4).

For those that do engage in sociable scholarship, mitigating these threats is a real concern, as are adapting to the new platforms and Web 2.0 tools that are developed and introduced to what can feel like an already saturated space. New apps appear every day, and it seems like whatever platform was in vogue today, like Snapchat, may be considered old news by the time a scholar learns how to harness the platform for their purposes. One such recent addition to the social media field is Facebook Live.

Facebook Live was launched in August 2015. Integrated within the Facebook app, Facebook Live allows for users to post live streamed videos on their Facebook accounts. According to the "About" page, "Live is the best way to interact with viewers in real time. Field their burning questions, hear what's on their mind and check out their Live Reactions to gauge how your broadcast is going" (Facebook Live, "About"). When the Live session ends, Facebook

Live videos are published to the appropriate page or profile so the video can be watched on demand. Producing a Facebook Live video is relatively easy. The user simply selects "Live Video" from the options when updating a status, and the streaming begins. Candace Payne (aka, Chewbacca Mom) did this on her smartphone in her car after purchasing a Chewbacca mask for her son. Her Facebook Live video, which is approximately four minutes of her wearing the mask, "roaring", and laughing, was the most watched Facebook Live video of 2016 with 162 million views (Spangler, 2016). Other well-known Facebook Live videos include Buzzfeed's "Countdown to the 2020 Presidential Election" and the video of Minnesota police murdering Philando Castile while he sat in the driver's seat of his car, next to his girlfriend and small child.

While uptake among users has been slower than hoped, media companies were early adopters of the format (Hern, 2017). Facebook Live videos are pushed to the top of relevant newsfeeds to encourage real time interactions with the audience. And this real time interaction is connecting with viewers. Facebook Live videos receive 10 times more comments than other videos posted on Facebook (Greenberg, 2016). Spayd (2016) suggests that Facebook Live represents a "potentially transformational form of journalism because they let stories unfold organically, live, and with the audience able to change the experience" (para 4). This appeal is likely what drew traditional media in New Zealand to the Facebook Live format.

In 2017, Newshub began a weekly live panel show on Facebook Live. Each panel was centered on answering a question which was promoted to the Newshub audience via social media over several days preceding the show to excite users to participate and have their voices heard. Viewers were encouraged to post comments, ask questions of the panel members, and share "whose side you're on". Newshub instructs that a "FB like" expresses support for panel member A while a "FB love" shows support for panel member B (the designations vary; other signifiers used have been the "thumbs up" emoji, the "FB wow", and the "heart" emoji). Topics explored have included, for example, fat acceptance (8 February 2017; 85k viewers), racism in New Zealand (15 February 2017; 35k viewers), and decriminalising methamphetamine (2 March 2017; 25k viewers).

In March 2017, Newshub increased their use of the format to a daily 30 minute show including live content and studio interviews. The show was promoted as presenting the news at "a faster pace than traditional 6pm or late programmes" (Newshub staff, 2017, para 1). According to MediaWorks Chief News Officer Hal Crawford, this was a step the network took to meet audience demand while increasing the amount of news broadcast. Panel topics that have been part of this daily format include the gender pay gap (22 March 2017; 13k viewers), plastic surgery (6 April 2017; 31k viewers), and tobacco sales (13 April 2017; 22k viewers).

The show begins with the reporter introducing the panel members and their credentials are made clear. The reporter then introduces the question at hand before a short prepared video is played giving some context to the question. A debate between the panelists then ensues, with the reporter asking questions, inviting feedback from the audience, and occasionally introducing pre-recorded video clips of other speakers on the topic. At times during the show the reporter will stand and move to read audience posts which are displayed on a large screen. In this way, viewer input is used to direct the tone and following content of the show in real time.

Methodology

Collaborative autoethnography proved a useful method for exploring our experiences with sociable scholarship and the risks associated with being a scholar engaging with the public in a live streamed spotlight. Autoethnography encourages scholars to reflect on personal experiences and how they relate to, and refract from, existing theoretical frameworks and literature (Ellis, Adams, & Bochner, 2011; Geist-Martin, 2010). It is especially useful for exploration of topics and questions that have yet to produce other empirical work; while emerging, the literature on sociable scholarship is limited. By sharing our own experiences wrapped in the theory of sociable scholarship and understood through the lens of the research that does exist, we help build the literature in this area and contribute to the growing body of knowledge on sociable scholarship.

We used a concurrent collaborative autoethnography model (Ngunjiri, Hernandez, & Chang, 2010) which began with us sharing our recollections of our individual Facebook Live experiences, including reflecting on what we remembered most. This took place several months after our appearances on the show. We then independently wrote full narratives recounting the sequence of events, our emotional lived experience of them, and after-effects and behaviours we used to retain our commitment to social scholarship. Each of us were able to re-view our segments of Facebook Live as they are preserved online. Next, we independently read each others' story. We then discussed the common themes across our narratives, the range and variance in our feelings triggered by our experiences, and where our experience connected with contextually specific elements of the live social media experience and the broader social phenomenon of political polarisation and associated suppression of science (Sagner et al., 2017). Using a somewhat deductive analytic approach we identified content specific to the focus of our investigation, that is, we further reflected on the risks we could identify in engaging in this kind of scholarship, and whether our backgrounds as activists provided useful tools to negotiate the risks. We repeated this process several times, and each discussion included posing probing questions of each other. This is a vital step in the collaborative process as it mitigates against settling in one's own perspective and enables new insights (Ngunjiri, Hernandez, & Chang, 2010). Subsequently we updated our narratives to highlight excerpts that illustrated the key themes and lessons we had independently and collaboratively identified. At this stage we eliminated content outside the scope of this paper's investigation. For example, content about the viewers' opinions on the Facebook Live question, or fine detail about the chronology of events.

Autoethnography as a method is not without limitations and critics. Our experience reflects our historical, socio-political and professional contexts which are sometimes similar (we are both cis-gendered highly qualified employed women) and also very different (e.g. colonised Indigenous versus American expat). Our experience of live social media broadcasts cannot be extrapolated to how others would experience being publicly misrepresented or subjected to ad hominem attacks within such a context. Autoethnography has been criticised for not being objective, seeming to be just opinion. If the content is intimate in nature some readers may experience discomfort which can trigger a defensive reaction such as minimising the reported experience, needing to reframe it.

Sharing such stories and vulnerabilities opens us up to other risks; risks that are common to the autoethnographic method, such as the risk of disclosure, risk of shame, and risk to our reputations (Ellis, Adams, & Bochner, 2011; Lee & Pausé, 2016). Opening ourselves up in this way leaves us vulnerable to those who may suggest that there is nothing of substance behind the curtain; or to those who would seek to discredit our work and expertise by highlighting our human insecurities and pain.

Our Experiences – Two Cases

Cat –

It began like any other request from the media - am I willing to participate in a story they are doing about fatness? In this particular case, the invitation was from Newshub, to participate in a new format they were testing on Facebook: using Facebook Live to host short debates. Each segment would ask a question, and encourage viewers to answer the question through likes and loves on Facebook, as well as through comments throughout the show.

I wasn't quite sure I wanted to participate for two reasons. First, the topic, "The fat acceptance movement – does it encourage obesity", is about as clickbaity as you can get. (Can anyone out there explain to me what it means to encourage, or promote, obesity? This rhetoric is tossed around a lot, usually when a fat person is asking to be treated with respect or allowed to not hate themselves, but no one can ever actually explain to me what it means when I ask.) But, when dealing with mainstream media, clickbait is unfortunately par for the course in the days of the Interwebs. My second concern was related to the format proposed: the Live part wasn't a problem, as I've done lots of Live media before (TV and radio), but the idea that people watching the segment would be commenting in real time – and then those comments would become part of the story – that part gave me pause. I don't read the comments online, and the idea of coming face-to-face per se with a living breathing comments section didn't appeal to me at all.

I wouldn't normally agree to participate in a media story like this. I've long learned to say "no" to stories that I know will be exploitative. I also have riders that usually accompany my agreement to participate in a story, including that the information is factual (no claiming that New Zealand is one of the fattest countries in the world), and that the images associated with the story are not headless fatties (fat people without heads; presented as bulging abdomens only; Cooper, 2007). In the end, I agreed, largely to support the fat activist who I knew was going to be live in the studio for the segment. I did a short interview with a producer, going over my credentials, some basic Fat 101 Qs, and the details of the recorded interview. They then pre-recorded the interview for them to use during the Facebook Live stream when appropriate. The interview itself lasted around 30 minutes, and none of the questions were unexpected. I tried not to let myself be baited into any statements that they could clip away from the rest and use as an incendiary soundbite, but that's almost impossible when your footage is going to an editing room.

When the episode aired, I watched, along with around eighty five thousand other New Zealanders. From the start of the segment, I knew it was going to be bad. The opening clip package was full of fallacies and headless fatties, and I found myself grateful that I wasn't in the studio watching this unfold while others were watching me. It turned out, I played an almost insignificant role in the segment. My thirty minute interview was edited down into a clip of less than thirty seconds that was a slice of several different responses. This resulted in my contribution being a jumbled mess of reflections on what constitutes an epidemic, evolutionary trends of demographics and health, and the impact of telling fat people they can never be healthy. It was difficult to watch, even by myself in my office.

Cutting back to the panel after my pre-recorded bit, the reporter turned to the physical trainer on the panel and asked his response to my comments. He responded by calling me "delusional." Delusional!

According to Google, delusional means "characterized by or holding idiosyncratic beliefs or impressions that are contradicted by reality or rational argument, typically as a symptom of mental disorder." From his perspective, I'm out of touch with reality or rational argument; possibly insane. And now maybe the audience is agreeing (I'm trying very hard to ignore the comments that are popping up on the video as I watch; I never ever read the comments as a method of self-care). It isn't an uncommon attack on those who push back against structures of power – even more common when the individual making trouble is a woman. Witch. Delusional. They mean the same thing; hold the same purpose. And while the reporter makes an incredulous noise to this, she doesn't challenge him to back up his attack on my expertise or credibility with any evidence.

It's difficult for me to pay attention after this. I keep watching, almost in a daze, as the fat activist on the show does her best to hold her own – and the idea that fat people deserve the same rights and dignity as non-fat people – amidst the growing jeers of the others in the room with her and those who are participating from their own spaces through the Internet.

Marewa –

I was interested to participate in the show both to present an argument against the proposal to restrict sales of tobacco products to pharmacies, but also because this was a new communication platform reaching, as explained to me by the journalist, a younger audience that prefers social media platforms as sources of information. I saw it as a learning opportunity for me to experience this innovative format.

The programme started out with the journalist introducing the other panelist in the studio who was a tobacco control spokesperson known to me. I was introduced as an academic who had spent the previous 20 years focused on tobacco control and health promotion. The journalist then pointed out that given that we both wanted people to stop smoking we'd presumably have the same view on the topic but in talking with us prior to the show she'd found we had "conflicting views". This established the adversarial nature of the programme, which I had come to expect as New Zealand media had an obligation to present a 'balance' of both sides of an argument.

An innovative feature of the show was the inclusion of questions and comments from viewers. The first viewer comment introduced into the discussion was that further restrictions on access to tobacco would cause more black market activity. This was an unintended negative effect of tobacco tax hikes that I had been trying to raise awareness of. At this point in the show, my fellow panelist tried to stop me talking by speaking over me and raising her voice. Silenced, since I did not want to engage in a shouting match, I shook my head. The journalist took control and invited me to speak but my counterpart became animated and interrupted again. The journalist shifted to report viewer comments posted on the Facebook page over the previous 24 hours.

I liked the audience comments as they were aligned with my efforts to reveal the illogical premise underpinning restricting tobacco sales to pharmacies which as one viewer said are "supposed to sell medications that are good for you." At this point in the show a pre-recorded Skype interview with Joshua Geddy, representing a smoker's view was played. He argued against government infringing his self-determination over his own body. The journalist invited the other panelist to comment on this first. In her response she used a common tobacco control rhetorical strategy of justifying denial of adult autonomy to protect children

from initiating smoking. When invited, I challenged the portrayal that children were as at risk as implied by reporting that New Zealand had been very successful at reducing uptake of smoking among kids.

Again my counterpart reacted sharply and interrupted: "You know what? You sound more and more like you're coming from the place of tobacco industry thinking more than the public and the community and the future of our Māori children."

I was shocked by this attack on my credibility. I knew people in tobacco control globally had been levelling this kind of attack against anyone who challenged their proposals, but none had gone so far as to publicly frame me as aligned with, if not speaking for, the tobacco industry. I felt fear. This triggered an internal struggle to calm myself and maintain a professional composure.

I thought it appropriate to show a bit of dismay and, despite the internal panic I was feeling I said "Yeah so just trying to discredit me isn't very professional I think. What we really want to do is discuss and debate the actual issue [opposing panelist begins to interrupt] and not get into personal attacks."

I recognised these jibes on my identity as a Māori woman and as an 'ivory tower' academic, - hurtful comments I'd experienced before. This was a time when my history of having experienced numerous sorts of abuse as a child, as a young woman, as an adult partner and as an employee, did not serve me well. Internally, I dissociated - one stream of thought riled against what I felt was an abusive attack, another thought stream forecast the damage her portrayal of me could result in triggering more fear, fear that was well founded given the many things people in the sector had already done to undermine my career or drive me to abandon tobacco control. Meanwhile, one part of my mind worked to manage my external composure, to continue to carefully but quickly and authoritatively respond to the journalist's questions as you must always do regardless of the medium.

The journalist recovered control and changed the direction of the debate giving me an opportunity to speak uninterrupted for the longest time yet in the show. This helped me. The journalist also seemed to be sympathetic to my concern for the way minorities were being stigmatised and this helped quell my internal panic. Still, I felt trapped. The struggle between fear and anger had me wanting to walk out, but this would have appeared unprofessional. I believed that viewers wouldn't understand -they'd see such a behaviour as an over-reaction. I felt out of place because of the damage I had survived.

Avoiding Threats to Sociable Scholarship

Our common experience was that of dismay and hurt. We were both used as adversarial fodder in a live show reminiscent of reality TV shows that trade on unscripted displays of uncontrolled emotion (preferably shock, anger and hurt) wrested from unsuspecting players. This was facilitated by the programme journalist and directors framing the question as controversial and the panelists as polarised. Imagery was used in the show Cat appeared in, that deliberately attempted to dehumanise and ridicule fat people, including the two fat activist panelists. By contrast, the producers and journalist sought to mock the unjust prohibitionist ideas of tobacco control in the show Marewa appeared in. In each case, the audience was encouraged to pick a side and comment. The forum however lacks the traditional protections of academic professionalism or the shared values for engaging in mutually respectful debate. The audience got to 'enjoy' freely passing judgement on the tobacco control worker for her

"rude" behaviour and want to intrude upon people's rights to make their own decisions. Fat women were clearly the presented target for the audience to 'hate on' in the show Cat was part of. The wider social normalisation of abuse of women contributes to newscasters in New Zealand reporting that Facebook comments are the most abusive and gendered remarks they receive (Graham, 2017). These negative comments are also, unsurprisingly, related to the appearance of the woman herself.

Whilst an uncomfortable experience for both of us, the experiences we present are instructive for our purposes of illustrating the risks of sociable scholarship, and for considering ways to mitigate harm.

Ways to Mitigate Threats

At an individual level, it is important to understand the format and genre of a platform in order to make an informed choice about how or whether to participate. If Cat was informed that the show was going to incite abuse of fat people by dehumanising (e.g. cutting their heads off) and ridiculing them, and thus her, as she said, she wouldn't have participated. Second, it is important to know who will be opposing you. With a deliberately adversarial format, anticipating the counter argument and preparing reasoned evidence-based responses can help carry you through unexpected ad hominem attacks on your credibility. The old adage 'know your stuff' holds true here – you're going to need more than empty rhetoric to achieve cut through with a blood-baying audience.

The comments on the show Marewa was in revealed an expectation of value, not just infotainment. The audience wanted to have their say, and they expected to be given arguments for and against that they could adjudicate. They wanted real, as opposed to alternative facts, expert versus lay opinion. They saw themselves as the 'lay voice,' the community, in these formats and were rejecting of a lay voice claiming 'expert' space.

Another truism is 'be prepared.' Undertake training in speaking to the media. Attend talks and workshops offered by sociable scholars. Practice by participating on other platforms that afford more distance and protections, such as being able to block abusive Tweeters.

A pretty standard rule of thumb for surviving online, especially if you are a woman, is never ever read the comments (Graham, 2017; Williams, 2015). Comment sections, whether on news stories, blog posts, or elsewhere, are some of the most grim places on earth. Often filled with sexism, racism, comments related to women and women's issues, especially, are less likely to be about the issue or topic at hand, and more likely to be focused on reinforcing misogyny and targeting a woman's appearance. As Cat reflects,

> I never ever read the comments; this is part of how I stay active online. If I read the comments, which I can predict with alarming certainty, I would struggle to maintain an online presence. Why would I want to invite that kind of vitriol and nastiness into my life? As a fat woman, I consume a great deal of anti-fat hatred every day of my life. Through the media, in the common room at work, government policies on obesity, etc. I do not need to consume even more voluntarily by reading what people online think of my work or my activism (or my fat body).

While some news sites, like Popular Science, NPR, and Radio New Zealand, have closed their sites to comments (Goujard, 2016), social media companies like Facebook tout user comments as a key feature of what the site offers to advertisers. And Newshub Live promotes this as a key feature of their platform, inviting viewers to guide the

segments with their real time feedback. Marewa found reading the comments to her Newshub Live video comforting, as they reinforced her own experience of an abusive situation where she was unfairly belittled and harassed by her fellow panelist:

> Once the show ended, I told the other panelist that I had found her behaviour abusive and unacceptable. This was empowering for me since many times I had never been able to name the abuse at the time or come out of shock fast enough to do so. I left for the nearest cafe for a cup of tea hoping to settle myself in time for another TV news interview on a different topic.

> Cup of tea on its way, I accessed the Newshub Facebook page on my iPad to read the comments. There were hundreds of posts. I skimmed through to the comments made during the airing of the show. I was comforted to read many comments from viewers expressing disgust at the other woman's behaviour. They disliked her interrupting, preventing me from speaking and her attack. This was incredibly healing for me. I had been abused in public and for once, the public saw it as I did and they disliked it.

At an institutional level, employers can help to mitigate potential threats to faculty who engage in sociable scholarship. Unlike workplace harassment, scientific bullying in the public domain often goes unpunished (Sagner et al., 2017). Strong institutional support when being trolled or piled on ensures that the faculty member has access to resources if required and doesn't have to worry that their University may be the next to join the pile. Tertiary institutions, then, must have clear social media policies that outline how they will support faculty members who engage in sociable scholarship, as McMillan Cotton (2012) have said "making public scholarship less dangerous requires institutional commitment, allies, and advocates" (para 2). It is estimated that less than one quarter of universities in the United States have social media policies (Pomerantz, Hank, & Sugimoto, 2015); no study has been located to examine this worldwide, or in other countries. These policies usually address three issues: the legality of social media use, the appropriateness of social media use, and the branding/image of the institution being represented. In order to protect faculty, tertiary institutions should work with faculty and their Unions to craft policies on social media. These policies must balance the academic freedom of faculty with mitigating potential risk to the institution (Sugimoto, 2016). The AAUP (2013a) suggests that "any such policy must recognise that social media can be used to make extramural utterances, which are protected under the principles of academic freedom" (para 7). And while they should clearly identify the institution's expectations for the faculty engaging in sociable scholarship, they must also clearly identify what support the faculty can expect from the institution if they come under fire online. Further research is needed into what institutions are doing or can do to protect, train, and support faculty to extend their sociable scholarship.

For clear and extreme harmful acts of defamation or bullying there may be national laws that academics supported by their employer can appeal to. In New Zealand, for example, in addition to there being broadcasting standards and laws against defamation, harassment and discrimination, a 'Harmful Digital Communications Bill' was passed in 2015 to specifically prohibit cyber-bullying of individuals.

Conclusion

Social media offers a far-reaching platform for raising awareness of social injustices, lobbying for change, building collaborative action, and supporting community development. There are hundreds, if not thousands, of like-minded lay persons, academics and social and community activists working online on almost every socially unjust

issue there is. Much of the communication is "For Good" (Diaz-Ortiz, 2011). We, as academics, need to participate in this work. As Sagner et al. (2017) reminds us, "Genuine experts debating content are intrinsic to the scientific method, while non-experts implying improprieties, merely because they disagree... are a hindrance to it" (p. 523). As academics, we also need to study this phenomenon as social scholarship is fast becoming an everyday communication and dissemination tool.

Our paper provides a unique contribution to the literature highlighting the democratising opportunities that social media presents. Whilst autoethnography can be a challenging methodology for scientists unfamiliar with it, utilising non-traditional research methods, especially reflexive methods that reduce the artificial distancing of researcher from researched, is part of the changing role of intellectuals engaged in activism, as we are. Autoethnographic accounts appear highly personal, risking minimisation as mere subjective opinion rather than the empiricism that it is. Unfortunately ad hominem attacks on scientists are not uncommon and more research of all sorts is needed to expose the strategies being used to suppress science, understand why it is happening, and inform prevention efforts. Our tale is useful for alerting academics to the ambiguities, threats and harms which social media can present. There are risks, but these can be mindfully navigated rather than prohibitive of our involvement. If we allow uncivility to silence us it is science itself that will suffer. Thus we urge you to extend your reach and support of the lay public and their communities, and your peer-activitist – get online and get amongst it.

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Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

The Politics of Error: Rethinking the Power of the Symptom in the Case of ADHD Diagnosis in Chilean Society

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Abstract

This article seeks, mainly, to develop a critical approach to the problem of Attention Deficit Hyperactivity Disorder (ADHD) and, through this, to rethink the problem of activism and militancy in relation to the power of a symptom linked to a corporality that seems to overflow a determined moral political framework. For this reason, we seek to think of a militancy that intensifies error, as a political power, beyond the search for a specific and universal diagnostic associated with what is understood as evidence. We begin with the description of the emergence of what we have called the ADHD Situation. First, using field notes from a collective ethnographic investigation performed during 2017, we describe the ADHD Situation as an ongoing process. Then we connect it to a broader context by examining the role of the school in contemporary Chilean neoliberal society from a genealogical-affective approximation, trying to avoid substantializing readings. In the second section, we develop this connection, describing the production of the ADHD Situation through the lenses of epistemology, ethics, economics, and politics. We also use here a critical analysis of three key documents that help us chart the institutional development of the disorder: The National Mental Health Plan (2017), the National Children's Health Program (2015) and the Clinical Guide to Attention Deficit (2009). We demonstrate the existence of an epistemological connivance between macrosocial transformations and the community approach utilized in these documents. This provokes us to think about a militancy capable of trespassing the borders of academia, health definitions, and social interventions through the intensification of the power of error as an opening to radical transformations.

Keywords: ADHD, power of the symptom, epistemology, situational analysis, community psychology

The spirit that mobilizes the present work is born of a systematic inquiry into the ways in which it is possible to understand the link between the level of social organization, particularly around economic, political, and moral dimensions of social life, on the one hand, and the plane of individual suffering on the other. In this sense, we are not far removed from a long critical tradition that has taken on the problem of understanding social malaise

(Durkheim, 1992; Ehrenberg, 2010; Freud, 2010; Illouz, 2010; Lordon, 2013; Malabou, 2017). At the same time, we seek to construct an affective reading of the social world, in the line developed by Lordon (2013, 2015) and Lara et al. (2017). Marking a difference between feelings and affects, which pass through a higher level of codification in the case of feelings and are grounded in a more specific material reference in the case of affects, we understand affects as differences, transitions between one state and another, linked to environmental factors. For human beings, these are as much historical and structural as biological. Indeed, our capacities, or power (*potentia*), are a historical-biological composite. Environmental factors produce affect during transitions between one state of our power and another. The historical-biological dimension of this dynamic requires affective genealogies to reconstruct the heterogeneous forces that gave rise to currently operating environmental factors, for example, the moral, biological, and political dilemmas around attention deficit. (Clough, 2010; Deleuze, 2008, 2017; Gregg & Seigworth, 2010; Lordon, 2013).

We will focus on the way in which Attention Deficit Hyperactivity Disorder (ADHD) is understood and managed in key documents of the Health Ministry and Education Ministry, documents which claim a community psychology perspective. Nonetheless, we will first examine the assembling of what we have called the ADHD Situation (Claro Tagle, 2015; Rauthmann, Sherman, & Funder, 2015), linking it with broader social transformations that point to a *post-liberal era*, understood as the recent transformation of the neoliberal regime. In that sense, we seek a useful way to read and map both the diagnostic and the broad context of social transformations, specifically through the description of an *epistemological connivance* between the core of neoliberal doctrine, the search for standardization of knowledge about ADHD inside and outside the school, and finally a critical appraisal of the way in which "community" is understood in the official health and educational documents.

ADHD as an especially contested mental health category makes really clear the impossibility of understanding these without a broad sociological frame. Indeed, the "controversy over labelling children with ADHD and medicating them with potent psycho-stimulants has grown as the prevalence of ADHD has skyrocketed" (Wallwork, 2017, p. 257). Still, epidemiology studies state that ADHD is the principal mental health diagnosis received by Chilean children and its main symptoms are said to persist in adult life (Urzúa, Domic, Cerda, Ramos, & Quiroz, 2009; Wender & Tomb, 2017).

In Chile, the prevalence of the ADHD diagnosis is comparatively high among boys and girls of 4-11 years of age in the general population with an incidence of 15.5% nationwide and 18.7% in Santiago versus just 5% globally (Bergey, Filipe, Conrad, & Singh, 2018; Caliman, 2008b; De la Barra, Vicente, Saldivia, & Melipillán, 2012). That is why, in addition to ethnographic approximation, we will critically examine the National Mental Health Plan (Ministerio de Salud [MINSAL], 2017) and National Children's Health Program (MINSAL, 2013) in Chile. Furthermore, this disorder is mostly related to child behavior in school; therefore, we will focus on the Clinical Guide to Attention Deficit for Educational Institutions (Ministerio de Educación [MINEDUC], 2009). This clinical guide for diagnosing and treating ADHD in schools literally indicates that it affects critical areas of the educational institution.

Methods

We construct the critical analysis of the aforementioned documents mixing sociological discourse analysis and a genealogical approach (Gordo López & Serrano, 2009). We also use three field notebooks of collective ethnographic observations recorded in three schools during 2017[i] (Gordo López & Serrano, 2009; Ruiz, 2009, 2014).

In the following sections, we will describe the emergence of what we have called the ADHD Situation. First, using field notes from a collective ethnographic investigation performed during 2017, we describe it as an ongoing process. We then connect it to a broader context by examining the role of the school in contemporary Chilean neoliberal society from a genealogical-affective approximation, trying to avoid essentializing or substantialiting readings. Then, in the second section, we develop this connection further, describing the production of the ADHD Situation through the lenses of epistemology, ethics, economics, and politics. Finally, we will explore what kind of consequences these political changes and this diagnostic model could have for the comprehension of what a community is and for social activism.

The Development of the ADHD Situation: From the Ongoing Process to the Affective Scenario

"They Have Something That Doesn't Exist" or The Fabrication of Evidence

One of the first observations that seemed important in our collective discussion about the ethnographies we performed was the apparent evidence of the presence of ADHD. It was surprising and paradoxical because in all three schools, but particularly in the one with the largest School Integration Program (PIE Spanish initials)[ii], teachers and other professionals believed that ADHD wasn't a really existing disease but a name for disorderly kids. But, at the same time, they said to us that it would be completely "evident" which children "have" ADHD and which didn't have it. We asked them not to say which children were diagnosed in order to test that "evidence". Of course, both inside and outside the classroom it wasn't so obvious who had and who hadn't been diagnosed. Instead, we formed here our first hypothesis: this purported "evidence" could be a particular manifestation of a larger mechanism, one that could be analogous to the function of what more generally is conceived as evidence in evidence-based medicine and psychotherapy.

Class as Normative Order of the Attentional Flux

The function that the idea of *evidence* fulfils is the positioning of the individualistic point of view as the legitimate one. In a sense, it is similar to what Lahire (2013) or Ehrenberg (2010) show about the supposed return of the individual in sociological theory, to the extent that this could be understood as a point of view of the sociological practice itself rather than a shift in social ontology. This operation could be understood as the core of what we call here *epistemological connivance*, a non-explicit or even unconscious, i.e., tacit agreement that everything that we can study and intervene in are discrete substances, characterized by their completeness and self-determination (Lordon, 2013). That being the case, it then follows that a child with ADHD is evident because the child is considered "one thing" and the ADHD another. It is the presence of one discrete thing in another that is evident, and the relationships of this admixture with classrooms, classmates, families, and the society, in general, are posited as accidental inconsequential details in the life of the diagnosed child.

As we understand it, the situational approach implies a completely different point of view. If the child with ADHD is supposed to be evident, then we try to follow which elements compose this evidence. We adopt a pre-individual and fluid perspective. From an ethnographic perspective, a class is not an aggregate of individuals, it is at the same time an organic composition and more important for us now, an assemblage of fluxes. In particular, attention acts like a flux.

This statement is not a novelty at all regarding the different ways of problematizing attention. From scientific psychology (Ortega, 2014; Sadek, 2016; Sangüesa, 2012) to economics (Beller, 2006; Citton, 2013, 2014a; Franck & Degoutin, 2013), passing through several approximations from the social sciences (Bergey et al., 2018; Comstock, 2011; Stiglitz, 2006), attention has been understood as a flux. We want to emphasize this in order to avoid the individualization of suffering, even as a strategy to criticize the dominant point of view (Singh, 2013).

Taking account of attentional flux, organizing a class involves a recurring appraisal of what constitutes adequate flux. When does a class start? This question is directly linked to what is tacitly considered as an expected or adequate flux of attention. Of course, a class doesn't begin with the ringing of the bell. This is a great example of what Goffman and symbolic interactionism call the 'definition of the situation', understood as a working consensus about the issues at stake and the corresponding behavior (Goffman, 2006). The agents in the scene need a minimum certainty about what they have and what they can do. Any symbol that we can find in the ongoing situation (e.g. gestures, voices, positions, movements, etc.) can be understood as environmental factors that produce affects which compel agents to perform or not perform an action. In that sense, a class starts when the external signs of attention are mainly centered on the front of the classroom, i.e., on the teacher and the board. We try to emphasize that this is not a conscious reading of the situation. From an observational point of view, this is closer to a "state of body" to paraphrase Bourdieu (1999), in the sense that this is something that various agents seem recognize together, as a body, almost spontaneously.

Nonetheless, anyone who has taught a class once knows that attention is subject to variations. That's why it is so easy to associate it with flux. At the same time, this implies a *variation threshold* (Deleuze, 2008) where the presence of other foci of attention is acceptable. The persistence of certain behaviors (e.g., an interruption) or a remarkably violent conduct (e.g., a disruption) mark the limits of an acceptable contest for the expected attentional flux. In that sense, a class constitutes a normative order related to appropriate or adequate flux. The variation threshold is associated with the organic composition of the class itself and, at the same time, with the affective regime in which the school is inserted.

Two Fixations: Name/Behavior and the External Signs of Attention

An ADHD Situation emerges from a school-class situation when two fixations are produced. Again, from an observational standpoint, the purported evidence of a child with ADHD is the construction of the evidence itself. As we were physically (and symbolically?) on the opposite side of the room from the teacher, we could observe what was happening literally behind their back, including the circulation of the social workers and other professionals from the PIE inside the classroom.

In classrooms with an average of 40 children, lots of things are happening when teachers are not able to watch the students and make decisions regarding the adequate flux of attention. Even if these "new classrooms" have other adults (PIE professionals), there are many opaque fluxes: whispers, jokes, images (a lot of images in cell phones or similar clandestine electronic devices), rumors, love, sadness, rage, fears, etc. There are also opaque misbehaviors, bodies which are able to stop acting in the exact moment when the teacher turns around and faces the class again. What happens with the evidence of a child diagnosed with ADHD is exactly the opposite. In the midst of a wider situation made up of little misbehaviors, an interpellated conduct is fixed with a name due to a relative inadequacy, a failure to show the external signs of attention in the precise moment where it is required. This could be related as much to a kind of overreaction in relation to an opaque bullying situation or silent collective joke as to the continuation of a conduct beyond the limits of opacity, claiming the attention of the teacher or another

adult with authority. Then, as different children said to us, their name would be linked with misbehaviors even if they were just arriving at the classroom or they were not present at all. As far as we can see, what is considered as evidence is basically the reduction of a situation to an individual cause, the misidentification of the relational clash of forces with a substantial causality.

This can lead us into a discussion of the second fixation. As far as we can see, the prevailing exigency is regarding external signs of attention more than a specific academic performance. The presence of the PIE professionals demonstrated this paradoxical situation. On the one hand, we can read in official documents that ADHD impacts the academic performance of children (the declining of which is considered one of the first indications of attentional problems) and that the PIE is a way to integrate students with "special learning necessities" (NEE, Spanish initials), including ADHD. On the other hand, we can observe the everyday intervention of PIE professionals as an attempt to keep the attentional flux inside the acceptable variation threshold, through an individualized and silent relationship with one student diagnosed with ADHD (assistance) or through making loud orders, joining to the teacher in the labor of discipline.

Assistance and discipline work together for the maintenance of the external signs of attention. We talk here in Foucauldian terms, i.e., assistance as a non-authoritarian way to conduct conducts, which implies an emphasis on the preeminence of the benefits for the conducted, and discipline as vigilance associated not only with punishment but also with the further intention of forming bodies able to comply with a norm of conduct (Foucault, 2006, 2012). This means that a micro-social operation is connected to the wider diagram or strategic situation of power where it occurs (Deleuze, 2014; Foucault, 2005). In that sense, we wish to expand the notion of the situation, understanding that those everyday life scenes are deploying within a larger affective scenario related to a historical development (affective genealogies) as much as governmental rationalities (Anderson, 2010; Castro-Gómez, 2015). Particularly in Chile, it seems that the insistence on the external signs of attention, associated mainly with easiness and respect for a clear authority, could be linked to an affective sensation called positional inconsistency (Araujo & Martuccelli, 2011, 2012).

The School in Contemporary Neoliberal Chile: The Anxiety of Positional Inconsistency

Araujo and Martuccelli (2011, 2014) describe positional inconsistency as the feeling "that every social position may suffer active processes of destabilization due to the transference of tasks related to the level and quality of their social integration to individuals" (Araujo & Martuccelli, 2014, p. 33), which means that Chilean socio-economic structures compel the individuals to manage collective affairs such as health, education or retirement income on their own. They describe it as "a structural phenomenon of primary importance in contemporary Chilean society" (Araujo & Martuccelli, 2011, p. 164), which at the same time is an *effect* of structural changes. Thus, the authors stated that the "relational hyper-actor as the modality of the individual in Chile must be put in context" (Araujo & Martuccelli, 2014, p. 33). When individuals are compelled to manage their entire social security on their own, they must become a "relational hyper-actor", i.e., they need to put themselves in contact with a lot and diverse kind of actors and institutions in order to survive in a society characterized by a constant insecurity and the extreme reduction of the public sector. This comes mainly from the neoliberal transformation initiated by the Chilean civilian-military dictatorship and consecrated and deepened with *the return of the democracy*. This neoliberal transformation demonstrates a profound ambiguity, varying between the destruction of institutionalized social solidarity and the (contradictory) expectation of the democratization of society (Araujo & Martuccelli, 2014). Nonetheless, we think that it could be useful to think about it not only as an *effect* but also as an *affect*.

As we said before, affects imply a pre-individual reading, another dimension of social reality one might say. From our point of view, the so-called positional inconsistency is not a consequence of some changes that occurred in the past, rather, this past is a force still working in the constitution of structural and personal relationships. The map here is different; we don't have human actors facing structural challenges, we have bodies in the middle of affects and affective environments. In that sense, this economic and political legacy is constantly mobilizing historical bodies in different directions, contrasting with the idea of individuals as a production of institutional interpellations (Araujo & Martuccelli, 2014). In a certain way, there is no individual as a product, but relations of singularization, i.e. singular social folds (Lahire, 2013).

The main difference from an individualistic approach is that the relationship with the past is not a causality, one which produces and interacts with substances (individuals or institutions), but a force still insisting and acting at each and every moment. On the one hand, we have the contemporary composition of the Chilean school, in the midst of a generalized anxiety about education as almost the only way to avoid poverty (Radiszcz, 2017b; Sir, 2016). And, on the other hand, we see a very close connection between the expectations of democratization and the development of new information and communications technologies, mainly in the 1990's (Mayol et al., 2013). We try to show this in the first draft of an ADHD map (Figure 1), as neoliberal exigencies and rhizomatic connections.
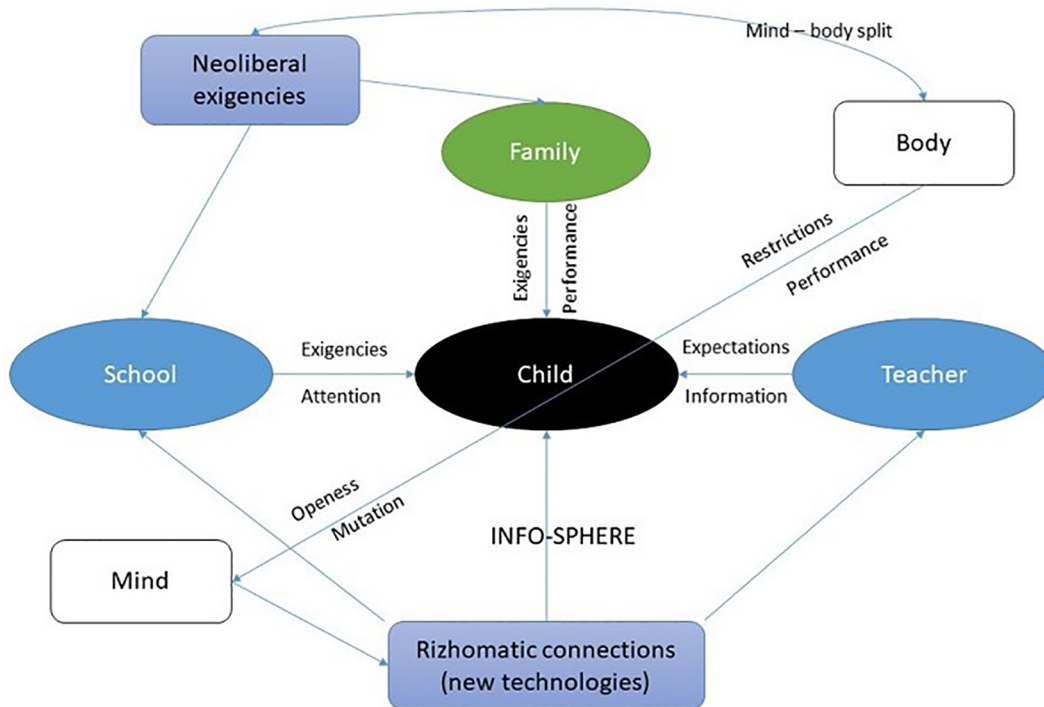

Figure 1. Building an ADHD map.

With this figure, we aim to establish that the main forces named above (expressed here as "neoliberal exigencies" and "rhizomatic connectivity"), act on different areas of the ADHD situation. Family, school, teacher, and child exist in the midst of affective-historical forces. At the same time, each singularity inclines the affects in diverse ways: with openness, restriction, exigencies, and expectations. The neoliberal exigencies imply, as we said, the necessity to manage individually the affairs related to health, education, retirement, etc., which will force very long working days but given the low incomes, it will produce high rates of private debt. At the same time, Chilean inte-

gration in the globalization as an open-market country imply a deep impact of technologies in everyday life, concerning what we called rhizomatic connections[iii], making possible to think in new ways to make profitable what is built as an attentional deficit. Between a social reality with a lot of pressure in individual lives and with a fluid use of new technologies, the bodies of children seem to be crossed by a paradoxical order, which forces children to have a highly still body in a time of increasing mental stimulation. This is critical for children and their families due to the position of the school in Chile.

Given the lack of social solidarity in contemporary Chilean institutions, education becomes the only legitimate way to avoid poverty, in accordance with the consolidation of meritocratic discourse during the 90's (Araujo & Martuccelli, 2012; Barozet, 2006; Mayol et al., 2013). This implies a restrictive and individualized approximation to life in society, and it has been at the center of the politicization of social malaise, as arose in the student protests, first in 2006 and then in 2011[iv] (Mayol et al., 2013). This anxiety is expressed at the institutional level, too. Here, the school itself (and, of course, the university) is increasingly pushed to meet a wide range of performance indicators, including "inclusion indicators". Thus, ADHD, as a special learning necessity (NEE), is currently a way to generate economic resources for impoverished schools via PIE (Radiszcz, 2017a, 2017b).

The epistemology behind school measurement via benchmarking and market standardization has a high elective affinity (Weber, 2002) with the individualized conceptualization and governmental management of society (Foucault, 2006). It compels families to be extremely careful about their choices regarding childhood education and to intensely surveil childhood behavior, in order to give children individual weapons for social competition and survival. Thus, children themselves feel the obligation to focus their attention, trying to accomplish the required posture (external signs). This exigency introduces limits to their imagination about various ways to produce themselves materially and symbolically. Feelings of guilt and indebtedness to their parents are combined with the intention to be considered a non-problematic child.

That's why the deficit of attention is mainly understood as a failure which must be repaired. Even when it is considered, by some researchers, as a different cognitive style (Aboitiz & Carrasco, 2009; Aboitiz et al., 2006), or when some organizations of parents of children diagnosed with ADHD express that this is a different way to be human, ADHD is still linked with the possibility to make this difference profitable and, in that way, *non-problematic*[v]. Children seem to have two alternatives: normalize, through therapies, what is constructed as their deficit or use it as a productive trait, i. e., utilize inattention as a particular form of creativity to incorporate into specific areas of the labour market in the future, related to a kind of attention useful according to the new demands of the rhizomatic technological connections. In both cases, this seems to be stimulated by an active quest to stop being problematic. This affective search for being non-problematic is interesting because, in a certain way, it allows us to think of a bond between the discourse of failure associated with ADHD diagnoses (with the following stigma) and the discourse of gift, privilege or hidden potential (Radiszcz, 2017b). This spectrum between failure and gift as a hidden potential is also associated with the main trends in the way as current neurosciences based therapies understand human being and its relationship with the profitability of differences instead of just its normalization (Ehrenberg, 2018). In ethnographic conversations with children taking ADHD pills, we did identify a strategic dimension linked with a regularization of academic performance, which means improvement to a high enough level to avoid further problems. They did not seem to pursue outstanding scores nor a kind of general optimization. They were, however, generally more concerned about their family's expectations and efforts on their behalf

The possibility to be responsive to and fulfil family ideals is a constant fight against what Juguetes Perdidos (2014) calls "totalitarian precarity"[vi]. These efforts are focused on the school and educational performance because it seems to be the only legitimated way, not even to be successful, but just to not be poor. From the affective standpoint, the situation is also composed of historical forces, not as a causal relation, but as a constant mobilization of bodies and institutions. We can now map the more general link between the moral, biological and economic factors contributing to the ADHD Situation. In doing so, we try to rethink the possibilities for a militancy at the border of and outside the academy, and beyond a reified notion of community.

Attention Disorder: Epistemology, Politics, Moral Order

The Values of Attention

A certain epistemological connivance links the anthropological imagination of neoliberalism, the normative exigencies of the school, family expectations, child behavior, and the guilt associated with these efforts. This connivance is related to a universe of delimitated individuals, substances, mechanical interactions, and causal relationships. This epistemological frame is also manifest in the way that the notion of community appears in official documents. The following quote from the last Chilean Mental Health Plan (2017) illustrates correctly what the problem is:

> The Integral family health model as much as the community-based mental health model understand health as a social good and the health network as the coordinated action of the service providers' network, the organized community, and intersectorial organizations. Both models – states the official document – stimulate a modality of relationship between the health team members and people, their families, and the community of a territory where i) people are in the center of the decision making process; ii) people are recognized as members of a diverse and complex socio-cultural system in which the members are healthcare assets (MINSAL, 2017, pp. 37–38).

Of course, this notion of community shows ambiguity. It doesn't appear only as a determinate substance, it is also associated with adjectives like "organized", referring to the inner, creative power of the neighborhood. In another part of the text, community is linked with intervention practices, composing an even more dynamic concept. The complications begin when the "models" are discursively applied in concrete situations. In these moments, "people", "family", and "community", for example, seem to be clearly distinct realities or substances, reducing all the acknowledged diversity and complexity to mechanical relationships between clearly distinct elements. This makes it more difficult to read what is going on *within the borders* of those apparently discrete, uniform elements, including by the organizations trying to intervene in a given community.

As we stated above, what is considered evident is, in fact, the result of the construction of that evidence, a process which is immediately disavowed, which masks itself through its very operation. That's why the mere notion of evidence is often associated with relatively violent practices of exclusion of other kinds of knowledge, including others' ways to understand what evidence is. In Chile, in particular, it has been acknowledged that the communitarian modality of inclusion in various public policies from the 1990's to the present, has signified a confrontation between the "political dimension of social-communitarian psychology (PSC, Spanish initials), represented by concepts such as emancipation, autonomy, and citizenship [and] paternalistic public assistance programs, social control, and dependency" (Wiesenfeld, 2014, p. 12). In a certain way, the epistemological suppositions and logic underlying neoliberal public policies define the contours of possible interventions, but never exhaust the assemblage

of forces that constitute a given situation. A careful reading of the internal complexity of the discrete substances involved and their interrelation is required. The notion of situation, utilized in our analysis of three educational programs, avoids exploring the relations between the "thing" (kids, for example) and its context (the school or the home).

The clinical guide elaborated for the Ministry of Education (MINEDUC, 2009) states, according to the psychiatric description of the disorder, that the problematic behavior occurs in two or more contexts or situations, indicating a given conduct is manifested in certain situations and not in others; it has a substantial and independent existence. The description of ADHD in that clinical guide was made following the DSM IV indications (American Psychiatric Association, 2001) which states that the disease can develop before the age of 7, whereas in the more recent DSM V it cannot develop until the age of 12 (American Psychiatric Association, 2014). The document establishes that this disorder troubles abilities crucial to successfully navigating educational institutions, those concerning the capacity for self-control and adaptation to immutable rules, both explicit and implicit. Even if the clinical guide does acknowledge the existence of cultural differences in the manifestation of the disorder, it also offers the following list of culturally-independent "frequent associations": i) Short attention span, with great susceptibility to distraction by any stimulus; ii) Hyperactivity and uneasiness linked to excessive levels of energy; iii) Difficulties following instructions; iv) Rash actions to reach something without evaluating the consequences; vi) Impulsive corporal, emotional, verbal, and cognitive behaviors" (MINEDUC, 2009, pp. 12–14).

If we follow this practical description, as a description intended for application in schools, we find some affective links that the epistemological connivance tends to hide, especially in the aftermath of the diverted conduct when the given attention problem involves a problem with obedience. The ADHD Situation emerges in the middle of the diagram in Figure 1 (Deleuze, 2014). As a representation of the composition of the strategic situation (Foucault, 2005), it describes the encounter of multiple and heterogeneous forces. In this perspective, what actually emerges as a problem and a value[vii] within this disorder is *attention* itself.

Attention as a moral value has a long history that we cannot widely cover here, but we can briefly highlight its links with diverse epistemological matrices. From the XVII to the XIX Centuries, philosophers first and then psychologists were concerned about the problematization of attentional problems. Here we can find different projects and models in competition trying to define what is the problem when we are talking about attention (Caliman, 2008a, 2008b, 2012). Attentional problems were associated, for example, with the development of the *Will* and also with a *capacity* that we can train in order to increase our power as human beings, among other perspectives. Following Caliman (Caliman 2008b, 2012), between the XVII and XVIII Centuries, attention was considered as an intrinsically mobile capacity, even in that time an excessive attention in just one kind of activity could imply a health problem both for children and adults. At the same time, attention was defined as a capacity that could be mastered. Later, between the XVIII and XIX Centuries, feelings and emotions were considered as problems that impeded a more focused attention, and the ability to focus one's attention came to be conceived as an adaptive issue.

According to Caliman (2008a), it was between the end of the XIX Century and the beginning of the XX Century when a strictly neurophysiological model was developed. The problem with attention since then will imply a failure of inhibition, meaning a certain excess of movements. In other words, a disturbance of the civilizing process in Elias' sense (2010): an error, a failure in self-discipline, which means at the same time an *adaptation* problem (Stiglitz, 2006). In spite of the emergence in the middle of the XX Century of various critiques against this mono-

lithic scientific discourse, at the beginning of our current century Caliman (2008a) identifies the rise and consolidation of what she calls a "new attentionism" strictly attached to the neuroscientific and biological discourse (Caliman, 2008a, p. 643).

We are not trying to reintroduce a simple dichotomy related to neurosciences, painting it merely as a "bad" point of view. Instead, we follow Malabou (2017) in trying to perform a closer reading of this new discourse about psychic suffering. The problem appears when the possibilities of an insubstantial materialistic approximation to the brain is reduced to a substantial and mechanic causality. And this is what seems to happen with most of the politically useful approaches of psychiatry and neurobiology in the post-(neo)liberal era. Thus, new attentionism tends to naturalize and biologicize the moral discussion related to the adequate training of attention, and in so doing depoliticizes the new attentional exigencies and affective demands linked with the affective and political genealogies of the contemporary era (Caliman, 2008b, 2010, 2012).

This conceptual problem seems to permeate and influence the action of so-called civil society, too. Indeed, as in other mental health diagnoses, ADHD organizations, families, and individuals frequently pursue a clearer diagnosis, even if they want to say that ADHD is not a disease but an alternative way of thinking or behaving (Bergey et al., 2018; Stiglitz, 2006; Zepf et al., 2017). As a result, some of them are developing a kind of "evidence-based activism" (Rabeharisoa, Moreira, & Akrich, 2014). The problem with this kind of activism is that the search for a more precise medical diagnosis could restrict a broader perspective, reinforcing the biological perspective of the new attentionism. Instead, we want to stress the importance of the intensification of what could be understood as errors or failures, in order to map in a better way what is happening in our current time *through* "individual" symptoms.

Performance: Attention, Adaptation, Obedience

This diagram that describes where ADHD is deployed could be better understood if we follow the critical reflection on the *attention economy* (Beller, 2006; Crary, 2014), linking it with a genealogy of ADHD (Caliman, 2008a, 2008b, 2010, 2012; Comstock, 2011). On one hand, we have the moral problem of disciplining the Will and the naturalization of the association between certain behaviours and the brain. These converge with the economic shift of the 1970's, adding an economic/structural dimension to the attention problem and situating it, specifically, in the midst of so-called cognitive capitalism or semiocapitalism (Berardi, 2003; Fumagalli, 2010). We can find an archaeological trait in Simon's work (1969) that is relevant to the new economy and to organizations that are characterized by the importance of information gathering and processing machines. He stated that in an information-rich world, attention becomes scarce, and therefore it becomes necessary to carefully manage its focus inside organizations. Nonetheless, it wasn't until the 1980's and 90's, with the spread of cybernetics and the internet, that this became a clearly relevant issue (Celis Bueno, 2017). Even a complete theory on the economy of attention emerges (Beller, 2006). At first it was associated with attention in publicity and at the point of consumption (Jhally & Livant, 1986) But now, in scientific psychological experiments and neurobiological theory, attention itself becomes a valorising activity (Aboitiz et al., 2006; Celis Bueno, 2017; Citton, 2014a, 2014b; Ortega, 2014).

Even more interesting is that attention can be profitable, both through therapies or pills designed to increase focus on determined activities, as well as through the exploitation of what is conceived as diverse cognitive styles associated with creativity, in the sense of a hidden potential (Mollon, 2015; Sangüesa, 2012).

As Caliman (2010, 2012) shows, the moral problematization of attentional conduct was always associated with what is understood as obedience. That idea is not so far removed from what we could observe inside the classroom,

where assistance and discipline converge to produce obedience as manifested through external signs of attention. Nowadays, the moral problem of obedience converges with a simplistic appropriation of new discoveries about brain functioning, producing the naturalization of new attentionism. Given the underground epistemological connivance, this biologization remains uncontested by both governmental programs and mainstream organizations that work on ADHD. This seems to align with a whole range of understanding that regards attention as a potential source of profit, since the need to focus it, on the one hand, and the celebration of wild and unpredictable cognitive styles on the other, contribute to the ideological and material maintenance of capitalistic accumulation. Precisely here, facing this description which tends to close on itself, the power of the symptoms seems to be relevant; we should instead follow the diverted conducts to contest this new kind of uniformization (Liebert, 2017).

The Power of the Symptom: Activism in the Permanent Crisis

This map is a work in progress; it will probably always be unfinished. Connecting apparently distant realms, behavioral problems in school could reveal some unexpected relations with the uses and problematizations of attention in society at large. What exactly are the children adapting and/or resisting adapting to? Given the "totalitarian precarity" of and the anxious place occupied by Chilean schools, the prevalence of ADHD seems to be related to the use of mental health diagnoses as a way to simultaneously collectivize and depoliticize individual discontent (Ehrenberg, 2010), associated with the chronification of the crisis of political imagination in Chile and the world.

At the same time, the biologization of the new attentionism could be understood as part of our *biohistory*, where man might modify "life itself" with his knowledge, even in unwanted ways (Foucault, 2005; Rose, 2012). Here is where our new politics and scientific maps should follow carefully the diverted conducts, avoiding reified external readings. That's why ontology is really important for political activism. As Rabeharisoa et al. (2014) show: the production of knowledge itself has become part of the struggle. In a certain way, the organizations fighting for more precise definitions of their malaise and for the recognition of their own experiences generate 'experiential knowledge' capable of contesting official knowledge and reconstructing medical frameworks (Rabeharisoa et al., 2014, p. 120). Nonetheless, they remain by and largely unable to include social conflict in their schema for knowledge production (Rabeharisoa et al., 2014, p. 126). This evidence-based activism seems to derive from a kind *of militant activism for itself*, searching for recognition and greater visibility of their own disorder. It thus becomes essentially a form of struggle for a depoliticised, better diagnosed, and more livable medical condition. However, "a politicised collective illness identity can emerge when people's understanding of their condition contradicts the 'dominant epidemiological paradigm' of the illness perpetuated by medical, scientific, and government institutions" (Edwards, 2014, p. 54).

We suggest, then, that following the power of symptoms could imply the intensification of the contention between medical knowledge and experiential knowledge, and through this contest redefine the boundaries of the politicisation of this 'collective illness identity'. An activism in the midst of crisis must resist a substantialist ontology, in order to be able to draw affective maps which allow us to regard the power of diverting intrinsic to the symptom as a possibility to explore new imaginable arrangements, resisting the post-liberal era as a "war on the imagination", to paraphrase Liebert (2017).

This is particularly important given that the lack of political imagination on the left (Keucheyan & Elliott, 2013) results in a remarkable difficulty to read what is going on in a non-representational dimension. Thus, as a methodological exercise, following what escapes from a given diagram, the *error* in the form of a symptom, has sociological, psychological, and political relevance. And, particularly, tracing the emergence of the ADHD Situation back to the

diverting behaviors, allows us to link these with the moral, biological, and economic problematization of attention itself. This work continues now following the persistence of the behaviors inside and outside institutions and along the trajectories of actually lived lives. In so doing, we hope to delineate -in cooperation with people, families, and organizations- new cartographies of the modalities of dealing with the physical and cognitive exigencies of contemporary Chilean neoliberalism, helping in this way to develop a militant knowledge on the edge of the academy, and beyond inside-outside and intellectual-anti-intellectual dichotomies.

Notes

i) The ethnographic observation was performed during 4 months in 2017 in three diverse schools in Chile: A private, a public, and an alternative one.

ii) According to official documents PIE is a inclusive strategy to students with Special Educational Needs, based on the "medical view of the difference" (Torres, 2013, p. 127), working with precise medical categories. Since 2009, through this program, schools with a determined number of PIE' students obtain a special public subside (Radiszcz, 2017a).

iii) We utilize the concept of rhizomatic for 2 main reasons. First, because the new technologies impact producing a world densified with many dimensions at the same time (e.g. when children are in the classroom and at the same time they are chatting, playing and sharing things with people in different parts of the world). And, second, because the impact of technologies are not only associated with specific areas of the economy, instead, it rebuilt the way to do things in a broad sense, affecting several areas from art to precarious employment, trought the entrepeneurial discourse. See (Deleuze & Guattari, 2002)

iv) During 2006 the biggest protest since the return of democracy exploded. It was conducted by high school students mostly, and came to be known as the "Penguin Revolution" because the school uniform used by most primary and secondary school students in Chile resembles a penguin's "suit". The protests included street demonstrations and the occupation of numerous school buildings. Their principle complaints had to do with the inequity of the Chilean educational system alongside the maintenance of the juridical legacy of the dictatorship in education. In 2011, mostly the same generation, now slightly older, occupied the universities, this time raising their demands to include an end to for-profit educational institutions. Chile has one of the most expensive and segregated educational systems in the world. For further details: (Domedel & Peña y Lillo, 2008; Mayol, 2013; Rodríguez & Tello, 2012).

v) The majority of ADHD organizations in Chile try to give advice about the most effective and harmless therapies, linked with the core idea that having this diagnose is not "necessarily" a disease. In an informal interview with a member of the mental health organization "Locos por nuestros derechos", they said to us that the current ADHD organizations are not really politicised. Moreover, there are few of them and they are mainly online virtual communities.

vi) In the vein of (López Petit, 1996), (Berardi, 2014), or (Lorey, 2016), the Argentinian collective understands precarity as an existential condition, and also an affect that mobilizes bodies in heterogeneous contexts and scenarios.

vii) Both in the economic and the moral sense.

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Competing Interests

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Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

A Hidden Activism and its Changing Contemporary Forms: Mental Health Service Users / Survivors Mobilising

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Abstract

This commentary concerns how the organisation of State welfare benefits in the UK have changed over the last 20 years, arguing that this has had harmful, even fatal, consequences for people with disabilities and particularly those with mental distress of psychosocial disabilities. This current situation may be called that of austerity. The paper describes how a 'hidden activism' has emerged to contest this situation and explains why it is, and to a degree, must be hidden. I then focus on the discourse of responsibilisation where every citizen must take responsibility for embodying the virtues of the good, working person. To ensure this, unemployment has been framed as a psychological problem and psychologists are now employed to 'treat' this problem in order that everybody might enter the world of work. I argue that in current conditions this is not possible for all with mental distress. Engaging then with community psychology, I address the issue of allies and how the absence of attention to mental distress might be remedied by this form of work. I draw on the emerging field of user / survivor-led research in mental health and argue that collaboration with community psychology will not be without problems.

Keywords: mental health, austerity, responsibilisation, activism

In this commentary I will describe a new way in which people who use (or refuse) mental health services are radically disempowered, with an attack on their basic means of survival. This situation is part of the wider policy of 'austerity' introduced progressively in the UK over the last twenty years. The aspect of this I shall discuss concerns welfare benefits although service users are obviously affected by cuts to other parts of the welfare state. The article will describe a concomitant 'hidden activism' whereby the most disenfranchised of citizens try to fight back. This activism is 'hidden' partly for material reasons but also because the concept of mental patients organising for their rights is alien to Western societies so even when this activism enters the public arena it is not visible. I will chart the effects of austerity on that aspect of the welfare benefits system that is targeted at those assessed for their

fitness to work in terms of long-term health conditions and the forms of resistance which this has prompted over the last two decades. I will also consider if there is a place for academics to intervene here by focussing on the question: what kind of social justice movement is this? If mental health service users want equity but not normalisation, what kind of movement are we dealing with here? Finally, the article is focussed on the UK because the kinds of intelligence by which one knows about such activism is not always a matter of public record but of local and personal networks.

The last sentence might be read to mean that I am being 'subjective'. I would like then to introduce the field of user /survivor research, which is where I situate myself intellectually. Although the arguments are complex and varied, this is a field that gives a prominent place to individual and especially collective experience (Bereford, 2003; Faulkner, 2017; D. Rose, 2017; Voronka, 2016). The exact status of experience is a matter of debate but what is agreed is that 'mental patients' have been silenced for centuries, their speech conceptualised as incoherent, meaningless and their defining feature a lack of reason (Foucault, 2013). The embryonic discipline of user / survivor research, in one incarnation named Mad Studies, is an attempt to reclaim that knowledge and that speech and codify it theoretically and in terms of praxis. The key is that the knowledge and experience of the insane is a critical part of any discourse about psychiatry and mental health. It should not be a surprise then that I start by positioning myself in relation to what I will write in this paper.

Positioning Myself

Because of my own life trajectory and because of the subject of this paper, I must begin by positioning myself in relation to what I will write. I am a service user / survivor academic which should mean I ground my work in activism. It could be argued that working on the 'inside' whilst retaining an 'outsider' identity is itself a form of activism – contesting privileged academic work on what it means to be mad and what are suitable forms of support. That's why I work in a university, the dominant site of knowledge-production although it is certainly not the only way to contest such understandings. However, I would argue that a grounding in activism needs to go further to generate new and challenging forms of knowledge. So it is relevant that in the years 1972-1986 I had another academic career. I entered academia as a social psychologist but found myself drawn incessantly towards critical theory and activism, in the first instance feminism. Between this and my current position lay ten years as a 'community mental patient', not a desirable position. But during that time I became an activist through involvement in the mental health service user / survivor movement and that was a life-changing moment and the start of a journey that is not over. I write this because I am going to discuss austerity, mainly in the UK though the situation is duplicated in many other countries. Part of the enactment of 'austerity' is to cut the public sector and this includes welfare benefits. So I want here to begin by comparing my experience of receiving welfare benefits with those receiving them now. For ten years these were my main sources of financial support. But if I compare myself to people in that situation now, there is no comparison at all. Although it was two years into the Thatcher government in the UK, its welfare policies were hardly formulated and certainly had not begun to bite. Deinstitutionalisation in the UK had not led to the anticipated horrors, murder and violence of course but neither homelessness (Leff & Trieman, 2000). Unlike our American counterparts, we were not living on the streets. One of the early service user groups, Survivors Speak Out, drew up a Charter of Demands which insisted on financial security, but we were not using foodbanks. Today in this environment of austerity, murders by those designated mentally ill continue to be rare events but attempted suicides by people trying to claim what are now the most meagre of benefits

have increased dramatically in ten years, although published statistics make it difficult to be precise. I did not live in fear of the brown envelope as people do now. The 'brown envelope' is the paper in which communications from the Department of Work and Pensions arrive by post and people literally live in fear of their contents. And there are worse things that I shall describe. This situation has led to new forms of mobilisation amongst those with mental distress who are directing energy as much towards policies which threaten the means of survival as towards the psychiatric system as such. And the final thing to say is that this takes its toll. I am reflecting on some of the most marginalised, disenfranchised and so vulnerable members of society and activism requires energy and numbers. People withdraw, people become burned out. There is much mutual support, online as well as face-to-face, but sometimes it is not enough and sometimes people don't make it.

Academia and "Mental Health"

If I situate myself as a user / survivor academic, this special issue draws upon and interrogates the fields of community psychology or community social psychology and there are methodological similarities between this and user/survivor research. Both take as a main method 'participatory research' although this has multiple methods and meanings (C. Campbell & Jovchelovitch, 2000). Health was a focus early on (Cornwall & Jewkes, 1995) and the same authors a decade later saw promise for participatory research in democratic spaces (Cornwall & Coelho, 2007) although critiques had started earlier (R. Mason & Boutilier, 1996). There has been abundant work on people living with HIV / AIDS (Epstein, 2000; Houston, Osborn, Lyons, Masvawure, & Raja, 2015) as well as some focus on physical disability (Radermacher, Sonn, Keys, & Duckett, 2010). Such work has often engaged large communities or sometimes small organisations. Work on mental health within this body of literature is conspicuously absent. There is Brazilian work with those in distress which claims a participatory tradition (Campos & Campos, 2006; Onocko-Campos, Diaz, Dahl, Leal, & De Serpa, 2017). However, the latter concentrates on the difficulties posed by those with 'severe mental illnesses' in a focus group setting – not just access and ethics but the fact that narratives are fragmented and not coherent. In other words, the illness disrupts the focus group method and the solution is to involve clinicians and managers. This does not meet the criterion of levelling power relations in my view; rather it reproduces them.

Other authors have interrogated the concept of 'community' and I will use this work (Choudry & Kapoor, 2010; Cooke & Kothari, 2001). But one of my conceptual goals is to weave empirical data with concepts of power, individualism and especially the ideas of 'recovery' and 'empowerment' to pose what may be some difficult questions for the wider academic community but also to open some doors, admittedly ones that would be hard to push.

Current Hidden Activisms

However, before broaching this I will describe some current 'hidden activisms' in relation to mental distress and mental health. These have a long history but I will focus on the current mobilisation in response to the austerity policies which had their seeds in the Labour government's introduction of Work Assessments for disabled people in 2002 but which have become progressively stricter since the election of the coalition in 2005 and especially as austerity has been tightened since the success of David Cameron's campaign resulting in the Conservative Party

in the UK coming into power in 2010. Particularly important was the privatisation of the assessment process of fitness to work because this deregulated criteria for who could carry out assessments.

The ostensible reason for the drive to get 'disabled people back to work' was that tens of thousands of people had been put on a sickness benefit ('invalidity benefit') in order to cut the numbers appearing on the unemployment register. In other words, it was a deliberate ploy by the Labour government to minimise the numbers apparently on the unemployment register and to make it seem as if full employment was in reach as a result of their economic policies. However, this was turning out to be very expensive and together with an ideological shift towards individuals taking responsibility for themselves a policy was progressively forged to enable (or force) people with disabilities, including psychosocial disabilities, into open employment (Beatty & Fothergill, 2015; Scruggs, 2006). The ideological climate was not one where employers and employees might discuss 'reasonable accommodations' whereby a person could work safely and effectively in a job. No, the material and cultural environment was hostile with newspapers speaking of 'scroungers' not 'strivers' and there was a rise in disability hate crime (Brown, 2012).

By 2005, those who would have previously been on 'incapacity benefit' were progressively subject to the 'Work Capability Assessment (WCA)'. This was normally an interview with copious documentation and it is not irrelevant that it was run by a private company whose employees knew little of the effects of ill-health on people's capacity for work. Those subject to the WCA were divided into 3 groups. There were those found 'fit for work' and they joined the existing ranks of the unemployed, at that time termed 'JobSeekers'. Second were those placed in the Work Related Activity Group (WRAG) upon whom was a duty to attend for various activities to make them 'work ready'. Finally, was the Employment Support Group (ESA) which, whilst seemingly most like long-term unemployment benefit, required repeated assessments to see if people might be better placed in the WRAG.

Physical and Mental Disabilities

The WCA is almost exclusively concerned with physical and sensory impairments and limitations:

> how far you can walk, what weight can you lift, can you wash, dress and toilet yourself all broken down into the smallest of elements. If you cannot go outside because of fear of open spaces this is not equivalent to being unable to go out because you cannot walk 50 metres and therefore does not attract the 'points' which are summed to allocate you to one of the three groups: your terror is at once rendered invisible and penalised.

By 2011 it was recognised that the WCA disproportionally affected people with mental distress as it focused almost exclusively on physical capacities. The Harrington report in 2012 (Harrington, 2012) tried to resolve this with some success in reducing the numbers found fit for work. However, this was very partial. In 2014 Disabled People Against the Cuts (DPAC, 2014) demonstrated using official statistics that people with mental distress, or mental disabilities, continued to be discriminated against at every turn.

In this work, DPAC were joined by a small mental health organisation called the Mental Health Resistance Network (MHRN). This is one of the groups I refer to as comprising a 'hidden activism'. DPAC itself is to some extent hidden as the idea of disabled people organising for themselves is counter-stereotypical. However, DPAC has some formidable statisticians on board. But the image of the madman or woman as violent or pitiable, unpredictable or hopeless means that groups like MHRN never appear in the mainstream media or popular culture. If they do, they morph into the weak and hopeless, the shiftless, the unemployable or the just plain crazy. That they might have agency and something to say is not on the agenda.

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Old Struggles in New Bottles

But just at the moment rules were relaxed for people in distress, there was a call for increasing 'evidence' to back up a claim for benefits. Letters from GPs were necessary but so too were letters from specialists. In the case of people with mental distress this meant psychiatrists. And this posed a dilemma and a tension. Many of those who had been campaigning on the benefits front had opted out of the psychiatric system but they now needed support from a psychiatrist. Indeed, they needed a diagnosis. Some swallowed hard to accept this or found a friendly psychiatrist but there was another development. A group of psychologists from the British Psychological Society had been developing an alternative to diagnosis known as 'formulation' and they were very vocal going round the country and with a lot of social media activity (British Psychological Society [BPS], 2018). In what looks like a paradoxical move, given the debates about the harms of diagnosis, some of the austerity campaigners contested the psychological concept of formulation saying that they needed a diagnosis to receive benefits. Some went as far as to say psychiatry was no longer the main problem; it was the state and its incessant tentacles. This debate on social media, which I cannot reference, became extremely heated and hostile.

Austerity and Disabled People in the UK Today

In 2017, NHS digital released the results of the 2014 Adult Psychiatric Morbidity Survey for England (https://digi-tal.nhs.uk/catalogue/PUB21748). The figure that caught the headlines was that almost 25% of 16-24 year old women reported self-harm, mainly self-cutting, in the previous year. Suicidal thoughts and attempted suicide had also increased. In, to some, a quite astonishing Foreword, Paul Farmer, Chief Executive of the NGO MIND, pronounced that the reported increases in mental health problems were a result of stigma reduction. That is, 'reporting' had increased to reveal a 'true' and apparently stable state of affairs as people were now less afraid to admit to mental health problems. To some of us, the idea that 25% of young women had been hiding self-harm for decades was laughable although it is clear some do and this is particularly so for those from BAME backgrounds (Pembroke, 2005; Wilson, 2006). But another figure stayed under the radar of press and public reaction:

> Benefit status identified people at particularly high risk: two-thirds of Employment and Support Allowance (ESA) recipients had suicidal thoughts (66.4%) and approaching half (43.2%) had made a suicide attempt at some point (Chapter 12, p. 3)

This figure had doubled since 2007. The calculation was consistent with a quantitative study of local authorities which also showed widening inequalities in the rate of suicide attempts with regard to indices of deprivation (Barr et al., 2016) as well as a qualitative study of recipient's responses to the assessment process itself (Garthwaite, 2014). Again, I would argue this figure stayed under the radar, remained hidden, because although we had been encouraged that it was 'time to talk' and celebrities like Prince Harry had indeed talked, the lives, or deaths, of those on the margins of society, the 'seriously mentally ill' were not newsworthy, perhaps even an embarrassment.

This information regarding suicide attempts was not new to those working in the field. Disabled People Against the Cuts (DPAC) had been amassing statistics and cases since 2010 and analysing official data collected well before that. They had in fact brought two cases of violation of the rights of disabled people to Convention for the Rights of Disabled People (CRPD) Monitoring Committee at the United Nations. One of these resulted in a judgement, in 2016, that austerity policies had resulted in 'grave and systematic violations' of the rights of disabled people (CRPD, 2016). This action again involved the small organisation the Mental Health Resistance Network (MHRN). The second was similarly judged and like the first the government declined to act. Then in 2017 the CRPD Monitoring Committee issued its report on the implementation of the CRPD in the UK and again found that

the rights of disabled people, including those with mental distress or 'psychosocial disabilities', were violated in the case of nearly every article (CRPD, 2017). They specifically mentioned the treatment of service users from BAME groups in the mental health system especially in respect to coercion: detention and compulsory treatment and now Community Treatment Orders. We have a new Independent Mental Act Review which claims to pay close attention to this issue but neglects to mention that the situation has been in this parlous state for at least two decades (Fernando & Keating, 2008) and has been endlessly brought to the attention of the authorities.

The CRPD explicitly uses the term 'austerity' as a reason for its finding that the rights of disabled people are systematically violated in the UK especially in the case of positive rights such as to adequate housing, financial security and community living.

Psychology Enters the Frame

Three years before the CRPD Committee delivered its judgement, the UK government started to employ what is termed 'welfare conditionality' (Nevile, 2008) and at about the same time benefits recipients who received money on grounds of being unfit to work in the long term – Employment Support Allowance or ESA – had their benefits reduced by £30 per week to the same level as those on short-term unemployment benefits. In other words people on long-term sickness benefit (not that it was called that) were expected to live on £73 a week. A discourse of responsibilisation, which had always been present, then began to pervade debates on welfare reform (Deacon, 2005; Patrick, Mead, Gregg, & Seebohm, 2011). In terms of people claiming benefits on grounds of long-term mental distress, this took a particular form. Work was (re)defined as a 'health outcome'. Employment had always functioned in research and clinical practice as a part of 'quality of life' (Stansfeld & Candy, 2006). But now it was firmly positioned as a part of positive mental health (Shanks et al., 2013). And the converse of this was that one could not be mentally healthy if not in the open labour market. This raised protest, physical and discursive, from groups such as the MHRN and the influential FaceBook group Recovery in The Bin (RiTB). The power of social media to initiate new forms of mutual support and ultimately new forms of protest and action should not be under-estimated (see, for example, https://recoveryinthebin.org/2016/03/30/workfare-coercion-in-the-uk/).

Welfare Conditionality

Welfare conditionality involved a regime of 'sanctions' whereby claimants could have money stopped for several weeks if they missed appointments, including appointments to assess how 'work ready' they were. This especially applied to those in the WRAG group. In framing work as a health outcome, not working was framed as a psychological condition and one that might (or might not) be amenable to treatment. This was not a new idea (Perkins & Corr, 2005) but opened the gates to placing psychologists in job centres in 2015 in England. As a result, people could be sanctioned for not attending appointments with psychological professionals. Friedli and Stearn termed this 'psychocompulsion' (Friedli & Stearn, 2015). There is a history to these developments in debates about 'recovery' to which I shall return. For the moment let us note that it has always been said that, unlike medication, psychological treatment cannot be 'forced' on someone. You cannot hold someone down and inject them with CBT. Yet now a way seems to have been found: submit to psychological treatment or be destitute.

There are two other points I would like to make regarding the impact of austerity policies on those with mental distress and how some responded. I have already mentioned one which is the toll this 'hidden activism' takes on

those who become involved and especially the leaders. Whilst much takes place on social media there are constant rebuttals to make in terms of written pieces, demonstrations to organise and conferences to attend. The latter can be particularly bitter when seemingly sympathetic conference organisers insist on charging full fees or at least will not cover travel costs. People give up, temporarily or completely, they become unwell. Their arguments are profound, their stories heart-breaking and they are producing critical thought on the streets and the internet. But they cannot go on forever, ironically, unfunded.

The second point to make is that we are talking here of people with long-term mental health conditions. The situations in which they find themselves can nourish their distress. If there is a CCTV camera at the gym is it filming me to give to the Department of Work and Pensions to show I am fit for work? If the man next door sees me going out regularly will he inform on me to the DWP? Is the State deliberately trying to kill us? Many have said we are reaching the edges of Nazism in some quarters but for people like this they can come to believe their life is in peril. We did after all go to the gas chambers first. I do not believe these things but I can see how they could be believed. And my experience of the welfare benefits system was benign as I have said.

A Social Contract?

But what does this mean for the 'social contract' between citizen and state; of Nye Bevan's aphorism *From Cradle to Grave*? There was always a social category of the 'undeserving poor' but now this seems to have been expanded exponentially to include people who hitherto were explicitly excluded from the open labour market at least since the Enlightenment and the industrial revolution in the Industrialised West (Foucault, 2013; Foucault, Stastny, & Şengel, 1995). And once unemployment is positioned as a psychic failing then those already diagnosed are the first suitable cases for treatment: IAPT for those with 'common mental disorder' and psychologists by coercion in the case of people with a diagnosis of 'serious mental illness'. Increasing Access to Psychological Therapies (IAPT) is a scheme targeted at those with 'common mental disorders', such as anxiety and depression which though ostensibly therapeutic is a major tool to cut the numbers on sickness benefits. What has been termed 'psychocompulsion' is focused on daily living skills and normalisation in order to place people in jobs. As such, we have a new social contract where citizens have responsibilities to 'achieve' and 'contribute' (which means economically through paid work) which is defended by many (Fleurbaey, 2008) and the Work Capability Assessment is barely criticized in mainstream evaluations (Litchfield, 2013). It is true that the original Assessment was recognised as 'sometimes inappropriate' to people with mental health problems and was adjusted as a result (Harrington, 2012; Litchfield, 2013). Nevertheless, reading the advice given by the NGO Rethink to persons filling out this form makes me imagine nothing less than a labour of humiliation (https://www.mentalhealthandmoneyadvice.org/en/advice-topics/welfare-benefits/will-i-need-a-work-capability-assessment-to-claim-benefits/how-do-i-fill-in-the-health-questionnaire/). Bevan's dream appears to have evaporated as all claimants, but particularly those with disabilities and therein those with psychosocial disabilities, are positioned as everything from scroungers to psychological failures but, interestingly not only as 'mentally ill'. Everyone must strive to be normal and the normal / abnormal boundary is shifting in both content and where one draws the line (McWade, 2016). But however these subtleties work they pose mental health issues as the most intractable problem for the state. In turn, austerity policies would appear to have given rise to an increase in those in distress and diagnosed (N. Rose, 2018) and Paul Framer is wrong in his assumption that we live now in a tolerant society where everyone feels able to be open about mental illness. Depression and anxiety maybe but hearing voices, mania or believing that the state is out to get you are certainly not part of public discourse, benign or otherwise.

Resistance

I have mentioned grassroots organisations such as DPAC and the MHRN and there are others such as Black Triangle. Kindred MINDS, a BME network, has just published a Manifesto for Black people in relation to the mental health system which has caught the eye of the UNCRPD. Some of this work is very local (two of the organisations cited are active mainly in one Borough of London which happens to be where I work!). But local organisation, be it protest, campaigning or support seems to be typical and national connections are made through social media especially on closed Facebook groups. Local organisation was also found to be predominant in 2003 (Wallcraft, Read, & Sweeney, 2003). However, there is a national organisation of users and survivors of mental health services: the National User Survivor Organisation (NSUN) (www.nsun.org). This is a network of networks and includes the Survivor Research Network (SRN). They struggle to survive. In 2017 it was estimated that 25% of their membership groups had closed and this seemed to be associated with the outsourcing of state provision in health and social care such that big charities like MIND and RETHINK were in receipt of £b to provide services previously provided in statutory organisations. And yet, it is often small and local organisations where service users get the support they need. There is little research here – this is my informed impression.

There is one thing that connects these embryonic organisations of resistance on the part of mental health service users and survivors and that is a deep distrust of anything mainstream. This includes mainstream academics. As an example, we repeated a 'consultation' exercise on grassroots priorities for research (Robotham et al., 2016) with people from BME communities who had not known about or felt alienated from mainly white groups. Whilst some of the research priorities they suggested were similar to the mainstream groups, particularly medication although differently inflected, they also suggested we stop 'treating us like guinea pigs' and 'research yourselves and the white, racist institutions you inhabit'. NSUN too tried to collaborate with the umbrella organisation the Mental Health Alliance on new Mental Health legislation but when they saw the questionnaire and consequent results they felt compelled to withdraw and wrote a long statement on what Mental Health Law based on rights could look like and their conditions of involvement with non-survivor organisations (https://www.nsun.org.uk/news/nsun-members-to-get-involved-in-the-mental-health-act-review). The Vice-Chair of NSUN is committed to a form of 'coproduction' but it has to be on the terms of the group that is marginalised (Needham & Carr, 2009). It is interesting that the person who founded the mental patients liberation movement in the USA, Judi Chamberlin, and who held out for user-controlled services for 30 years, in one of her last articles talked about collaboration with service providers. But her condition was that all parties had to be aware of their power position and lay that on the table from the start (Chamberlin, 1978, 1990, 2005). To be frank, I do not know if that is possible in mental health. But we can dream.

What Kind of Social Justice Movement Is This?

And there is more of a conceptual issue here. In the original framing the terms of this special issue, the editors say "We suddenly find ourselves in an era when these liberal values are no longer taken for granted, and where the social preconditions for relations of dialogue, trust and mutual respect have been eroded." I would argue that these 'relations of dialogue, trust and mutual respect' were always deeply controversial in social movements in mental health and that this has been so for 30 years, spanning more than the lifetime of community and critical psychology (P. Campbell, 1985/2005, 1996, 2001; P. Campbell & Rose, 2011; The Survivors History Group, 2012). The role of 'allies' both clinical and academic has always been contentious and fraught with problems. I remember this as my own local user group became progressively user-led as there was something about mental

health service use that, hard as they tried, allies just did not 'get' and so they hindered the development of a collective discourse that could change understandings of mental distress and new forms of support. This was a very common situation (Faulkner & Thomas, 2002; Rogers & Pilgrim, 1991) although, as Judi Chamberlin's trajectory shows, we kept trying. Added to this, the 'community' at stake here is not homogenous and there have been particular struggles for BME communities who felt it impossible to join with the mainstream user movement because it refused to understand that racism was fundamental to the experience of Black service users (Francis, David, Johnson, & Sashidharan, 1989; Kalathil, 2008, 2010; King, 2016). Similar arguments have been made from an LGBTIQ perspective (Carr, 2014) and intersectionality is high on the agenda.

This can all be framed as an integrative / separatist debate and there would be some legitimacy to that. But in my view what is happening here is a call for attention to local specificities, a rejection of universalist epistemology and methodology as well as a politics that rejects both the predominance of mainstream psychiatry and, even worse, the transplantation of its activities to very different local situations be they diasporic or in the Global South (Davar, 2014). Insofar as that attention is appreciated and also extends to 'alternative' ways of offering support, then engagement is possible but will always be precarious (Bayetti, Jadhav, & Jain, 2016).

So what kind of social justice movement is this and how can community and critical psychology support it? The first thing to say is that there will always be suspicion – we are talking allies and academics both of whom, at best, misconstrue. There is a rejection of liberal values here but it is not of the order of supporters of Brexit or Trump. The rejection at its simplest, I would argue, is because 'liberal' and 'neoliberal' values privilege the individual and what we are told is that we are *individually* pathological, that there is something wrong with our brain or our person, our cognitions or our emotions, at worst, in the diagnosis of 'personality disorder', of our whole self (Bonnington & Rose, 2014; Jones & Brown, 2012; D. Rose, 2014b). So this social justice movement, if such it be, is not one that denies distress, not at all, but explains that distress socially and fights individualism by collective endeavour. Of course this comes in stronger and weaker forms (D. Rose, 2017; Jones & Kelly, 2015). This collectivity is not homogenous at all and for some to speak of the 'mental health user movement' as a 'community' is patently absurd because it consists of 'small groups of unrepresentative people' who are either sicker (angrier) or more articulate than 'ordinary' patients (but never both at the same time). These arguments were addressed 15 years ago and nothing has changed there (D. Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2002). To summarise, there is a difference between being 'representative' and striving to 'represent' a collective discourse of contention, collaboration and change. Psychology positions us as 'unique individuals' to be treated with 'personalised medicine' and as such rips us of context and constraint (Israel et al., 2014). To the extent that community psychology and other academic disciplines approach the 'community' and not a 'collection of individuals', for me at least it is on the right tracks.

But in the UK and elsewhere in the Industrialised West, mental health services are trying hard to prevent us from even associating with one another as day centres are closed in the name of preventing 'dependency', small groups lose their funding and this is disproportionately so for BME groups, secondary services are discharging people to GPs in their thousands and, ironically, there is now a burgeoning of research into 'isolation' most of it not yet published but with precedent (Perese & Wolf, 2005). The figure that '1 in 4' people suffer from mental illness again assumes some random set of individuals across a homogenous community. But this '1 in 4' is socially structured, structured by inequalities as we have known for more than half a century (Hollingshead & Redlich, 1958) and 'mental illness' is not a faulty brain or faulty person but a primarily socially determined response to adversity that requires social solutions (N. Rose, 2018). By closing and disallowing collective spaces and supports it seems

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liberalism still rules here as individuals are responsible for their own wellbeing. Social networks and social capital are alluded to but very poorly conceptualised by the field (Perry & Pescosolido, 2015; Webber et al., 2014).

The Dominance of 'Recovery'

To try to illustrate the remarks above I shall conclude by alluding to a specific debate. It exemplifies the point concerning individualism and revolves around the concept of 'recovery' and its potential for 'normalisation'. I shall do this briefly as I have written about it, including its personal impact on me, elsewhere (D. Rose, 2014a).

The Road to Recovery

Recovery discourse has taken hold as an 'alternative' to mainstream psychiatry and its focus on medication (Repper & Perkins, 2003; Slade, 2009; Slade et al., 2014). Recovery is about 'personal', that is 'individual' recovery and although the importance of 'social networks' is noted, it is the individual who must set goals (their own goals) and achieve them. There was a literature on recovery in the 1990s and later and its focus was on the importance of peer support (Deegan, 1988; Mead, 2014; O'Hagan, 2004). But the professional literature focuses on 'guiding' the person to a position of 'hope' (we always emphasised that) where they can take their place in society and in particular where they can work. This has been conceptualised as a form of 'normalisation', as forcing people to be as like the image of the 'normal' citizen as possible (Harper & Speed, 2012; McWade, 2016; D. Rose, 2014a) and linked to austerity and neoliberalism. And of course it is not only those in mental distress who are enjoined to be normal, contributing, self-actualising members of society. Political contexts position and shape subjectivity profoundly for all (Ransom, 1997; N. Rose, 2009). But those in distress cut an emblematic figure.

So in mainstream circles one measure that is used to assess an individual's recovery is the 'Recovery Star' (Dickens, Weleminsky, Onifade, & Sugarman, 2012) whose points represent goals and whose spokes say how far they have been achieved. In response, the Face Book group Recovery in The Bin has responded with the 'Unrecovery Star' (https://recoveryinthebin.org/unrecovery-star-2/). The points on the Unrecovery Star are not goals to be achieved but reasons – such as racism, poverty, patriarchy and transphobia – why recovery is not possible for many users and survivors under current conditions of existence. It should be made clear that for many it is not a question of a desire not to work but that most available work today for people with mental distress and fragmented cvs is either unattainable or has been shown in a systematic review to make the kinds of work on offer detrimental to mental health (Kim & von dem Knesebeck, 2015). At the same time, it is my view that some people are so intensely affected by their mental distress that supports are constantly necessary and work not possible at all. Additionally, nobody has really addressed the question of what 'reasonable adjustments' might mean for those severely affected by distress. They are not the equivalent of ramps and toilets accessible for disabled people and the ones we can think of are probably unacceptable to nearly all employers. For example, to say from the outset I will probably have at least 3 months per year when I am unable to work will kill any possibility of employment. But, for some, this is the reality. On the other hand, there are those who go for inversion, embrace their madness and promote MadPride. This is an international movement now but there was an early book in England (Curtis, Dellar, Leslie, & Watson, 2000). Recovery need not mean 'being normal' but accepting your madness and making the most of it when you can often because you have the first-hand experience allowing support to others when in similar distress. This is the basis of real peer support (Faulkner & Kalathil, 2012). This is not to say that 'normality' is not a goal of many – the situation is complex and so is the 'community' (Lofthus, Weimand, Ruud, Rose, & Heiervang, 2018).

What Kind of Activism Is This?

So in terms of this special issue, we find a kind of activism that is neither pre- nor post-liberal, that is suspicious of the mainstream and experts, yes, but promotes a kind of radical left politics that does not sit easily with the ideas of some radical thinkers but not for the usual reasons. This activism is barely visible socially because 'the mad organising' is an oxymoron and there are material conditions for not being persistently open. It is hidden, it is suspicious and it is angry but with a righteous anger. The title of a film shown on Channel 4 in the 1990s was '*We're not mad we're angry*'. There is then distrust of those who would 'empower' us because to accord power is structural not psychological as has been argued for some time (Swift & Levin, 1987). It has been well-argued that handing back power to a community, or co-producing change, is not easy whether attempted by large organisations (Henkel, Stirrat, Cooke, & Kothari, 2001), or NGOs apparently on the side of marginalised groups (Choudry & Kapoor, 2010) or research (Campos & Campos, 2006). On the whole, I would argue that the wider academic community including community psychology has not thought about madness, about distressed people as activists or as survivor researchers. We represent a liminal group but perhaps arguments about power, individualism and normality as well as a very different kinds of suspicion of experts can be helpful. Many experts have talked about us from positions of authority: now we are speaking back. Maybe an expertise that has been silent can learn and be helpful.

Conclusion

I have described a hidden activism and the political and discursive arguments which ground and frame it. I have, it will be noted, made use of official statistics. But facts, as we know, do not speak for themselves and these figures are positioned within a particular discourse of exclusion, marginalisation and rights. 'Facts' may be used to produce alternative truths as long as they are grounded in peoples conditions of existence which may be wretched (Harding, 2008). I have the impression, I may be wrong, that insofar as the wider academic community (outside the 'psy' disciplines) thinks about madness and distress it is from an ethical position of wanting to help, to ameliorate suffering and to do this not from a position of containment and control but, to use a term, in order to 'empower'. It may even be that what I have written here has intensified that sense: something must be done! But if other academic disciplines are to do anything effective they must get rid of every last vestige of charitable but patronising approaches and be ready to face anger, suspicion and dark, sometimes shocking, humour.

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Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Re-Engaging Social Relationships and Collective Dimensions of Organizing to Revive Democratic Practice

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Abstract

The weakening of the everyday practice of democracy around the world presents profound challenges for social scientists working with an applied focus on issues of inequality and justice in social change. This paper examines community organizing (in the US) as an instrument for equitable and just social change, and argues that three interrelated trends are subtly undermining a core practice of organizing: developing social relationships. An expanding technocratic influence on politics, an inflated focus on individual-level metrics for evaluating organizing, and a growing belief that digital technologies and big data leverage greater power, combine to engender an atomized view of people, who are increasingly treated as consumers rather than producers of social change. In contrast, cultivating social relationships fuels the building of community and expanded networks that enables the exercise of social power necessary to effect change. Scholars promoting change for social justice should work to shape tools and measures to serve social dimensions of organizing and support people and collectivities as agents of democracy.

Keywords: community organizing, power, social justice, democracy, participation, collective action

There is no shortage of evidence for the challenges posed by the degradation of democracy and democratic practice around the world (Levitsky & Ziblatt, 2018). As political leaders embrace ideologies of neoliberalism and global capitalism, economic power and wealth have become more concentrated, and people around the world experience greater degrees of social disfranchisement and economic precarity. Meanwhile, the hollowing of democracy across the globe diminishes the ability of ordinary people to use levers of democracy to respond to these challenges. Too often, social and political actors conceptualize democratic voice as akin to consumer choice, turning people into clients of the public sphere instead of agents within it (Brown, 2015).

Rebuilding democratic societies' capacity to respond to pressing social problems requires rebuilding the core relational practices that constitute the everyday practice of democracy (Ganz, 2018). The logic of democracy derives from the idea that ordinary people can exercise individual and collective voice. This ability to exercise voice distinguishes the logic of democracy from the logic of markets, in which consumers do not exercise voice but instead choose exit when faced with unsatisfactory products (Hirschman, 1970). The ability to exercise voice, however, is not born but made. People must learn the skills, capacities, and motivations to exercise citizenship in a democracy (Munson, 2009; Skocpol, 2003; Verba, Schlozman, & Brady, 1995). At the heart of that learning are social relationships, through which people cross the bridge from being passive consumers of democracy to becoming agents within it.

This paper argues that three interrelated societal trends are subtly undermining a focus on this core practice of cultivating transformative social relationships. In particular, we focus on how these trends manifest in the sphere of US community organizing, a practice explicitly dedicated to solving social problems through people building democratic power. These three trends undermine relational practice, because they shape the context within which community organizers work. First, an elevated value ascribed to both social scientific and professional expertise in the practice of politics has lessened the appreciation for citizen input and participation. Second, an emphasis on individual-level outcomes in both practice and theory has de-emphasized the importance of social relationships. These two trends shape the way a third trend – the rise of new technological and data capabilities afforded by internet communications – affects the practice of organizing. Social scientists and public affairs consultants enjoy increasing prominence in evaluating efficacy and strategy in the practice of organizing. Combined with the new affordances created by information and communication technology (ICT), such evaluations often overlook the value of critical social processes in organizing. We argue that these trends diminish the capacity of organizing to exercise power, direct social change, and bolster vibrant democratic practices. We begin by describing community organizing as a practice for social change and examining its evolution within the American context. Then, we outline why social relationships are crucial to the practice of organizing, focusing particularly on how social relationships enable organizing to become a vehicle for challenging power. Then, we examine how the three trends have evolved, and how they impact the dominant social contexts within which organizing happens. Finally, we conclude by reflecting on how these trends link to undercurrents of neoliberalism, and the implications for scholarship and practice.

Community Organizing as a Practice for Social Change

Community organizing brings together mostly low- and moderate-income people – through organizations or collective structures – to promote social justice and the common good, and this is done by developing their individual and collective capacities to exercise voice in socio-political processes (Pyles, 2009). Diverse other approaches to social change, such as information sharing, service provision, and moral persuasion, are based on causal assumptions about the social problems addressed. For example, the approach of information sharing presumes that those suffering from social problems simply have a lack of information; that presumption reflects a view that individuals have informational deficits, but that the social system itself is fair and just (Brager, Specht, & Torczyner, 1987; Ginwright & James, 2002). In contrast, community organizing operates from the causal assumption that systems create social problems, and that systems change requires the exercise of power (Mills, 1959; Pyles, 2009).

Organizing has many styles, traditions, and contexts, including the labor movement (Milkman & Voss, 2004), iconic social movements like the civil rights movement (Payne, 2007), and neighborhoods (Boyte, 2004), as well as issue-specific efforts like ableness-advocacy (Fleischer & Zames, 2001) or environmental work (Gibbs, 2002). Across this range of contexts, organizing is one of the few practices that explicitly pursues social change through mechanisms engaging individuals in participatory and democratic civic practices (Pyles, 2009).

Organizing practices in the US have changed over the last four decades of upheavals in social, political, and economic circumstances. Deindustrialization and globalization weakened labor organizing, contributing to a shift toward organizing in residential or community settings (Christens & Speer, 2015). Urban disinvestment, suburbanization, and decline of social capital dramatically weakened urban institutions, which contributed to faith-based organizing rather than geographic or neighborhood models, as faith groups were one of few viable local institutions in lower-income urban contexts (Warren & Wood, 2001). Organizing efforts working explicitly with youth represent another adaptation (Christens & Dolan, 2011), which emerged in response to increasing alienation seen in increased youth violence and prevalence of youth depression and other mental/behavioral health challenges (Ginwright & Cammarota, 2007). In addition, the rise of digitally-based communities like Black Lives Matter has sparked another debate about the extent to which digital tools are enabling development of a different set of organizing practices shaped by people of color, women, and leaders from other historically marginalized constituencies (Freelon, McIlwain, & Clark, 2018). In addition, as globalization pulls decision-making power away from local communities to broader regional, national, and international settings, the scale and scope of organizing expands, leveraging relationships and new kinds of partnerships to affect change (Christens, Inzeo, & Faust, 2014; Wood, Fulton, & Partridge, 2012).

These trends challenge the study of community organizing practices, confounding a clear classification system for the diverse organizing approaches that these trends have evoked. An early taxonomy (Rothman, 1996) identified social planning, locality development, and social action as the three most common organizing approaches. This framework no longer holds, as organizing efforts are conceptualized in diverse ways, whether through goals, methods, tactics, constituents, issues, or any number of other lenses (Christens & Speer, 2015; McCarthy & Walker, 2004). Organizing labels include power-based, constituency, youth, faith-based, labor, democratic, neighborhood, electoral, pressure group, congregational, identity-based, civic, transformative, women-centered, community-building, Marxist, participatory, school-based, progressive, and social-action, among others. Our analysis is most aligned with what is termed democratic organizing (Wood, 2002), which emphasizes broad and inclusive participation, bottom-up decision-making, and developing social power for affecting systemic change.

Social Phenomena at the Heart of Democratic Organizing

The heart of democratic organizing is its ability to build social relationships between people, and then transform those relationships into collective power. These fundamental social relationships stimulate interpersonal dialogue, the sharing of lived experience, and reflection on common struggles, and these relationships are the basis through which ordinary people engage meaningfully in ways that create new commitments and capacities. We argue that the investment in social relationships is what makes organizing a powerful vehicle for people to exercise voice in society. We begin here by describing our understanding of power and its relationship to organizing, and then describe the importance of social relationships in generating that power.

What Is Power in the Context of Organizing?

Because the goal of organizing is producing social change, power in the context of organizing is about the ability of organizing groups to influence social change outcomes. In this context, there are different dimensions of power to consider, as reflected by scholars studying this phenomenon in the past (Dahl, 1957; Fung, 2006; Ganz, 2009; Mann, 2012; Tarrow, 1994). For our purposes, the most relevant dimension of power in the context of organizing is the fact that power is, in many ways, dynamic and invisible (Lukes, 2005).

Political theorist Steven Lukes famously formulated power as having 'three faces' (Lukes, 2005). The first face of power refers to all the visible ways in which power is exercised in society. Visible power emerges in myriad interpersonal interactions—such as when a boss tells an employee what to do—and in more macro political processes, such as when one side wins a vote in Congress, one party wins an election, or a judge issues a ruling. Organizing groups seek to win visible victories that reflect the interests of their constituencies, including things like favorable policy outcomes, ballot initiatives, elections, or changes to corporate policy.

Lukes (2005) enunciates two additional dimensions of power which are harder to see. The second face of power is 'hidden' and occurs when constraints are activated out of public view, by parties or interests who, while influencing community values and manipulating political processes, keep more fundamental issues and resource distributions intentionally out of such public debate. The ensuing public struggles, then, relate to issues that are of less consequence to those powerful actors who are limiting public debate, thus determining who has a seat at the table and what is on the agenda. The hidden face of power, for example, goes beyond the first face to impact not only which side wins a vote in Congress, but who gets to determine whether Congress was even taking a vote. It also reflects the undercurrents that shape strategic calculations by political stakeholders about whether to engage in given debates; stakeholders may opt out of a particular political debate if they feel that chances of victory are too slim or their resources will be too greatly impacted. The forces shaping these choices are, Lukes argues, another reflection of the second face of power.

The third face of power, which Lukes calls 'structural' or 'invisible', is even harder to discern, and comprises the assumptions and ideas that shape people's understanding of what is appropriate, proper, or possible in a given situation. What are the ideas in people's heads? What are their conceptualizations of what is possible? These 'invisible' notions govern the way people interact with each other and with society. Lukes argues, however, that this third face of power is also 'structural', because these invisible assumptions govern the kinds of socio-political institutions and processes we construct (Lukes, 2005). Implicit racism, for instance, is a manifestation of the third face of power and governs not only our social interactions but also the kind of socio-political structures we create.

Illuminating the three faces of power in the context of organizing is important, because it means that when organizing groups seek to make social change, they are trying to change not only the visible face of power, but also the non-visible faces of power. Not only do they want to win policy victories, elect candidates into office, and force corporations into socially just practices, they want to shift the invisible assumptions people make about how the world works (third face of power), and whose voice matters (second face of power). In the context of racial justice, for instance, not only do organizers want police departments to adopt body cameras and state legislatures to reform sentencing laws, they want to win those victories in a way that challenges people's implicit racism, and to reduce people's reluctance for constituencies of color to have seats at decision-making tables.

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How Do Social Relationships Shape the Ability of Organizing Groups to Build Power?

Social relationships are foundational to the power generated through community organizing. Only by cultivating and strengthening relationships with and between individuals can organizers transform people's understandings of themselves, each other, and their relationship to public life (Ganz, 2009; Han, 2016; Warren, 2001). Beyond merely activating people to act within political processes, organizing creates new individual and collective capacities within and amongst constituencies, and such capacities are stimulated by social processes.

These individual and collective capacities unfold over time, and require diverse processes and experiences, before the kinds of power we describe are realized. One way to understand the importance of social relationships in developing these capacities is to examine a foundational organizing practice called the 'one-to-one'. This practice is described in the civil rights movement (Morris, 1984; Payne, 2007), labor organizing (McAlevey, 2016; Rosenfeld, 2014), and community organizing (Alinsky, 1971; Whitman, 2018), and detailed in scholarship on community organizing processes (Christens, 2010; Han, 2014; Speer & Hughey, 1995). The one-to-one is time-consuming (Payne, 2007), requiring people to meet, listen to one another, reflect on the challenges of their lives, and generate new understandings of themselves and the world they inhabit, as well as new shared commitments stimulated from these exchanges (Ganz, 2009). The one-to-one is designed to develop a parity between those interacting, based on the commonality of human experience, even while confronting the roles of race, gender, class, and other social constructions that operate to divide and entrench hierarchies rather than allow parity between people. The one-to-one process becomes the basis for developing collective leadership, a notion built on the idea that everyone has inherent value (Payne, 2007).

While foundational, one-to-one conversations are but one step in a longer process of producing social change. Describing other elements of the organizing process leading to social change is beyond the scope of this paper, but it is critical to understand that these relational conversations designed to generate new commitments are essential for the production of the kind of transformational change we are addressing. Fundamentally, one-to-ones are 'radical' in that they open up the possibility for change. Rather than presuming people are fixed in opinions and beliefs, organizing stimulates reflection on experience, inviting an exploration of one's life, meaning, and choices. Such a process is indeterminate, but the possibility for change lies in this uncertainty. Describing the work of Gerard Duveen, Gillespie and Cornish (2010) focus on direct interpersonal interactions as "the engine driving change" at individual, psychological and identity levels (termed ontogenetic change). Furthermore, when these interpersonal interactions produce psychological and identity change, this then becomes the 'motor' for change at social and cultural levels (termed sociogenetic change). Community organizing, at its foundation, employs a dialectical process between interpersonal practices (like the one-to-one) and systemic analyses facilitated through collective efforts at community change (Christens, 2010; Han, 2016; Speer & Hughey, 1995). This process reflects the interdependency between lived experience and social structures, in turn undergirding the understanding that developing social power is necessary to produce systemic change impacting people and communities.

Interpersonal interactions like the one-to-one are thus the bedrock of community organizing. They allow people to understand that the challenges and pain they experience in their own lives is often shared with others in ways previously unknown, building the bridge from private pain to public problems. As C. Wright Mills (1959) asserted, the main challenge for our modern era is to translate private pain and personal troubles into social issues, by cultivating an understanding of how the public milieu that creates personal troubles is a function of social structure.

Processes Undermining the Relational Focus in Democratic Organizing

The ascent of neoliberal values prioritizing efficiency, expertise, and a focus on individual-level outcomes, along with the rise of ICT, erodes the focus on relational dimensions of organizing in several ways. In describing how these trends have manifested in recent decades, we recognize that we are not painting a complete picture; as with any rule, there are exceptions, and important pockets of work are certainly underway, in which organizations and leaders are resisting these trends. Nonetheless, our argument is that these trends are dominant, and shape the socio-political context within which organizers work, and thus merit examination.

The Increasing Influence of Professional 'Expertise' in Organizing

A major shift in the practice of organizing in recent decades has been towards an increased focus on professional expertise as a valued resource, and the concomitant rise of a class of professional consultants who shape people's understanding of how to generate democratic participation and what it means. Skocpol (2003) describes the replacement of organizers with professional managers and aptly titles her book, *Diminished Democracy*. Writing about public affairs consultants in American democracy, Walker (2014) describes the evolution of a new professional class at the intersection of marketing, public relations, polling, data analytics, political consultancies, and civic engagement. He defines public affairs consultancies as "professional service firms that contract with an organizational client in order to manage the client's political and social environment strategically through campaigns that mobilize public participation, often in coordination with traditional forms of lobbying" (p. 23). He documents the rise of these consultants since the 1970s, and their increasing dominance in the world of politics. Similarly, Sheingate (2016) describes the transformation of democratic practices driven by the political consulting industry. For example, he describes how big data and new analytic methods have been combined to identify and target refined subgroups that can be mobilized for electoral outcomes. His conclusion is that US politics have been transformed from a civic practice into a business practice, and that professional control of politics is so pervasive that the magnitude of this shift is difficult to discern.

The rise of professional consultants who shape people's understanding of democratic participation has also become a major conduit for the expanded influence of social scientists in democratic engagement. This trend is perhaps clearest in the world of electoral organizing. *The Victory Lab* (Issenberg, 2012) chronicles the increasing use of social scientific expertise in political campaigns, showing how both partisan and issue-based campaigns work with academic researchers to identify the most efficient strategies for identifying and activating voters. For example, the level of private investments in deep canvassing shifted up and down around controversy regarding social scientific evidence for the efficacy of the practice (Van Noorden, 2015), demonstrating the elevated role of social science in shaping professionalized campaign practices.

The rise of this kind of professionalization impacts community organizing because it reshapes how people understand what it means to participate in democracy. In her study of labor organizing, McAlevey (2016) describes a kind of 'shallow' mobilizing that characterizes many organizing efforts run by consultants and experts. Such campaigns rarely suggest that people link their actions to the production of power for social change. In contrast, she articulates how relational processes that build trust and stimulate the sociological imagination develop into collective structures for exercising social power. McAlevey emphasizes the importance of a thoughtful and sys-

tematic power analysis that constituents themselves conduct. Only by moving from the one-to-one relational process into analysis of political power will constituents develop the sustainable commitment to affect social change. She describes constituent engagement and leadership development as flowing from member participation in every step of the organizing process: issue identification, causal analysis, strategy development, and power analysis of the opposition. One hazard to outsourcing this work to experts is that some organizers internalize these practices and privileged positions. McAlevey describes:

> … professional staff directs, manipulates, and controls the mobilization; the staff see themselves, not ordinary people, as the key agents of change. To them, it matters little who shows up, or, why, as long as sufficient numbers of bodies appear – enough for a photo good enough to tweet and maybe generate earned media. The committed activists in the photo have had no part in developing a power analysis; they aren't informed about that or the resulting strategy, but they dutifully show up at protests that rarely matter to power holders (p. 10).

McAlevey's analysis illuminates how the role of expert, itself, is a concern. In our large and complex society, experts are a valued resource. However, the role of expertise is in tension with the role of expansive democratic participation.

As a result of these trends towards professionalization, the world of traditional community organizing has come to occupy a smaller and smaller space in American democracy, with far more resources going towards electoral campaigns and other organizations run by consultants and professional managers. Large community organizing networks still exist (Han & Oyakawa, 2018), but they often lack visibility on state and national stages. Instead, most people's understanding of democracy is dominated by ideas and experiences determined by technocratic civic professionals (Sheingate, 2016). This professionalized form of participation, however, lacks a relational component. Without the kind of transformative relationships that turn people into agents of democracy, people become props in campaigns and organizations run by professionals. Use of the acronym "RP" by some political campaigns to refer to "real people" – as in, 'We have to find some RPs to stand behind the candidate' – exemplifies how professionalization of politics has turned ordinary people into pawns. Organizers seeking to do the kind of transformative work that has long been the provenance of community organizing are thus facing an uphill battle, having to dismantle the internalized assumptions that constituents, donors, the media, and other actors have about their work (Oyakawa, 2017).

A Focus on Individual Rather Than Relational Accountability

A second inter-related trend is the shift towards holding organizers accountable to a set of individualistic instead of relational metrics. Community organizers of all kinds are accountable to a wide range of stakeholders, from funders to the media, from academics who give voice to organizing, to constituents themselves. In many of these domains, organizers are increasingly beholden to individualistic outcomes as indicators of their work.

Social science research on community organizing has increasingly tended to focus on individual attributes rather than relational or collective qualities of organizing efforts (Brady, Schoeneman, & Sawyer, 2014). Many scholars studying organizing concentrate on perceptions and behaviors of individuals involved in community organizing processes (Granner & Sharpe, 2004). Often, this is for methodological reasons such as available data sources or ease of data collection (i.e., behavioral activities or participant perceptions). Quantifying individual behaviors and attitudes, while less challenging and expensive than, say, accessing relational qualities of voluntary activities, largely misses critical organizing processes. Furthermore, scholars draw on similar metrics when comparing organizing processes between groups and over time. In the end, much organizing research focuses on participant

characteristics at the expense of scholarship about relational or collective dimensions of organizing practices. This individual focus is not limited to the academic sphere; organizers themselves are held accountable to individualistic metrics as well, due to professionalization of organizing (Brady, Schoeneman, & Sawyer, 2014; Fisher & DeFilippis, 2015) and funder priorities (Kubisch, Auspos, Brown, Buck, & Dewar, 2011), where efficacy is mischaracterized as aggregation of individual activities (Oyakawa, 2017). Collective outcomes, in other words, are often conceptualized as the sum of a series of individual actions, ignoring the transformational, collective capacity that organizing engenders when the whole becomes greater than the sum of its parts. The logic of a politics of aggregation instead of a politics of articulation (de Leon, Desai, & Tuğal, 2015) dominates this thinking and results in deprioritization of relational qualities and, ultimately, diminished expressions of social power.

The overemphasis on organizing outcomes as an aggregation of individual actions distorts fundamental concepts in organizing, such that scale often is equated with power. For example, 'community actions' have traditionally been viewed as collective efforts of organizing groups to alter or change a community policy. However, some studies tabulate each individual acting as part of an organizing effort as executing a 'community action' (Fawcett et al., 1995), thus supplanting the notion of a collective community acting together, into a focus on how many individuals are acting within a particular community and equating many individual acts with one collective act, thereby gutting the meaning of community action. This shift deemphasizes collective capacity, community cohesion, and social power. Research exclusive to the individual level of analysis captures one side of a dialectical process, thus marginalizing the social and relational processes foundational to social change outcomes. Paralleling a hidden form of power, social science metrics equating aggregated individual counts with collective impacts reflects an unstated assumption that exercising social power is not required for social change.

The Rise of Technology and Big Data in Organizing

In ways that many scholars have documented and debated, the rise of digital technologies have fundamentally changed the landscape in which organizing is embedded, interacting in important ways with an individual-level focus and social science methods for conceptualizing and measuring practices of organizing (Bennett & Seegerberg, 2013; Bimber, 2003; Bimber, Flanagan, & Stohl, 2012; Karpf, 2012; Tufekci, 2017). In addition, because people leave digital traces all over the Internet, these new technologies have also enabled the rise of big data, or data about current and potential constituents, on a scale never before imagined, leading many social scientists to envision 'better' ways to organize communities. In many cases, the way technology and big data has been used has sublimated the focus on relational commitments and replaced it with individualistic actions.

There are many examples of how the use of new technologies, big data, and analytic techniques have transformed our understanding and practice of social change. Occupy Wall Street and the Arab Spring are perhaps most emblematic of this thinking. The use of Twitter in those major political upheavals highlights the potential of social media to uniquely generate participation in social change efforts (Eltantawy & Wiest, 2011), and many activists have embraced these changes. Penney and Dadas (2014) conducted interviews with Occupy Wall Street activists who used Twitter in conjunction with face-to-face interaction in the service of protest efforts. Those interviewees identified Twitter as the linchpin for the success of their movement, despite acknowledging shortcomings and vulnerabilities of that platform. Similarly, in a survey of advocacy organizations, Obar, Zube, and Lampe (2012) found that most advocacy organizations believe social media is a mechanism for effective social change. Bond and Exley (2016), architects of the digital engagement strategy behind Bernie Sanders' 2016 run for president, argue that new digital tools are "… not brilliant new inventions. They are just a part of good old-fashioned mass

movement organizing coming back to life – shaped by the communications technology of the day – in an environment that made it easy for people like us to orchestrate the resurrection" (2016, p. xix). They contrast the dynamic potential created by these tools with what they describe disparagingly as the "plodding, one-by-one organizing orthodoxy" that dominates traditional organizing.

Alongside the use of new technologies in organizing sits the use of big data. Big data, drawn from people's online behavior, consumer actions, and other publicly or commercially available information, is distilled to generate predictions about who will vote, take action on certain issues, or likely participate in grassroots activities. However, big data analytics draw on existing records to pull data about what has happened in the past to predict the future. These analytics draw heavily on attributes of individuals, conceptualizing and classifying groups of people by demographic characteristics, consumption patterns, and the like (Kitchin, 2014). A number of cautionary notes about the way big data is used have emerged, focusing on things like the way they fuel reproduction of existing patterns of behavior (Barocas & Selbst, 2016), create 'echo chambers' that drive increased social and political divisions within society (Wagner-Pacifici, Mohr, & Brieger, 2015), or fracture collective identity and behavior through the constant segmentation of information and action (Fenton & Barassi, 2011).

In recent years, social media platforms have been cast as new forms of community, and debates have unfolded between scholars who view these tools as the instruments through which social and collective needs will be manifested in the future (Mutekwe, 2012; Obar, Zube, & Lampe, 2012). Alternatively, other scholars claim that such tools undermine something fundamental about the way ordinary people build the kinds of social connections needed to generate power in democracy (McNutt & Boland, 2007; Tufekci, 2017). Tufekci (2017) argues that the ability of movements to achieve rapid scale through digital tools inadvertently undermines their ability to generate the kind of collective leadership and structures needed to translate that scale into political power. Thus, she argues, we see many large-scale public actions that do not lead to meaningful social change.

In practice, although not of necessity, the rise of technology and big data has reduced focus on the practice of generating relational commitments, because of the allure of generating far more actions at a larger scale. The appeal of scale has contributed to the shift away from an emphasis on relational commitments, and axiomatically to the shift toward an emphasis on individual actions. McNutt and Boland (2007) argue that technological advances provide the opportunity, or at least the idea of an opportunity, that grassroots engagement and activity can be generated without traditional, time-consuming, and often challenging relational processes. The ways big data are utilized seem to substantiate this belief in grassroots involvement without time-intensive relational efforts, as big data and social media 'generate' participants drawing on attributes of individuals, whether behavioral patterns and preferences, or indexes based on the aggregated behaviors of the individuals one is affiliated with (Kitchin, 2014; Wagner-Pacifici, Mohr, & Brieger, 2015). In this way, some assert that big data is altering fundamental epistemologies and replacing theory with data-driven science (Kitchin, 2014).

The Concern for Democratic Power

The trends we describe here create tempting shortcuts in the urgent and desperately needed efforts to create social change. Facilitated by ideas anchored in neoliberalism, this earnest impulse has undermined relational work within large pockets of organizing work in America. The uncritical embrace of elite expertise, individualistic outcome measures, and digital technologies and analytics has both shaped and become symptomatic of these

trends. Well-meaning social change organizations have absorbed these trends in ways that can be destructive to their effectiveness as well as to democracy itself. We should be clear that we believe that social science expertise, professional politics, and digital technologies have important value for organizing and social change, but they have in recent years been applied in service of efficiency, scale, and distorted social science metrics instead of equity, collective health and wellbeing, and justice.

The bias toward individual metrics is evinced by the dominance of mobilizing over organizing practices (Han, 2014; McAlevey, 2016). Organizing, as we have described, is a transformational process in which constituencies develop the individual and collective capacities to exercise voice over socio-political outcomes that matter to them. Mobilizing, in contrast, is transactional activation of people, in which scale is often substituted for power. That is, in traditional organizing, citizens 'produce' their own analysis about problems confronting their community, interpret why the problems exist, and strategize approaches for change and improved conditions (McAlevey, 2016). In contrast, mobilizing creates 'consumers' of public events, hosted by experts and others. Individuals who have been mobilized have not been engaged throughout the process as with traditional organizing; they are responding to an invite for a public meeting, much as they would attend a musical performance or a sporting event. The alteration of citizens from producers to consumers in social change activities corresponds to the rise of neoliberal ideology; this alteration is accepted by many organizers and advocates out of a belief in expert-defined metrics and an earnest desire to affect change.

Taken together, these processes shaping the field of organizing are an example of the third face of power, where invisible mechanisms shape the assumptions held by both scholars and organizers about how to effect change. The focus on individualistic outcome metrics, the value conferred to elite expertise, and an uncritical enthrallment with digital tools have all contributed to undermining relational strategies in community organizing practice. Relational organizing is about starting with people where they are, and engaging people in deep conversation about lived experience and reflection on those experiences. Bypassing this approach curtails basic elements of organizing practice.

Moving forward, we argue for a re-focus on understanding that human beings are fundamentally social, and intentional social change efforts are human endeavors; expertise and technology, no matter how new or innovative, are simply tools, rather than solutions. Our position is that technological advances, social scientific capabilities, access to big data, new analytic methodologies, and professional expertise are promising tools, but have value only to the extent that they magnify the efficacy of organizing practices that cultivate the relational processes which develop individual and collective capacities for power. Social science activism, to support social justice practitioners, must magnify the social dimensions of change processes, and develop technological and data tools that illuminate social and collective processes for organizing practitioners, as they work to build power for social change.

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The authors have declared that no competing interests exist.

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Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Building Spaces for Controversial Public Engagement – Exploring and Challenging Democratic Deficits in NHS Marketization

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Abstract

The Brighton Citizen's Health Services Survey (BCHSS) was developed to explore and potentially challenge how knowledge is used and by whom in the production of local health commissioning institutions and relations. Through the creation of an 'animating set of questions', it sought to open up spaces through which to make visible some of the ways of knowing and valuing the NHS and health services that had been minimised through the commensuration practices of post-2012 public engagement. In this way there was a clear agenda to facilitate a form of knowledge democratisation which opened up and validated different 'health publics', in order to explore and broaden participative engagement opportunities. The paper provides an account of the project. It considers the theoretical and methodological underpinnings of this example of 'evidence-based activism', reflects on the impact of the project on local commissioning and considers the range of controversies that arose as a result of the work. It explores the way that research straddling the boundary between academic inquiry and political activism speaks to the many issues that are prevalent in the changing HE sector as well as NHS privatisation, health commissioning and public sector cuts.

Keywords: health, policy, commissioning, public engagement, activism, privatisation

Introducing a Controversy

In recent years the growth of evidence-based medicine, coupled with the establishment of external standards and national benchmarking audits, has facilitated a shift away from professional autonomy and dominance to external accountability through objective, statistical tools (Speed & Gabe, 2013). The increasing dominance of measures

focussing on external readings of clinical effectiveness can be understood as part of a redistribution of account-ability within health care systems, where third parties attempt to gain access to the 'black box' of clinical judgement (Timmermans & Berg, 2003). In this context, how such a shift impacts on how accountability is practiced, and the consequences for the recipients of health and care, is a key focus of our paper.

In recent years, evidence-based activism has been established as a means through which to understand the de-velopment of modes of activism that focus on knowledge production and mobilisation in the governance of health issues (Rabeharisoa et al., 2014). Such a term pays attention to the ways in which patients, organisations and activist groups have become key actors in the reflexive work of weighing up, sorting, assessing and reordering heterogeneous sets of data on their health problems, in ways that suit their own interpretation of their context.

This makes possible the development of forms of contestation which shed light on the fragmentary and uncertain nature of biomedical knowledge, and the policy practices through which they are institutionalised (Rabeharisoa et al., 2014). While there have been plentiful studies on how activist groups intervene in health policy monitoring, there have been far fewer that have sought to understand the epistemic activities mobilised to contribute to the issues at stake (Rabeharisoa et al., 2014). Here, knowledge is not a mere resource in which to ground political claims but rather it is a legitimate and fruitful target of social activism.

Such developments take on particular significance when public knowledge controversies become live in a given social space. The Health and Social Care Act (HSCA) (2012) was one such recent public knowledge controversy. This type of controversy resonates with Calon's 'hot situations' and Latour's 'matters of concern' (Whatmore, 2009); the moments of ontological disturbance in which the unexamined parts of the material fabric of everyday lives become molten and make their agential force felt. These controversies produce circumstances where what is at stake is sufficiently important that people want to participate in collectively mapping it into knowledge and hence social ordering. Such knowledge controversies are likely to have multiple and contested identities, indeed so much so that participants in a problem may not only disagree about what is understood about a problem but on whether such a problem even exists (Barry, 2012). Furthermore, Barry (2012) suggests that the analysts of such situations must attend to the relations between claims to knowledge and diverse experts and publics. When such controversies play out, and claims to knowledge become 'molten', there exists the potential to disturb conditions such that everyday reasoning is forced to slow down. According to Whatmore (2009) this creates opportunities to arouse a different awareness of problems and debates as to which experts, non-experts and publics should have a legitimate voice in the knowledge controversy.

Through the HSCA, £80bn of UK health commissioning budget was entrusted to newly formed Clinical Commis-sioning Groups (CCGs) (Department of Health, 2013). During its passage through the UK parliament and after its successful enactment a number of dimensions of controversy emerged concerning what this legislation meant for the delivery of healthcare nationally and locally. One dimension concerned whether this legislation mandated for the privatisation of the NHS. A second dimension arose around whether or not such privatisation (if indeed this was what was being mandated) was necessarily a 'bad' thing. For example, well-reported issues around lack of affordability, poor efficiency and the wide-scale publication of the care failures of 'Mid-Staffs' (Francis, 2013) appeared to contrast with findings from the Washington based Commonwealth Fund (2017), which had rated the NHS as the most efficient and effective health service in the developed world. Another disagreement emerged over whether the medical establishment supported the legislation. These debates were played out publicly during the legislative process and in particular, the 'listening pause', which emerged during the passing of the bill.

Subsequent research has since suggested that health care professionals, including GPs, say they do not feel that their CCG policies reflect their own views and that they have very little chance to impact CCG's policy decisions (Murphy, 2015). Moreover, there have been suggestions that cost-efficiency appears to be overriding service quality during the CCG tendering process and problems of transparency have been considered to routinely arise due to the institutionalised secrecy through which these contracts are procured, awarded and performed (Deith, 2013).

Reports from across England described 'dysfunctional commissioning', perhaps as a result of confusing and complex accountability frameworks (Checkland et al., 2013). Until 2014 CCGs were under a duty to be financially solvent and were directly accountable to a range of potentially conflicting stakeholders, including the Secretary of State for Health, Healthwatch, the regulator (at the time Monitor), Local Authority Health and Wellbeing boards and the public. While CCGs had a requirement to engage with patients on commissioning, some suggested that the creation of Healthwatch represented a move from a form of patient involvement which sought to influence health and social care services to one which was intended to promote patient choice (Tritter & Koivusalo, 2013). This may be a contributing factor as to why, in terms of commissioning decisions made by CCGs, accountability appears to be focused upward toward the NHS commissioning board rather than to local residents (Tritter & Koivusalo, 2013). Post-2014, the 5 Year Forward View has been endorsed by NHS England but with questionable legislative legitimacy (Madden & Speed, 2017) and the impacts of the developing sustainability and transformations plans on commissioning accountability remain to be seen.

Five years on and we are now afforded an opportunity to construct an analysis of this public knowledge controversy and the emergent and interrelated local controversies. Drawing on a descriptive account of an action research project in the South East of England, this paper describes a case study of a project which attempted to create a provisional space to explore, extend and challenge the knowledge claims and practices mobilised in post-HSCA healthcare public engagement and commissioning. We interrogate the forms of democracy and attendant publics that were produced through HSCA legislation and outline a manifestation of 'statactivism' where a University was mobilised as a claimed space of engagement (Gaventa, 2006) to disturb, slow down, and create opportunities to arouse a different awareness of the tensions around healthcare commissioning and public engagement. First we will consider the post-HSCA engagement spaces of healthcare commissioning and the publics that they produce.

Spaces of Engagement, Consultation and Publics

'Policy spaces' have emerged since the 2012 Health and Social Care Act that allow moments where citizens and policymakers come together. Healthwatch England is a body established under the Health and Social Care Act 2012. It is the national representative body of a series of local Healthwatch organisations in each of the 152 local authority areas in England. Its purpose is to 'understand the needs, experiences and concerns of people who use health and social care services and to speak out on their behalf' (Healthwatch, 2017). The second public policy space which emerged following the 2012 HASC are regional Health and Wellbeing boards. Here, members of the public can engage with the statutory local authority bodies tasked with improving integration between practitioners in local health care, social care, public health and related public services. In some cases (as in Brighton & Hove) HWB's contained several members of the clinical commissioning group, the organisation whose primary remit is to commission health services for the locality.

There have, however, been suggestions that the engagement and accountability practices that have emerged post-HASC have suffered from many of the previous limitations that have befallen their predecessors (Hudson, 2015; Tritter & Koivusalo, 2013). Many public spaces for citizen engagement in health policy are fraught with difficulties (Fischer, 2009a). Health systems are framed by an increasingly prescriptive and centrally driven set of performance metrics such as waiting times (Currie & Suhomlinova, 2006; Speed & Gabe, 2013). Such institutions tend to exhibit a very specific approach to processes of accountability, centred on notions of operational control based on audit regimes working in combination with central command structures and vertical control (Dommett, MacCarthaigh, & Hardiman, 2016), which may account for the fact that in general there are very few examples where citizen participation has led to tangible improvements in services or changes in policy (Smith, 2006). In terms of the set of social relations between patients and providers (or commissioners), Gulbrandsen (2008) talked about this 'dis-improvement' in terms of how new accountability processes, such as those that have been adopted in post-HASC health commissioning, rather than being seen as new, continue to be seen to operate as 'business as usual' whereby people perceive that the governance model, whilst appearing to be open to new and novel forms of stakeholder participation, in fact works to restrict those self-same opportunities.

In such circumstances the adoption of accountability tools and procedures can be understood as a form of 'organisational hypocrisy' if such tools and procedures are more enabling of practices which enact restrictions on stakeholder voice. Fischer (2009a) and Hudson (2015) suggest that the possibilities and benefits of participation are now seriously limited by social and technological complexity which, through the hierarchical authoritarian relationships found in public administration, enable people only to participate as consumers rather than citizens. Here, an idealistic and utopian theory of deliberative democracy has taken centre stage with many in positions of power unwilling or unable to discuss matters that might adversely impact their own interests (Fischer, 2009b).

Smith (2006) suggests that powerful interests are more than capable of agenda-setting by defining problems in particular ways or avoiding or sidelining or restricting participation to 'safe' issues. Indeed Martin et al. (2015) suggest that that cultures of denial, secrecy, protectionism and fragmentation of knowledge and responsibility are often implicated in these failures in meaningful engagement. In this context the more participation there is, the more the power relations of local communities is masked (Miraftab, 2004). Indeed engagement can become a reified form of pseudo-participation that works idiomatically, and with very little connect to the messy 'real world' of compromise, where the sometimes conflicting demands of different actors need to be acknowledged and addressed if a truly democratic version of participation is to be practiced. Miraftab (2004) suggests that to understand the meaning of advanced liberal governance we must understand not only what possibilities for engagement emerge but also which possibilities are silenced. In this context, it is crucial that we accept the position that creating new institutional arrangements will not necessarily result in greater inclusion. Rather much depends on the nature of the power relations which surround and imbue any new, potentially more democratic, spaces (Gaventa, 2006).

Similarly, while transparency has gained a central significance in debates over matters of governance in recent years (Barry, 2010), greater transparency does not necessarily confer or imply greater openness. Rather, and more straightforwardly, it simply transforms the nature of what is kept secret and what is not (Barry, 2010). Transparency entails a set of processes that don't simply make information public but instead mould institutions into forms that are able to perform certain versions of accountability. Moreover, the audit measurements employed to record transparency and governance initiatives can play a central role in producing specific versions of accountability (Barry, 2010).

Policy spaces reflecting dominant state agendas also have direct implications for those 'publics' that engage with them. Hudson (2015) posits that we have seen the development of a consumerist model of post-HASC public engagement in line with the broader marketization in the health sector. This model depends on accountability and measurement practices that position service users (actual or potential) as health consumers. Discourses and practices that position service users as consumers are a hallmark of neoliberal governance. When such accountability metrics are employed to 'make people up' (Hacking, 1990) they can perform a powerful productive role by vindicating, limiting, incentivising, legitimating and justifying certain social and political activities (Beer, 2015). They can be, and frequently are, used to facilitate competition, between both institutions and people. Indeed such techniques of notation, computation, examination and assessment can be understood as technologies of governance which impose norms and shape social order through their capacity to translate diverse and complex processes into a single figure with the veneer of political neutrality (Donovan & O'Brien, 2016).

But while Beer suggests that we all consciously (and unconsciously) adapt to the systems of measurement that we live within, it is also the case that under certain circumstances, those accountability metrics can be questioned, sidelined and subverted (Bruno et al., 2014). In the case of a given social system, the central level can exert forms of regulation through a monopoly over the production of statistics (Baudot, 2014), for instance with the recording of crime or employment statistics. Under such public engagement conditions, the figures that do not appear can often be as revealing as the quantitative performance indicators that take centre stage. The analysis of the non-production of information can make visible the social configurations enacted via a given socio-political environment. Indeed public knowledge controversies can make possible the conditions for interrogating such dominant social configurations and the measures (and non-measures) through which they are made possible.

While it could be argued that the implementation of the recent Sustainability and Transformation Partnerships that have emerged in the post-HSCA engagement landscape have been characterised by many of the issues above (Boyle et al., 2017), engagement spaces do still exist currently that offer opportunities, moments and channels where citizens can act to potentially affect local health policies, discourses and decisions and the relationships that affect their lives (Gaventa, 2006).

In terms of turning these problematic engagement practices into more positive social spaces for activism, Bruno, Didier, and Vitale (2014) suggests that there exists 'margins affording a certain liberty' when social movements or social actors are able to work across each of the dimensions of space and power (Gaventa, 2006). Despite the dominant consumer model of engagement that has emerged in post-HASC engagement spaces (Hudson, 2015), we would argue that margins and opportunities exist that allow room for manoeuvre toward the construction and implementation of alternative engagement practices.

Statactivism as a Means to Create Alternative Accountability Space

The forms of post-HASC public engagement could be argued to reflect what Arvitzer (2002) calls 'democratic elitism'. That is, a system of citizen accountability premised on a concern for protecting democracy from *too* much participation by ill-equipped masses, which functions by closing down rather than opening up possibilities for participation. A central problem is that such democratic elitism is premised almost entirely on an instrumental ra-

tionalism where health service planning and commissioning are regarded as technical exercises where health services have only an instrumental value to a consumerist public (Madden & Speed, 2017).

However people do not only have a consumer-oriented relationship to health services. Health services, and hospitals in particular, are important to peoples' ideas about local identity and sense of place (Brown, 2003; Jones, 2016). In the UK, hospitals play an important symbolic role; they are more than just buildings where healthcare is delivered. Jones (2016) suggests they are perceived as the physical incarnation of the NHS and its values within a particular locality. Hospitals are places of suffering, death, life, hopes, fears, anxieties, emptions, relationships and values. Whether by collective imagination or individual experience, hospitals exist at the juncture between life and death and are bound up with our notions of ontological security. And such security is central in mobilising people to protect local health services at risk when such instrumental rationalism is driven to excess by central government ideology (Jones, 2016).

However, during a time of little support for governments' ongoing policy package among health professionals (Murphy, 2015), and where local health care professionals are often in opposition to local and national changes in health policy and commissioning (Murphy, 2015), the importance of local communities is self-evident (Florin & Dixon, 2004). They can play a key role in balancing the rational pragmatics of cost control with forms of protest informed by the lived experiences of health outcomes.

'Statactivism' could be articulated as a way to rebalance the engagement deficits of democratic elitism. Statistics are often contested and have been accused of freezing human relations (Bruno et al., 2014) and providing 'realities' that are mediated by what schemata designed in other worlds can capture (Burton & Gomez, 2015). That said, quantification can also reveal and create feelings of social injustice that can lead to protest. Indeed there are numerous examples of such statactivism where calculation and statistics are used, not as tools for subjection, but as weapons to 'analyse, negotiate and limit dominant players' (Samuel, 2014).

The capacity of a quantitative measure to capture what it is purported to represent can be brought into doubt and attention to the introduction of measures and indicators helps to reveal their creative (rather than 'objective') character (Bruno et al., 2014). This is especially the case during moments of controversy where the ways in which statistics and big data are implicated (and contested) in the articulation of state space become particularly salient (Lury & Gross, 2014).

Here, emerging forms of collective action use numbers, measurements and indicators as means of denunciation and criticism and, as such, make possible a form of re-appropriation of the hegemonic logic of quantification (Bruno et al., 2014). Social critique often relies on statistical arguments and it has been suggested that much can be gained by creating spaces where public debate about remote and previously intangible technocratic processes can happen (Desrosieres, 2014) and where a 'militant use of figures' can be employed to defend the utility and quality of public services (Baudot, 2014). It is through this frame that we should interpret Martin et al.'s (2015) suggestion that the particular benefit to be gained from efforts to gather and manage knowledge is not necessarily clarity but disruption - to create a space for multiple knowledges and marginalised voices. Such a mobilisation of 'knowledge as disruption' (Martin et al., 2015) is the starting point for piece of work that has been established in the South Coast of England in 2016.

The Case Study – The Brighton Citizens Health Services Survey

In response to a perceived need for greater public say in local healthcare commissioning, the first Brighton Citizen's Health Services Survey (BCHSS) was conceived by academics and students at the University of Brighton. The project was initially designed to hold regular 6 monthly public consultations with a substantial number of citizens from Brighton & Hove.

It was informed by Fischer's (2009b) premise that, while citizens may have incomplete understandings of many of the problematic health policy issues, once these issues are re-described in a jargon-free way, most people understand them well. Within the BCHSS the intention was to use survey methods to identify and 'map' moments of commissioning controversy and, through the process of collecting data and reporting the survey results, to provide the basis for a disruption or slowing down of the practices that function to stabilise and legitimise current healthcare commissioning and the limited forms of democracy that they make possible.

The BCHSS was developed as an 'engagement technology' to explore the conditions for developing a form of evidence-based healthcare activism that foregrounded many of the commissioning and budgetary activities that were operating beyond public knowledge and consent (Desrosieres, 2014). In so doing, the project team hoped that the findings could be used to start a local conversation where disparities between commissioning decisions and public needs and values can be made clear and acted upon. In this context, citizen information was used as a legitimate counter point to 'official' information.

Through the creation of an 'animating set of questions' (Espeland & Sauder, 2007), the BCHSS sought to open up a space through which to make visible some of the ways of knowing and valuing the NHS and health services that had been erstwhile minimised through the consumer-oriented commensuration practices of post-2012 public engagement. In this way there was a clear agenda to explore and broaden participative engagement opportunities. In so doing this work sought to heed the OECD call for new ways to include citizens in policy making through citizens actively engaging in defining the process and content of policy making (Gaventa, 2006). Such a venture could be regarded as a replication of the central problem of this paper - that is, idealised forms of pseudo-participation being held up as evidence of democratic engagement. However, in this context the implicit use of reflexive practice and the articulation and presentation of the work clearly signposted the boundaries and intentions of the project team. The job at hand became about working through practices and resources of the university to positively affect policy spaces – aligning or contesting them.

The project developed surveys that were designed to move beyond the post-2012 HASC accountability dominance of recording consumer experience with the health services they used. Rather they sought to capture unmeasured and excluded forms of knowledge representing the voices of the people of Brighton & Hove on important topical health issues like funding cuts, privatisation and the broader tensions between local commissioning and national funding policy directives. These potentially controversial issues were not at the time of data collection any part of the suite of accountability and transparency practices employed across the city.

The project was established using a distinctive approach to survey design and involved developing a public engagement tool aligned to public consultation, participation and deliberation rather than the production of a 'validated instrument'. The methodology that underpinned the project enabled the survey design to evolve as part of a par-

ticipatory, consultative process. In line with a wealth of critical scientific literature, the choice of a co-constructed and value-driven survey can be considered a valid measurement tool. In spite of the criticisms that can be raised, the research process entailed continuous reflexivity (Cohen, Manion, & Morrison, 2007; Thuo, 2013) therefore contributing to the integrity of the findings and analysis (Guba, 1981; Shenton, 2004), and the ethics of the project (Edwards & Mauthner, 2002; Orb, Eisenhauer, & Wynaden, 2001). This process was overseen by the steering group of academics, a member of the University of Brighton's Community University Partnership Project, a member of a local health research charity (The NHS Support Federation) and several students. The coordinating group was made up of a range of people whose relationship to the project was complex. This included those who took part as academics, as academics and activists and as neither. However this group coalesced around a set of values to define the purpose of the survey and ensure that its aims and objectives remained consistent.

The intention of the project was to

- facilitate public education and deliberation on health service commissioning

- promote public engagement on controversial healthcare commissioning topics in order to extend and enrich the public engagement space for health service commissioning

- explore and improve commissioning accountability mechanisms

Initially a survey was designed that focussed on asking the Brighton & Hove public about their

- core values on health commissioning

- current controversial commissioning issues

- future local commissioning intentions

The questions on current commissioning issues were drawn from the minutes of local Health and Wellbeing Board and Clinical Commissioning Group discussions, with a focus on issues of that were or had to potential to be controversial. For instance, the transfer of the contract for patient transport from a statutory to a commercial provider was the subject of considerable debate and press coverage. The list of currently tendered contracts and their end-dates were available on the CCG website. However, since upcoming commissioning intentions were unavailable on the public website, a Freedom of Information request was submitted for a list of services that will be subject to new tendering processes in the forthcoming calendar year. Given the claims that the post-reform English NHS was in the midst of privatisation by stealth programme, this tendering process was (potentially at least) very controversial.

The first survey was a two-page, multiple option questionnaire that took 3-4 minutes to complete. Online and paper versions of the survey were produced. It was disseminated by the survey teams through various forms of social media, including most prominently Twitter and Facebook. The project team sought to sample as broadly as possible and so for this reason the survey was circulated to organisations and groups who might be expected to display a broad political and demographic membership. This included all major local political parties, all resident's associations in the city, all church groups, two universities, and the three local trades unions. Moreover several hundred surveys were complete by a convenience sample of passers-by in Brighton city centre over four consecutive Saturdays. In total, 1,300 completed first surveys were collected and analysed, and 700 of the second survey. Table A.1 in the Appendix shows an abridged quantitative version of the first survey findings.

When the survey was released, the survey team attempted to contact the local CCG, Healthwatch and the Health and Wellbeing Board. Despite numerous attempts at contact, no reply was received from either the CCG or Healthwatch. The lead councillor from the local Health and Wellbeing Board replied by email that they would be interested in viewing the findings.

Once the results had been collected, an initial report was produced (Brighton Citizens' Health Services Survey team, 2016), and a launch event of the initial report was held at the University of Brighton (BCHSS, 2016). A press release was issued to all local media outlets, including newspapers, radio stations and online news sites. The launch event drew 40 local stakeholders, including local politicians, academics, NHS staff, and campaign groups. While the CCG did not attend the launch event, their lay representative did although it was not clear whether he was there in a personal capacity or representing the CCG.

The report (BCHSS team, 2016) presented the findings outlined in Table A.1. It concluded that the public in Brighton & Hove held clear and compelling views on the values that they felt should underpin the ways that they wanted their health services to be commissioned, and it restated Brighton & Hove CCG's statutory remit to ensure that these views were appropriately reflected in their decision making. It stated that, in the city of Brighton & Hove, a vast majority of the public were against the use of private companies in the local health economy and very concerned about some of the recent decisions that had been made to commission private companies to undertake certain services. Finally, there was an acknowledgement that further work was needed on the part of B&H CCG to reflect the public needs and values in their commissioning decisions.

In terms of engaging with the CCG, a deputation to the local council Health and Wellbeing Board was arranged for July 2016. Formally, a deputation consists of a member of the public presenting a statement which is submitted to the board 7 days in advance (selected members of the CCG are also members of the HWB). All board members see the pre-submitted statements and have a prearranged response at the ready. Prior to this there were two points of contact with the CCG. First, an invited meeting with their public engagement officer was used by the engagement officer as an opportunity to show the range of engagement work that they had been doing themselves, almost as a counterpoint to the survey.

Second, the Survey coordinator was asked to ensure that this ongoing CCG work (i.e. not the survey work) was made visible during the deputation, lest local councillors think that the CCG were not carrying out engagement work. There was a discussion as regards the differences between the CCG engagement work and the results of the survey. It was agreed that the CCG's engagement portfolio would be recognised at the meeting.

A few days before the deputation, the CEO of the CCG sought (at short notice) a meeting via third party intermediaries. The CEO visited the office of the survey coordinator and a civil, if tense, discussion covered the exact purpose of the survey and its potential ethical and methodological limitations. Specifically, concerns were raised about whether the survey, due to the orientation of questions, could be held to legitimately represent public opinion and whether the attempts to do so constituted ethical practice. The issues of the ethical and methodological legitimacy of the research were explained in an accessible way to those who sought dialogue with the BCHSS team. There was a discussion on the aims of the survey project. The survey coordinator made the point that it was important for the CCG to be aware of the strength of public opinion and for the public to learn more about the healthcare commissioning system that was (or was not) meeting their needs.

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In terms of issues raised by and through the survey methodology, there was a discussion on the respective latitude that the CCG had to avoid the use of private providers in light of the 2012 legislation. The survey coordinator suggested the importance of public knowledge of commissioning changes, potential CCG commissioning flexibility in light of the Monitor guidance and the degree of variability in CCG commissioning across the country (Kings Fund, 2015). There was an agreement that the discussion might be continued at the public deputation.

Two further meetings were had with CCG intermediaries prior to the deputation and a further public talk on the results was scheduled after the deputation. During these informal meetings, it was made clear to the survey leader that the CCG were not happy with the way the results were being presented and that there would be conversations had at a very senior level in the University if the work was to continue to produce problematic results.

At the deputation, the presenter is allowed to briefly reply to the HWB panel response. This board contains 5 members of the local CCG, a Healthwatch representative, a number of local councillors and other local stakeholders. Initially invited as a 15 minute presentation, the survey report was shortened to a two page deposition that required the signature of five local Brighton & Hove residents in support. On the day the results and recommendations of the first report were read out to the Health and Wellbeing Board. Other team members were sitting among the public, as observers. One councillor noted that the results were concerning. Another showed scepticism about the potentially leading nature of the questions. It was reiterated by the deputation presenter (who was the survey coordinator) that the survey was a public engagement tool, scientifically valid under different premises, to record information and citizens' voices, however the limitations of such an approach were acknowledged. From comments made by HWB board members, there appeared to be a general agreement that the findings were in line with the beliefs and values of those who sat on the board. The format did not allow further interrogation of the issues and particularly the examples of where commissioning activity had departed from the wishes of the local people; in the end there were publicly stated commitments of CCG members on the HWB.

A follow-up survey, was released to the public in June 2016. A similar approach was implemented, whereby a Freedom of Information (FOI) request was submitted prior to the drafting of the second survey in order to inform some of the questions in the survey. Initially the FOI request to obtain upcoming contracts for the following year did not prove fruitful in the way that it had with the first survey. Following an invited meeting at the CCG headquarters with the lead researcher and the CCG engagement officer, it became apparent that there was disagreement within the CCG board as to whether to readily provide the information to the lead researcher. Subsequently this information was provided.

The second survey developed the method of the first by seeking greater public involvement in the design of the questions on the survey. The project website was used for a call for members of the public to suggest potential questions of importance to be included in the survey – in terms of a piece of activism, it would prove harder to discount the survey results with the involvement of a wider group of public citizens involved. Hence the second survey was developed from three sources:

- From members of the public who asked the questions on our website.

- From topical and controversial health issues being discussed by councillors at the local Health and Wellbeing Board.

- From a Freedom of Information request on upcoming commissioning plans.

The second survey was widely disseminated through the same routes as the first survey. Less labour time was available to disseminate the survey which possibly contributed to the fact that 700 responses were received.

As the survey project developed over its first two iterations, numerous local media, (such as the local newspaper, 'The Argus', regional radio, BBC Sussex and Juice FM, and regional television, BBC South Today) started to pick up on the findings and use the data collected as a means through which to develop local healthcare stories and to check their information when writing their own stories. For instance, following the second survey, BBC Sussex, on seeing the increased difficulty in seeing a GP across the city and the spate of practice closures, used the data collected from the survey as a means through which to develop a feature on access to general practice across the city.

There were several moments where the stakeholders with the most powerful interests in this context sought to directly challenge the veracity, ethics and appropriateness of the survey project. These included emails and communications in personal and public meetings. The project was challenged by commissioners as potentially unethical, unrepresentative of the local population and methodologically flawed. It was suggested that the survey addressed national policy issues that were beyond local commissioner control. Moreover the local CCG suggested that their own consultations, and the work of Healthwatch were sufficiently substantive to gauge the interests of the Brighton & Hove public although there was acknowledgement that many of the issues articulated in the citizens' surveys were not present in local CCG consultations.

Discussion

The survey project revealed a range of local opinions on healthcare commissioning that resonated with some of the key broader moments of controversy that arose during the development of the HASC. A post-2012 appraisal of public involvement in health care commissioning would appear to speak to some of Fischer's (2009b) concerns about the proliferation of utopian theories and practices of deliberative democracy taking centre stage. In such practices there exists an unwillingness and/or inability to discuss matters that might conflict with or adversely impact the interests of dominant stakeholders. At the inception of the project, one CCG member replied to a member of the public's concern over the use of private companies in healthcare by suggesting that 'it was not within the gift' of local commissioners to discuss potential providers in such terms. As such, this public space was an example where the accountability procedure enacted restrictions on public voices.

There are multiple factors impinging on the capacity for public voices to be foregrounded in healthcare commissioning, not least the way in which CCGs are held as accountable to the legal strictures of the Health and Social Care Act and the legal responsibility to avoid operating in financial deficit. This imperative is further embedded under the STPs approach, where Sustainable Transformation Partnerships which have not had their financial plan approved by NHS England will be prevented from applying for any additional funding to provide healthcare services in their area. However, even within such confines, engagement is possible if well-developed political arrangements can be mobilised that provide people with multiple and varied participatory opportunities (Fischer, 2009b).

Post-HASC public engagement enacts a certain form of singular 'public': that of an 'active' constituent whose deliberations are welcomed if they fit within the areas of concern that board members had pre-agreed to be legit-

imate. Legitimacy was dictated not by topical relevance but by the versions of commissioning that board members felt were both possible and acceptable to voice. It could be argued that current engagement mechanisms articulate a statutory space which enables a very specific version of the public to be made visible and salient (Lury & Gross, 2014). This is a public who consume healthcare services and are measured as such via the engagement practices of Healthwatch and CCG consultations.

We suggest that the survey project allowed for different versions of the public to be made visible; versions that were oriented toward the value and ethics of service provision. Here, a space was eased open to allow the more fluid nature of the way that publics relate to health services to be foregrounded (Bruno et al., 2014). The inception of the survey project, and its broad public dissemination, revealed a range of interesting findings. Not only did it allow for the emergence of multiple and complex ways of publicly engaging with controversial local health commissioning processes (Graber et al., 2018, under review), it also provoked a range of defensive stakeholder practices, perhaps as a result of the controversial and challenging engagement topics that emerged.

To deal with the first point, the concept of health care as caring, loving and nurturing has been argued to largely have been lost in the process of commissioning (Wieringa et al., 2017). The NHS on one hand provides therapy but on the other, board and lodging and tender loving care (Askheim, Sandset, & Engebretsen, 2017). In the UK, hospitals in particular play an important symbolic role; they are more than just buildings where healthcare is delivered. They have been argued to represent for many the physical incarnation of the NHS and its values within a particular locality (Graber et al., 2018, under review; Jones, 2016).

The NHS symbolises the sites of care which were a key part of the post-war welfare state and relate closely to the idea of communality or common citizenship (Brown, 2003). Health services and sites are often more than the sum of their material characteristics; they are the centre of meanings, intentions and felt values, the focus of emotional attachment and significance (Brown, 2003). However post-HASC engagement rubric organises agenda-setting and problem definition in ways which avoid, sideline or restrict participation to Smith's (2006) 'safe' issues and so questions of value, local community and citizenship are lost or minimised.

The BCHSS survey created a space where such issues could re-emerge centre stage. In using quantitative social research to reveal diverse ways of making sense of health commissioning activities and public voice (Samuel, 2014), and to create a space for different ways of relating to NHS commissioning and for the emergence of previously marginalised voices (Martin et al., 2015), it foregrounded local commissioning controversies and mobilised a politics of 'knowledge as disruption' (Martin et al., 2015). As such, the hegemony of local consumer-oriented engagement practices could be challenged through this created space for deliberation that allowed disruption of such hegemonic practices (Gaventa, 2006). The survey project can be understood as a form of 'evidence based activism' which opened space for deliberation where the previously unmeasured could become measurable and where largely private conversations on healthcare commissioning could be brought to public notice.

The survey revealed not only a disjunct between the wishes of the Brighton & Hove public and commissioning activity, but also the problematisation of a singular consumer public whose engagement with health services starts and ends with individual experience of consuming services. The very considerable qualitative feedback highlighted the ways in which local identity, community and sense of place, as well as political and ethical value, are inseparable from the changing health services context (Graber et al., 2018, under review).

The experience of engaging the dominant commissioning stakeholders directly contested what Jones (2016) refers to as the assemblages of knowledge and practice rationalities which typically constitute the objects and subjects of policy and commissioning practice. Martin (2008) suggested that past research shows a tendency of professional staff to question the representativeness of involved members of the public and that this can function as a form of patrolling or controlling of the process of public involvement. Through this frame, public and user involvement can be understood as a technology of legitimation where the selection of appropriate or acquiescent individuals by health professionals might be disrupted via outside parties whose claims to represent the public will hence be contested.

The survey project revealed a series of practices, individual meetings, public meetings and communications where the challenging findings were welcomed, resisted and questioned depending on the stakeholder and the issue. The survey constituted a challenge to the normative engagement practices on health commissioning which are, to a large degree, controlled through the conduct of meetings where professionals and managers are seen to retain control over decision making processes (Martin, 2008). The response of local decision-makers was articulated through an amalgam of settings and practices in which power relations were played out and contests fought in acts that proved far from trivial (Samuel, 2014). Indeed there were several moments where the dominant stakeholders in this context sought to directly challenge the veracity, ethics and appropriateness of the citizens' survey project. This was addressed by the project team through: clearly stating the rationale of the project, and expressing the values driving it; sharing the results of the surveys; and being available for consultation with any stakeholder at any stage of the project.

Concluding Thoughts

This paper provided the socio-economic context in which the BCHSS project started and unfolded, and offered an overview of its quantitative findings. These were discussed through the lens of statactivism and the enactment of democratic processes which sought to bring a degree of meaningful accountability to the commissioning process. The analysis considers potential pitfalls of the survey as an academic tool, and addresses the concerns of the institutions on its reliability by advocating for the co-construction of alternative knowledges that voice communities' unheard positions on policies affecting their everyday lives. It was concluded that BCHSS is a participatory tool that enabled the opening up of a new dialogue between the citizens and the institutions that represent them with the clear aim that top-down decisions will be transparently conveyed, and the bottom-up concerns of citizens' will be taken into account.

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Appendix

Table A.1

Descriptive Findings of Valid Responses From Survey One

When asked who they would prefer to be treated by, almost **88%** of the respondents said the NHS. This compared with **9.1%** who had a preference for a private healthcare company.

When asked whether people believed that "health companies should not make financial profit from people's health problems", **92%** strongly agreed or agreed with this statement.

Participants were asked whether, in light of Optum's international legal difficulties, there should have been a full public consultation on Optum. **93%** said that there should have been.

Over **93%** of people said that they were concerned or very concerned about the award of the Optum contract locally.

The council recently revealed an intention to cut £21.9 million over the next 4 years from the Adult Social Care budget. Over **97%** of people were either very concerned or concerned about these cuts.

97% of people either strongly agreed or agreed with the following statement- 'The council should be actively resisting these latest cuts by evidencing their impact and sending the messages back to central government'.

In 2016 and 2017 the Brighton & Hove Clinical Commissioning Group are considering inviting health providers to bid to run a primary care mental health service. **93%** of people would be very concerned or concerned if this contract was given to a private provider.

Similarly, regarding the potential contract for NHS 111 service for non-emergencies, **85%** of people would be very concerned or concerned if this contract was given to a private provider.

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